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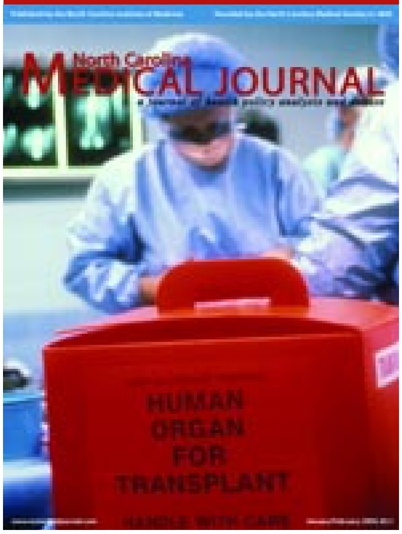

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ARTICLES

POLICY FORUM: *Organ Donation and Transplantation*

COMMENTARIES

SPECIAL ARTICLE

DEPARTMENTS

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> *"In fact, all major religions in the US support organ donation and transplantation."*
> *The Donation of Human Organs and the Evolving Capacity for Transplantation: Exciting Developments and Future Prospects,* page 22

ARTICLE

Moving from Medicaid to North Carolina Health Choice:

Changes in Access to Dental Care for NC Children

Rebecca T. Slifkin, PhD, Pam Silberman, JD, DrPH, Victoria Freeman, DrPH

Abstract

Objective: *The objective of this study is to identify the extent to which access to dental care changes as children move from a public program with low provider reimbursement and a reputation of non-compliant beneficiaries to another public program with higher reimbursement levels and enrollees that may be viewed differently by providers.*

Study Design: *The pre- and post-enrollment dental experience of NC Health Choice enrollees who were previously on Medicaid is compared to those who were uninsured prior to NC Health Choice enrollment.*

Data Source: *Parents of newly-eligible NC Health Choice children were sent a survey within two weeks of enrollment to determine their child's experience prior to program enrollment. Respondents were resurveyed approximately 11 months later regarding their child's experiences after receipt of NC Health Choice.*

Principal Findings: *Medicaid recipients were significantly more likely to have had a dental visit within the year before enrolling in NC Health Choice, to report a usual source of care, and have fewer unmet needs than were uninsured children. After enrollment there was improvement for both groups, and differences between the two groups disappeared.*

Conclusions: *Medicaid coverage appears to improve access to dental services for children who would otherwise be uninsured. Increased access to dental services for Medicaid children after enrolling in NC Health Choice may be due to higher provider reimbursement, but may also result from providers' perception that NC Health Choice beneficiaries are a different population and more likely to keep appointments.*

Relevance: *In a time of fiscal crisis, changes to NC Health Choice should be carefully considered to avoid loss of dental care gains afforded by this public insurance program.*

Access to dental services for low-income children in the United States is a well-documented problem.[1] Studies of dental access for low-income North Carolina children have found results that are consistent with national data. In a presentation to the North Carolina Task Force on Dental Care Access, Rozier noted that 36% (>31,000) of all NC children entering kindergarten had a history of dental caries and 25% had untreated dental disease.[2] Childhood caries are more prevalent in low-income children and those residing in rural areas without fluoridated water, and low-income children with dental caries are more likely to go untreated.[3]

The absence of regular dental care can impair the health of children in a number of ways. Untreated dental disease can affect a child's appetite and ability to eat, thereby leading to nutritional or growth problems.[4] A report of the US Surgeon General suggests that children miss approximately 52 million hours of school a year due to dental problems and related care.[5] Further, the inability to access dental services leads to more expensive use of the emergency room for care. In 1997, for example, North Carolina Medicaid paid $1,686,565 for 62,000 preventable emergency dental visits.[6] Children with oral and craniofacial conditions also can face problems with speech or their psychological well-being. Finally, poor dental health in children can also affect their dental and physical

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health as adults. There is now a growing body of research that suggests an association between periodontal infections and diabetes, heart disease and stroke, and adverse pregnancy outcomes such as prematurity and low birthweight.[7]

Barriers to the receipt of dental care are particularly acute for NC children receiving Medicaid. Only 16% of North Carolina dentists actively participated in Medicaid in 1998, which was at that time one of the lowest rates of participation in the country.[8] Lack of provider participation in Medicaid, coupled with other access barriers, has led to low use of dental services among Medicaid-eligible children. North Carolina Medicaid claims data from 1998 showed that only 12% of children ages 1-5 years, 27% of children 6-14 years, and 19% of children ages 15-20 made at least one visit to the dentist.[9]

A statewide task force convened by the North Carolina Institute of Medicine studied access to dental services among low-income populations in 1999.[10] The task force identified low provider reimbursement levels as the primary barrier to dental provider participation in Medicaid. On average, the North Carolina Medicaid program paid dentists 62% of the usual, customary and reasonable rates (UCR) for 44 of the most common dental procedures for children and only 42% of UCR for other procedures. Dentists reported losing money by seeing Medicaid patients. A 1996 study of North Carolina dentists reported that 56% of dentists in the state would be willing to see more Medicaid patients if reimbursement rates were increased to 80% of UCR.[10] In addition to low reimbursement rates, dentists also stated other reasons for their unwillingness to participate in Medicaid, including a high no-show rate among Medicaid recipients.

In October 1998, North Carolina implemented its State Child Health Insurance Program (SCHIP), called North Carolina Health Choice for Children (NC Health Choice or NCHC). NC Health Choice provides health insurance to uninsured children with family incomes that are too high to qualify for Medicaid but that are at or below 200% of the federal poverty guidelines. Most of the children enrolled in NC Health Choice come to the program immediately after losing Medicaid coverage, either because they are no longer eligible due to an increase in family income or because they are too old to qualify within their income category.

Like 19 other states, North Carolina chose to implement a stand-alone SCHIP program rather than expand Medicaid eligibility. The NC Health Choice program is administered jointly by the NC Division of Medical Assistance (which is responsible for administering the Medicaid program), and the Teachers' and State Employees' Comprehensive Major Medical Plan (hereinafter the State Employees' Health Plan). NC Health Choice is modeled after the State Employees' Health Plan, but includes coverage for vision, hearing and dental services. Blue Cross Blue Shield of North Carolina is contracted to pay NC Health Choice claims, and reimburses dentists for care delivered to children enrolled in the NC Health Choice program at its prevailing commercial dental rates of approximately 100% of UCR. Thus, while NC Health Choice is a form of public insurance, children enrolled in the program have slightly higher family incomes than children on Medicaid, and their insurance reimburses dentists at a higher rate than does Medicaid.

Although several studies document the difficulties that Medicaid recipients have in accessing dental services[1,11,12,] little has been written about the experience of Medicaid recipients as they move to other sources of dental insurance coverage. Further, there have been only a few studies that have examined access to dental services in SCHIP or comparable public insurance programs.[13,14,15] In this study, we compare the dental experience of NC Health Choice enrollees who were on Medicaid prior to NC Health Choice enrollment to that of NC Health Choice enrollees who had no insurance for at least a year prior to NC Health Choice enrollment. The pre-enrollment experiences of these two groups and the change in access once enrolled in NC Health Choice are examined. This analysis will help identify the extent to which access to dental care changes as children move from a public program with low provider reimbursement and a reputation of non-compliant beneficiaries to another public program with higher reimbursement levels and enrollees who may be viewed differently.

METHODOLOGY

The data for this study were collected as part of a larger evaluation of NC Health Choice conducted by researchers at the Cecil G. Sheps Center for Health Services Research at the University of North Carolina at Chapel Hill under contract to the North Carolina Division of Medical Assistance.[16] The findings from that study as they relate to access to general health services have been previously reported, as was an earlier analysis of access to dental care for school-aged children that did not consider enrollees' prior dental coverage.[13,17]

Beginning in July 1999, parents of newly-eligible NC Health Choice children were sent a survey within two weeks of enrollment to determine their ability to access medical and dental services for their child prior to enrolling in the program. Respondents to the first survey were resurveyed approximately 11 months later to examine their child's experiences after receipt of NC Health Choice. Although the sample for the larger study was stratified by three age groups (ages 0-5, 6-11, and 12-17 years, all at the time of enrollment in NCHC), in this study we report results for the two older age groups only. Because of survey space limitations, we were unable to ask enough dental care questions to explore why the children in the 0-5 year age group were or were not receiving dental care. An increase in dental service use is expected as these youngest children grow up and more teeth erupt. It is, therefore, difficult to determine the extent to which an increase in dental service use in this age group is attributable to the new NC Health Choice coverage. Patterns of care for children in this youngest age group are also difficult to interpret because there is not consensus between dental and medical professionals as to when children should begin receiving regular dental services. For these reasons, the results presented in this paper pertain only to school-aged children.

Baseline surveys were sent to the parents of 599 younger school-aged children (ages 6-11) and 599 adolescents (ages 12-

17). Seventy-three percent (N=875) responded. Respondents to the baseline survey were mailed a follow-up survey and again 73% responded, for an overall response rate of 53% of the parents originally surveyed. The resultant cohort for whom data were available at both baseline and one year later consisted of 639 children (325 younger school-aged children and 314 adolescents.) In the baseline survey, parents were asked to report whether their child's most recent dental visit had been within the last year, more than a year ago, or never. In the follow-up survey, they were asked if their child had seen a dentist in the year since enrollment in NC Health Choice. Their usual source of dental care and whether their child experienced any dental access barriers were also queried. Parents who reported access barriers were asked why they were unable to obtain needed dental services.

This analysis focuses on two subsets of school-aged children, those who had Medicaid coverage during the entire year prior to their enrollment in NC Health Choice (391 children, referred to as "Medicaid graduates") and those who had no insurance for the year prior to enrollment (201 children, referred to as "uninsured"). Medicaid graduates were defined as those with Medicaid coverage that ended within 31 days of enrolling in NC Health Choice. Since North Carolina provides 12-month continuous eligibility for children enrolled in Medicaid, these children would have been covered for a full year prior to NC Health Choice enrollment. Children in the uninsured group had neither Medicaid coverage nor any other medical care insurance (by parental report) at any time during the year prior to NC Health Choice enrollment. Our survey did not specifically ask whether children had private dental coverage prior to NC Health Choice enrollment, so it is possible that some uninsured children had private dental insurance at some time in the year before NC Health Choice. However, low income families nationally have low dental insurance coverage rates, so it is highly unlikely that many of these children had private dental insurance.[18] The remaining school-aged children (N=47) were excluded from this analysis because their insurance status changed during the year prior to NC Health Choice enrollment, with insurance (typically Medicaid) for part of the year, and no insurance for the remainder of the year. It was, therefore, impossible to determine whether those children's reported dental care experience prior to enrolling in NC Health Choice reflected their experiences while insured or not.

All data were analyzed using STATA 7 statistical software.[19] McNemar's Chi was used to compare change in dichotomous categorical data (yes/no questions) over time. Changes in questions that had multiple, ordered responses were tested for significance with the Wilcoxon signed-rank test. A paired t-test was used to compare changes in means for continuous ordinal data.[20] When data are presented for all children combined, they have been weighted to adjust for the distribution by age groups of the NC Health Choice enrollees. Throughout the paper, differences in statistics pre- and post-NCHC are considered significant if p<.05.

At the time of the follow-up survey, the baseline survey was sent to a comparison group of parents of children who were newly-enrolled in NC Health Choice to ensure that observed changes in the original sample were not due to changes in the health care delivery environment. There were no significantly different responses to dental access questions before NCHC enrollment between the two groups. It does not appear that changes in the dental health care environment occurring over the time of our study account for the change observed post enrollment.

RESULTS

Demographic Characteristics

Demographic characteristics that might explain differences in access to and/or use of dental services are compared for Medicaid graduates and uninsured children (Table 1). Rural areas traditionally have fewer dentists per population than do urban areas which limits access to care. The difference between the percent of respondents residing in rural areas across the two groups, while statistically significant, is small.

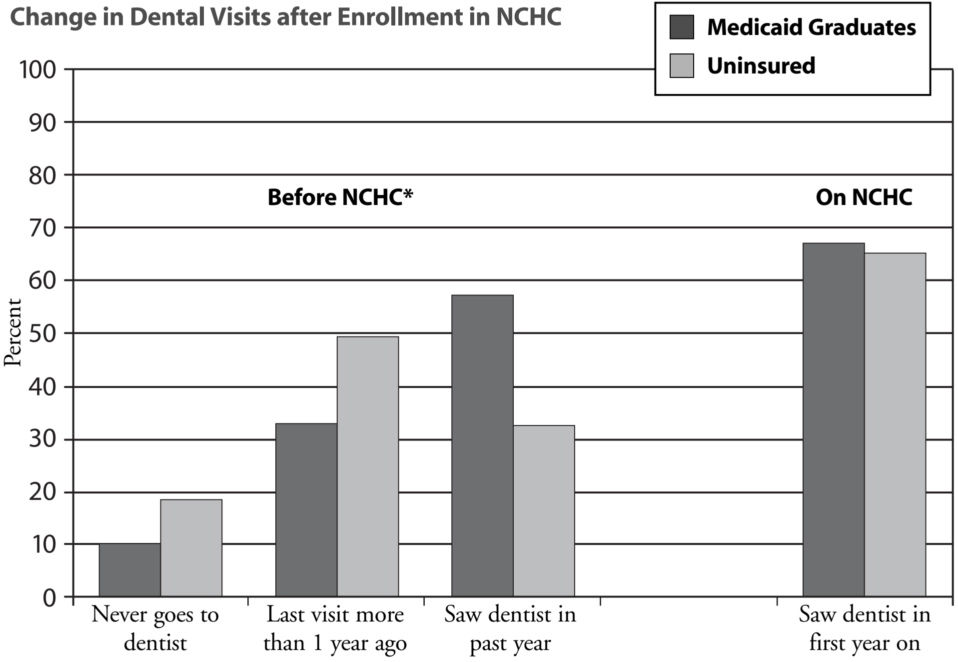
Table 1.
Demographic Characteristics

	Insurance Status in Year before NCHC Enrollment	
Characteristic	Uninsured (n=201) %	Medicaid Graduates (n=391) %
Rural Residence*	49	46
Race*		
White	51	42
Black	42	48
Hispanic	3	4
Mother's education*		
Less than high school graduate	15	15
High school graduate	36	44
Some college	35	32
College graduate	15	9

** The difference in distribution is statistically significant at p<.05*

There were significant differences in the racial composition of the two groups. Children who were uninsured prior to NCHC enrollment were more likely to be white (51%) than were Medicaid graduates (42%), and the mothers of uninsured children were more likely to have post-secondary education. Finally, although data on income prior to enrollment in NC Health Choice was not available, it is reasonable to assume that many of the uninsured children had family incomes that were slightly higher than that of the children on Medicaid, which is why they were uninsured rather than on Medicaid.

Figure 1.
Change in Dental Visits after Enrollment in NCHC



**Difference in distribution across insurance groups is statistically significant at p<.05.*

Dental Visits

In both surveys, parents were asked about the timing of their child's most recent dental visit. They were also asked where their child received dental care. There were significant differences in receipt of dental care prior to NCHC between the two groups: 57% of Medicaid recipients had a dental visit within the year before enrolling in NC Health Choice, compared with only 33% of uninsured children (Figure 1). Parents of uninsured children were more likely to report that prior to program enrollment their child had gone more than a year since receiving dental care (49%) or that s/he had never had dental care (18%), compared to the responses of parents of Medicaid children (33% and 10% respectively).

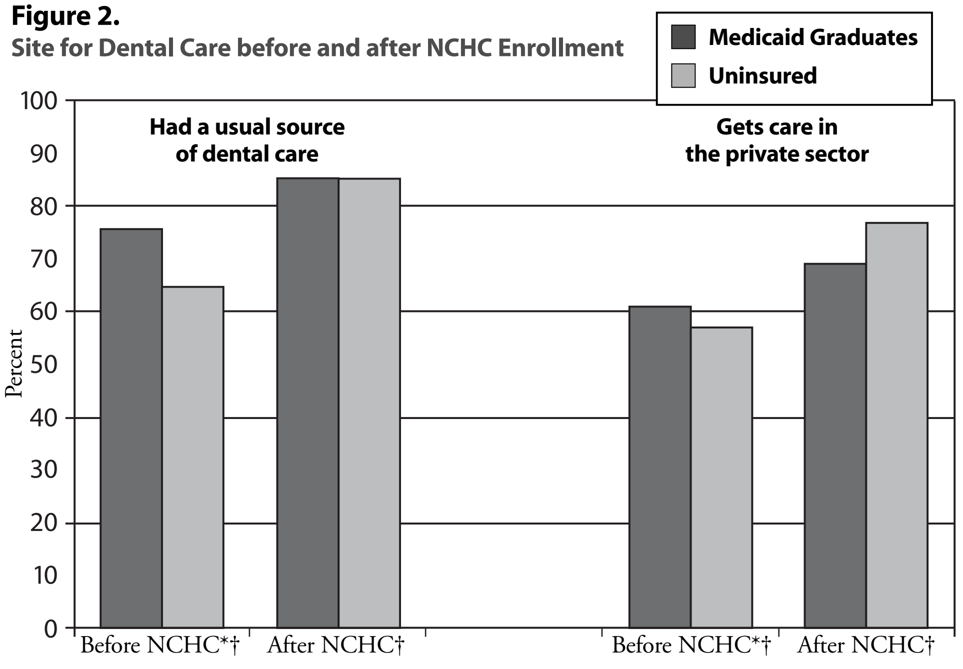
After program enrollment, differences in receipt of dental care between the two groups disappeared: 65% of previously uninsured children and 67% of Medicaid graduates made a dental visit during their first year on NC Health Choice. Although there was an increase for both groups in the percent of children who received dental care after NCHC enrollment, the improvement was much more dramatic for the uninsured children. The percent of uninsured children who had a dental visit in the previous year doubled after enrollment in NCHC compared to an increase of 18% for Medicaid graduates.

Source of Dental Care

Parents were also asked where they took their child for dental care. Children were considered to have a usual source of care if their parents reported taking them to a community clinic or health center, public health department or private dental office. Children were considered to have no usual source if their parent reported that they got care anywhere they could or that they never got care. In the year prior to NCHC enrollment, Medicaid recipients were significantly more likely than uninsured children (76% versus 64%) to have had a usual source of dental care (Figure 2). After enrollment, the percent of children with a usual source of dental care increased to 85% for both groups. As was seen with dental visits, the improvement was greater for the uninsured group, resulting in no significant difference between groups post-enrollment.

When receipt of care in the private sector is the only consideration, a different picture emerges (Figure 2). Prior to program enrollment, Medicaid children were significantly more likely than uninsured children to receive dental care at a private practice (61% versus 57%). After program enrollment the relationship was reversed, with children who were previously uninsured (77%) significantly more likely to receive care in the private sector than were

Figure 2.
Site for Dental Care before and after NCHC Enrollment



** Differences between insurance groups are statistically significant at p<.05.*
† Change across time is statistically significant at p<.05 for each insurance group.

Table 2.
Barriers to Dental Care

Characteristic	Insurance Status in Year before NCHC Enrollment	
	Uninsured (n=201) %†	Medicaid Graduates (n=391) %†
Had unmet need for dental care prior to enrollment*	58	33
Barriers prior to NCHC enrollment		
No insurance that would pay for care*	45	17
Not enough money to pay for the care*	51	16
Couldn't find dentist to see child*	6	17
Had unmet need for dental care after enrollment**	17	19
Barriers while on NCHC		
NCHC did not cover care child needed	7	8
Not enough money to pay for care*	3	7
Couldn't find dentist to see child	6	6

* *The difference in distribution between the two insurance groups is statistically significant at p<.05*
** *The difference within each insurance group prior to and after enrollment is statistically significant at p<.05.*
† *Denominator is all children in the insurance group.*

Medicaid recipients (69%), although there was a significant increase in private sector access for both groups.

Reported Unmet Need for Dental Care

Parents were asked if there was any time in the previous six months that they felt their child needed dental care that he or she could not get. For those with unmet need, barriers to care were queried (Table 2). To get a sense of the portion of all publicly insured children facing specific barriers, the percent reporting any particular barrier is reported as a portion of all those responding to the survey, not just those with unmet need for care.

In the six months prior to NCHC enrollment, a greater percentage of parents of uninsured children reported unmet need for dental care (58%) than did parents of Medicaid recipients (33%). For uninsured children, lack of insurance coverage and money were the main obstacles to care. Medicaid parents also reported these barriers, but they were significantly less likely to do so. Surprisingly, parents of 17% of Medicaid recipients (half of those with an unmet need) reported that they did not have insurance that would pay for the care although Medicaid does cover dental services. This may reflect need for a service that Medicaid does not cover, the parent's lack of knowledge about their child's benefits, or may indicate that dentists were unwilling to accept Medicaid coverage, so as to render the child's dental coverage ineffective. An almost equal proportion of Medicaid parents (17% of all Medicaid children and 49% of those with an unmet need) reported that they could not find a dentist who would see their child, an access barrier reported significantly more often for Medicaid recipients than for the uninsured.

After a year on NCHC, significantly fewer parents in both groups reported that their child had unmet need for dental care. On an additional positive note, the percent of Medicaid parents who reported that they could not find a dentist that would see their child dropped by two-thirds after enrollment in NCHC. Finally, after enrollment Medicaid parents were more likely than uninsured parents to report lack of money as a barrier to care.

DISCUSSION

The significant differences in access to dental care between the two groups prior to enrollment in NCHC suggest that Medicaid coverage does improve access to dental services for low-income children who would otherwise be uninsured, despite the known problems of low provider reimbursement and the reported reluctance on the part of providers to accept clients they believe will not keep appointments. Prior studies have found that whites and those with higher income and/or education are more likely to use dental services.[4] Those findings, however, might be attributed to private dental insurance coverage as those same groups are more likely to have such coverage, which itself predicts use of dental services regardless of socio-economic and demographic characteristics.[18] Since the uninsured group in our study was more likely to be white, have higher income and more education, one might expect this group to have greater access to dental services before NC Health Choice than did Medicaid graduates, and the pre-NCHC differences may understate the true difference between the two groups.

In general, the experience of former Medicaid children and uninsured children appears comparable after enrolling in NC Health Choice. Almost the same percentage of children in each group was reported to have visited a dentist in the first year on the program and to have a usual source of care. However, after NCHC enrollment Medicaid children were significantly less likely to report having a private dentist as their source of care than were uninsured children. Consistent with prior research identifying low reimbursement rates as a barrier to Medicaid children's receipt of care,[6] there was an increase in the percentage of Medicaid children who were able to access care in the private sector after NCHC enrollment. But, the fact that after enrollment in NCHC access to the private sector for Medicaid children was more limited than for the previously uninsured may be due to patterns of care prior to enrollment in NC Health Choice. Dental providers in Community and Migrant Health Centers and public health departments are far more likely to accept Medicaid coverage than are many private providers. Thus, Medicaid recipients may have continued to see a public dental provider with whom they had already established a relationship. It is also possible that differences in demographic characteristics between the two groups contributes to the higher likelihood that the previously uninsured group was seen in the private sector, as this group is more likely to be white and more educated.

Moving from Medicaid to NCHC improved dental access for all children in our study. The most obvious explanation for the improved access to dental services for Medicaid children after enrolling in NC Health Choice is the improvement in provider reimbursement, a known barrier to provider participation in the Medicaid program. The fact that NC Health Choice is administered by Blue Cross Blue Shield, coupled with higher reimbursement rates, may convince previously reluctant providers to participate in the program.

However, what is unknown is the extent to which the improved access afforded by NC Health Choice is a result of providers' perception that NC Health Choice beneficiaries are a different population and more likely to keep appointments. The social factors that make keeping appointments difficult, factors such as transportation problems and inflexible work schedules, will not have changed substantially with a child's transition from Medicaid coverage to coverage by NC Health Choice. It is not known if dentists even realize that the majority of NC Health Choice enrollees were previously on Medicaid. There is a public perception that NC Health Choice is a program for the working poor and that Medicaid is a welfare program, even though many children are served by both programs at different times in their lives.

Regardless of motivation of dental providers, NC Health Choice has improved access to dental care for North Carolina's poor children. In a time of fiscal crisis, changes to this insurance program, which currently covers approximately 100,000 children,[21] should be carefully considered to avoid loss of dental care gains afforded by this public insurance program.

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ARTICLE

Race and Colorectal Cancer Screening:
A Population-based Study in North Carolina

Deborah A. Fisher, MD, MHS, Karen Dougherty, MSN, ANP, Christopher Martin, MPH, Joseph Galanko, PhD, Dawn Provenzale, MD, MS, and Robert S. Sandler, MD, MPH

Abstract

Objective: *National and state data document racial differences in colorectal cancer (CRC) mortality and incidence. Screening for CRC reduces cancer incidence and deaths. Racial differences in colorectal cancer screening behavior may contribute to the racial disparity in incidence and mortality. The purpose of this study was to determine if colorectal cancer screening rates are different between blacks and whites while controlling for potential confounders.*

Study Design: *Cross-sectional survey.*

Data Source(s)/Study Setting: *We used data from the North Carolina Colon Cancer Study, a population-based case-control study conducted in 33 counties of North Carolina. We analyzed data from 598 control subjects who were eligible for colorectal cancer screening.*

Methods: *Trained nurses conducted face-to-face interviews from October 1996 through October 2000.*

Results: *Overall, 50% of the respondents were compliant with CRC screening guidelines. In the multivariable logistic regression model having a regular doctor and participation in a general medical exam were significantly associated with current screening status with odds ratios (OR) (95% confidence interval (CI)) of 3.8 (1.7-8.3) and 3.7 (2.1-6.7), respectively. Older age was a significant predictor of current screening status with an OR (95% CI) of 2.9 (1.7-4.8) for those 60-69 compared to respondents 50-59 and OR 3.2 (1.9-5.5) for those 70 and older compared to respondents 50-59. After adjusting for age, having a regular doctor and participation in general medical exams, race was not significantly associated with current CRC screening status, with an OR of 1.1 (95% CI 0.7-1.6).*

Conclusion: *CRC screening rates in North Carolina were low. Race was not a significant determinant of screening behavior and therefore does not explain the racial disparity in incidence or survival. Older age, having a regular doctor and participating in general medical exams were significant predictors of CRC screening.*

Relevance: *This study reinforces the fact that screening rates in North Carolina are low despite the strong evidence that colorectal cancer screening reduces cancer deaths.*

Nationally, colorectal cancer incidence and mortality is higher for blacks than whites.[1] State-level data in North Carolina also reveal this racial disparity.[2] The American Cancer Society and other organizations have endorsed several screening strategies[3,4] because colorectal cancer screening decreases colorectal cancer mortality and incidence.[5,6,7,8,9] Racial differences in colorectal cancer screening behavior may contribute to the racial disparity in incidence and mortality. Other possible predictors of colorectal cancer screening behavior include income, insurance status, education, participation in regular

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medical exams, current screening for other cancers, family history, and non-smoking status.[10,11,12,13,14,15] The purpose of this study was to determine if colorectal cancer screening rates are different between blacks and whites while controlling for potential confounders.

Table 1.
Characteristics of Study Sample N=598

Age mean (SD)	67.1	(8.0)
White	353	(59%)
Men	305	(51%)
Education		
<High school graduate	186	(31%)
High school graduate	155	(26%)
Some college	124	(21%)
College graduate	130	(22%)
Insurance		
Government only	121	(20%)
HMO or private	459	(77%)
None	18	(3%)
Annual Household Income		
Less than $20,000	236	(39%)
$20-50,000	209	(35%)
Greater than $50,000	153	(26%)
Married	385	(64%)
Smoking status		
Current	102	(17%)
Former	236	(40%)
Never	258	(43%)
Had a Regular Doctor	552	(92%)
Rural	469	(79%)

SD = standard deviation

Methodology

We used information from the North Carolina Colon Cancer Study (NCCCS), a population-based case-control study conducted in 33 contiguous counties of central and eastern North Carolina from October 1996 to October 2000. Control subjects younger than 65 were selected from Department of Motor Vehicle Registry tapes. Control subjects age 65 and older were selected from the Centers for Medicare and Medicaid Service's tapes. Trained nurses conducted face-to-face interviews with the subjects. Questions about screening tests included the total number of each test [fecal occult blood test (FOBT), colonoscopy, flexible sigmoidoscopy, and barium enema] done in the past 10 years, the date of the most recent test and whether the most recent test was for screening or a problem. The interviewers also asked about physical activity, tobacco use, family history, occupation, income, health insurance, source of health care, health seeking behavior and health status.

We considered a subject "current" for colorectal cancer screening if he or she had been tested within the time frame endorsed by the American Cancer Society and others at the time of the study: FOBT within one year, flexible sigmoidoscopy within five years, barium enema within five years, or colonoscopy within 10 years beginning at age 50.[3,4] We restricted the study sample to individuals eligible for screening. Thus, we only used data from the control subjects. In addition, we excluded subjects younger than age 50 and those who had tests performed for symptoms or problems. Individuals in the latter category would be at a higher risk for colorectal cancer and therefore would be surveillance candidates and not screening candidates who are, by definition, at average risk for a condition.

Analysis

Logistic regression modeling was the primary analytic technique. We performed all analyses using PC-SAS Version 8.2 for Windows (SAS Institute, Cary, NC).

We constructed unadjusted and adjusted logistic regression models with colorectal cancer screening status as the dependent variable and race as the independent variable. We developed the adjusted model by first including race and any predictor variables with a p value <0.1 in univariate analysis (chi-square test). We reduced the model by stepwise backward regression. We chose, *a priori*, p<0.05 as the level of significance for the models.

We categorized variables as follows: age (50-59, 60-69, 70 and older), education level (less than high school graduate, high school graduate, at least some college, college graduate), insurance status [government (Medicare, Medicaid, CHAMPUS, CHAMPVA), private/HMO, none], income (< $20,000, $20-50,00, >$50,000), residence (rural, urban), marital status (married, not married), health status (mental component summary and physical component summary from the Short Form-1216, smoking status (never, former, current), physical activity (MET-minutes per day by quartile) and participation in a general medical exam (yes, no).

The University of North Carolina at Chapel Hill Institutional Review Board approved this study. All subjects gave written informed consent.

Results

Sixty-two percent of the subjects screened agreed to participate in the NCCCS for a total of 1,051 subjects. After elimination of patients younger than 50 and those with a history of colorectal cancer testing for symptoms, 700 subjects remained. We further excluded 102 subjects with missing data for a response or explanatory variable, leaving 598 subjects. Approximately half all of the patients were men, 59% were white and 41% black. Table 1 lists additional characteristics of the study sample. Univariate analysis revealed associations between current colorectal cancer screening and the following predictor variables at the p<0.1 level: age, income, health insurance type, education, having a regular doctor, marital status, and participation in a general medical exam. In the unadjusted model, race (black vs. white) was not significantly associated with current screening status with an odds ratio (OR) of 0.74 (95% confidence intervals (CI) 0.53-1.02). The adjusted logistic regression model included race (black vs. white), age (50-59, 60-69, (70), income (< $20,000, $20-50,00, >$50,000), having a regular doctor (yes, no) and participation in general medical exams (yes, no). Having a regular doctor, participation in a general medical exam, higher income and older age were significantly associated with current screening status (Table 2). Race was not significantly associated with current CRC screening status, with an OR of 0.98 (95% CI 0.67-1.43).

Table 2.
Independent predictors of current participation in colorectal cancer screening*

Variable	Odds Ratio	95% Confidence Intervals
Race		
Black vs White	0.98	0.67-1.43
Household income		
>$50,000 vs $20-50,000 per year	2.38	1.47-3.85
>$50,000 vs <$20,000 per year	2.86	1.69-4.76
Age		
≥70 vs 60-69	2.84	1.68-4.78
≥70 vs 50-59	3.17	1.89-5.32
Had a Regular Doctor		
Yes vs No	3.79	1.67-8.63
Participated in General Medical Exam		
Yes vs No	3.79	2.13-6.71

* *each item was simultaneously controlled for other items in the table*

The sample size was insufficient to construct logistic regression models for gender subsets to explore the relationship between participation in breast or cervical cancer screening and colorectal cancer for women or participation in prostate cancer screening and colorectal cancer screening for men. Gender, itself, was not significantly associated with current colorectal cancer screening at the p<0.1 level in univariate analysis, and therefore, was not included in the logistic regression model.

Discussion

This North Carolina population study of subjects eligible for colorectal cancer screening confirms other reports of low colorectal cancer screening rates.[13,14,17] Race, however, was not a significant determinant of current screening participation. Income and age were associated with colorectal cancer screening behavior, but the strongest predictors of adherence to colorectal screening guidelines were having a regular doctor and participation in general medical exams. While 53% of the patients with a regular doctor were current with colorectal cancer screening only 17% of those without a regular doctor were current. Similarly, 55% of those who had participated in a general medical exam were current with colorectal cancer screening while only 20% of those who had not participated in a general medical exam were current. In multivariate analysis, the odds of being up-to-date with colorectal cancer screening were reduced by 74% for those without a regular doctor and for those who had not participated in general medical exams.

Other large survey studies have examined predictors of fecal occult blood testing or lower endoscopy and none have found a clear association between race and participation in the tests. An analysis of the 1997 Behavioral Risk Factor Surveillance System (BRFSS) data, a national telephone survey, found no difference in colorectal cancer screening rates between blacks and whites. Having health insurance and increasing age (up to 79), income, and education were associated with screening status. Healthy behaviors were examined and non-smoking status, seatbelt use, physical activity, increased fruit and vegetable intake and recent cholesterol screening were all associated with current colorectal cancer screening. Participation in medical examinations and having a regular doctor were not examined in this study.[14] Analysis of the 1998 National Health Interview Survey data (NHIS), a face-to face national survey, again found increased education and having insurance predict colorectal cancer screening status. The NHIS study found no association between race and colorectal cancer screening. The strongest predictor of colorectal cancer screening was having a usual source of care, which, while not identical to continuity of care (i.e. having a regular doctor), is related.[18] Another analysis of the same 1998 NHIS data did find a small but statistically significant association of white race compared to black race or "other race" and reported colorectal cancer screening. One explanation for the discrepancy was that different screening intervals were used in the two studies.[17] A face-to-face interview study performed in the Mid-West found that having had a physician visit in the prior year was a strong predictor of ever having had a FOBT and ever having undergone sigmoidoscopy. Higher education was also a predictor of having had each test. Smoking status was only associated with the FOBT and increased income was only associated with sigmoidoscopy. The sample was over 98% white and therefore racial differences in screening behavior could not be addressed.[15]

While our study does not provide an explanation for the racial gap in colorectal cancer incidence or mortality, it does offer insights to increase colorectal cancer screening participation for the general population. Our results suggest that health maintenance visits and continuity of a primary care provider may be facilitators of colorectal cancer screening participation. The association of higher income and screening behavior is likely related to an increased ability to afford the tests, both the costs associated with the test itself and the costs of missing work, traveling to the doctor's office and related expenses. Even in an insured study sample (97%), colorectal cancer screening is not without expense because of variable insurance coverage for colorectal cancer screening and the indirect costs listed above. Increased ability to afford colorectal cancer screening should increase compliance with provider screening recommendations. Additionally, subjects with higher incomes may have been more likely to request screening, knowing that they had the financial resources if the screening was not covered by their health insurance. Ensuring adequate coverage and educating consumers about their colorectal cancer screening benefits are important to increase colorectal cancer screening participation.

The strengths of our study include identification of test indication, determination of all endorsed screening strategies, use of a representative population sample and adequate response rate. The use of radiologic and endoscopic tests for diagnosis or therapy is important, but the accuracy of predictors of screening behavior relies on determination of the test indication. In contrast to the Behavioral Risk Factor Surveillance System (BRFSS) survey, we distinguished between CRC testing for screening and for diagnostic purposes.[2,14] Further, we asked about all recommended screening options allowing us to correctly identify screened patients who may have been missed using surveys, such as the BRFSS and National Health Interview Survey (NHIS) that only asked about certain screening modalities.[14,17] This study has the limitation of using self-reported data without validation from another source. However, a study in a community family practice setting found high correlations for fecal occult blood testing (0.78) and sigmoidoscopy (0.90) when comparing chart audit with patient survey.[19] In addition, two studies in the managed care setting investigating the relative sensitivity of patient survey compared to medical record audit found a 92-96% sensitivity of the survey to detect fecal occult blood testing, 79%-95% sensitivity to detect flexible sigmoidoscopy and an 89% sensitivity for detecting colonoscopy.[20,21]

In conclusion, older age, higher income, having a regular physician and participation in general medical exams were associated with colorectal cancer screening behavior. Several patient, provider and system level factors are likely to be responsible for the low colorectal cancer screening rates in North Carolina and nationally. Our study demonstrates that there are continued financial barriers. It also supports the importance of factors related to the primary care setting. Future directions include testing interventions that increase continuity of primary care and health maintenance visits.

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POLICY FORUM
Organ Donation and Transplantation

Introduction

Gordon H. DeFriese, PhD

Issue Brief:
The Donation of Human Organs and the Evolving Capacity for Transplantation: Exciting Developments and Future Prospects

Erika L. Rager, MD, MPH

> *"The current donor system depends on a patchwork of organ donor cards, driver's licenses, advanced directives, and durable power of attorney for healthcare statements as vehicles for citizens to state their wishes."*

COMMENTARIES

Increasing Donation: Key Factors to Save More Lives

Lloyd Jordan

The Gift Relationship in Process: From the Donor to the Recipient

Julie Landon, RN, CPTC

The Rapid Development of Solid Organ Transplantation in North Carolina

Michael R. Mill, MD

Building a Modern Transplant Center

J. Elizabeth Tuttle-Newhall, MD

Some of the Challenges of Organ Donation Among Minority Populations

Lynt B. Johnson. MD, FACS

A Minority Perspective: The State of Minority Donation in North Carolina

Debbie Mann Gibbs

"What's in Your Wallet?" Will Your Intentions Be Known?

Betsy J. Walsh, JD, MPH, and Judy Jones Tisdale, PhD

SPECIAL ARTICLE

Giving and Receiving when Vital Organs Fail

Donald L. Madison, MD (with Andrew, Susan, and James Pike)

INTRODUCTION

Policy Forum:
Organ Donation and Transplantation

Almost every week, we hear stories from North Carolina and elsewhere in the nation about an individual who is desperately waiting for word that a bodily organ is available to replace one that is seriously diseased or malfunctioning. Life is both literally and figuratively "in the balance" as the waiting game goes on, sometimes for months or years. Why is it that so few people, particularly so few from minority population groups, are willing to take the necessary steps before the time of their own death to assure both healthcare providers and their families of their intention to donate organs that might save or improve the lives of others? Why are we burying so many of these vital organs day-after-day, rather than extending the lives of those in need? Why is it so difficult to find live donors of organs that might offer the same life-saving benefits, without compromising the health of the donor? These are important questions of health policy significance, as well as tremendously important personal issues for those whose lives have been touched by the events and circumstances which have made either organ donation or receipt major issues of concern.

The other dimension that captured the interest and concern of our editors is that the science and skills of transplantation are now such that most recipients of donated organs have the prospect of living full and functional lives without overwhelming concerns they once would have had with rejection and the need for further transplantation. The rapid diffusion of transplantation technologies and skills and the development of multi-organ transplantation services within our state's largest hospitals, has given all North Carolinians access to some of the world's most advanced medical care for conditions where only transplantation offers hope.

In this issue of the *Journal* we are pleased to offer a set of articles providing a broad overview of many of these concerns in the hope that more attention will be given to this important aspect of contemporary medical care for those who could benefit from an expansion of both our donor networks and participation, as well as from the advancing science of transplantation. Erika Rager, MD, MPH, a surgical resident at UNC-Chapel Hill who is currently taking a two-year residency in preventive medicine, offers a comprehensive issue brief on the topic. We are pleased that leading figures from the transplant services of both Duke Medical Center and UNC-Chapel Hill have agreed to participate in this special issue forum. In addition we are pleased to include contributions from our two donor organizations in the state, Carolina Donor Services and LifeShare Of The Carolinas. Because of our concern over the rather low rate of participation of minority populations in organ donation and transplantation, we have invited Dr. Lynt Johnson of Georgetown University, an African American transplant surgeon, and Debbie Mann Gibbs of LifeShare Of The Carolinas to help address these issues. Finally, Contributing Editor Donald Madison, MD, offers an interesting interview with a North Carolina family who has experienced a broad spectrum of these issue first-hand.

For those who may not have previously signed (and had witnessed) a donor card, one is provided in this issue of the *Journal*, which may be clipped and placed in one's wallet along with a driver's license.

As always, we invite the comments and reactions of our readers to these and other topical issues covered in these pages.

—Gordon H. DeFriese, PhD
Editor-in-Chief and Publisher

The Donation of Human Organs and the Evolving Capacity for Transplantation:

Exciting Developments and Future Prospects

Erika L. Rager, MD, MPH

Solid organ transplant is the best treatment and only cure for many people suffering from end-stage disease. Over the past 20 years, improvements in immunosuppression and increasing experience in caring for transplant patients has resulted in massive increases in the use of this therapy. Now, the numbers are truly staggering. As of December 15, 2003, there were 83,686 patients with end-stage organ disease awaiting transplant in the US. In 2002, there were 12,801 deceased and living organ donors; 24,900 patients underwent transplantation; and 6,187 died while waiting on the list.[1] About 56 people receive an organ transplant every day in the US and four North Carolinians die each week waiting for an organ transplant. The therapeutic application of organ transplantation is limited only by a shortage of donor organs.

Brief history of organ transplantation

Development of organ transplantation as a widely applicable therapy depended on technical advancements in the field of surgery and increased understanding of immune function. The initial technical advancements in vascular anastomosis (surgical techniques to sew together blood vessels) that were necessary for later organ transplantation were developed by French surgeon Alexis Carrel in the early 1900's. Animal studies over the next 50 years resulted in techniques for the transplantation of kidneys, abdominal and thoracic organs.[2]

Based on studies of skin grafting, by the 1940's scientists understood that rejection of transplanted tissues was an immunological event. Initial attempts to modulate the immune system in humans used sublethal doses of total body irradiation to suppress bone marrow production of white blood cells. This immunosuppression led to occasional long-term survival of transplanted organs, but was unreliable. By the early 1960's, researchers were using drugs to suppress the bone marrow. Medication regimens based on azathioprine and prednisone improved patient survival in the 1960's and 1970's, especially for living-related kidney transplants.[2,3] In the late 1970's, the immunosuppressive drug cyclosporine was introduced. Cyclosporine dramatically changed the course of organ transplantation. One-year survival rates increased from 30-60% to 70-90%.[4] Transplantation of kidneys, livers, hearts, and lungs became widespread.

The first transplant that enjoyed long-term success was a living-related renal transplant performed between identical twins in 1954 by Dr. Joseph Murray. In 1990, Dr. Murray was awarded the Nobel Prize for Medicine for his achievements in the field of transplantation. Aside from the first successful renal transplant in 1954, most of the first successful solid organ transplants occurred in the late 1960's.

Table 1.
Milestones in Transplantation in North America

1954	First successful kidney transplant
1966	First successful kidney-pancreas transplant
1967	First successful liver transplant
1968	First isolated pancreas transplant
1968	First successful heart transplant
1981	First successful heart-lung transplant
1983	Cyclosporine receives FDA approval
1983	First successful single lung transplant
1986	First successful double lung transplant
1989	First successful living-related liver transplant
1990	First successful living-related lung transplant

Source: Adapted from www.optn.org

Organ procurement and preservation, tissue matching, and immunosuppression are the principal ingredients for successful solid organ transplantation. The technical aspects of the organ procurement operation allow multiple teams to work together to procure all useful organs from a single donor. Modern preservation fluids increase the length of cold ischemic time (time outside the donor's body for transport to the recipient)

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that an explanted organ can tolerate. Preservation fluids are ice-cold solutions that include electrolytes, antioxidants, hydrogen ion buffers and sugars.[5] Appropriate tissue matching depends on blood group matching (e.g. blood type A, B, or O) for all organs. Kidneys are also tissue-matched based on HLA (human lymphocyte antigen) type and lymphocyte (white blood cell) cross-matching tests.[2] Cross-matching mixes the recipient's serum with the donor's lymphocytes to test immunologic compatibility. Today's immunosuppressive regimens typically include three drugs: a glucocorticoid such as prednisone, an antimetabolite such as azathioprine or mycophenolate, and a calcineurin inhibitor such as cyclosporine or tacrolimus.

Table 2.
ABO Blood Type Compatibility

Transplant	Acceptability
O to non-O	Safe
Rh- to Rh+	Safe
Rh+ to Rh-	Relatively safe
A to non-A	Dangerous
B to non-B	Dangerous
AB to non-AB	Dangerous

Source: Adapted from Starzl, World J Surg 2000

STRUCTURE OF THE NATIONAL ORGAN PROCUREMENT AND TRANSPLANTATION SYSTEM

Current Scope of Solid Organ Transplantation

Solid organs that are transplanted in the US include kidney, liver, heart, lung, pancreas, and small intestine. There is an allocation policy specific to each donor organ. Potential recipients are listed based on objective criteria that include blood type, tissue type, size of organ needed, medical urgency of the recipient, time on the waiting list and distance between the donor and recipient.[1] The process of identifying potential organ donors, placing their organs with appropriate recipients and coordinating the transplant operations is a complicated process involving many organizations working together.

Organ Procurement and Transplantation Network

The Organ Procurement and Transplantation Network (OPTN) was created by the National Organ Transplant Act of 1984. The OPTN facilitates organ matching. It develops policies and procedures for organ recovery, allocation, and transportation. It also collects, manages and distributes data about organ transplantation. Finally, it provides both professional and public education about organ donation and transplantation. In order to receive Medicare funds, all transplant centers and OPO's must be members of the OPTN. The OPTN has a variety of other members, including independent histocompatability laboratories, professional organizations, patient advocacy organizations and members of the general public.[1]

All organ transplant programs in the US are members of the OPTN. Members of the OPTN are certified as compliant with the rules that are in place to ensure the public safety, and highest level of care for organ donors and recipients. The OPTN membership bylaws explicitly outline the requirements for a transplant center. Program staffing requirements include a medical director, clinical transplant coordinator (usually a nurse), financial coordinator, and staff to provide social support. Transplant centers must have specially-trained transplant surgeons and transplant physicians with extensive qualifications. The OPTN also monitors survival rates at each transplant center, and those who fall below a given threshold level are reviewed.[1,6]

United Network for Organ Sharing

The United Network for Organ Sharing, or UNOS, is a private, nonprofit organization that contracts with the federal government to administer the Organ Procurement and Transplantation Network. The centralized computer network at the UNOS Organ Center links OPO's and transplant centers. All patients on the transplant waiting list are registered with UNOS.[1] On average, UNOS receives 350 calls per day from OPO's.[7]

Regions

The US is divided into 11 regions. North Carolina is in Region 11, along with Kentucky, South Carolina, Tennessee and Virginia.

Organ Procurement Organizations

Organ Procurement Organizations (OPO's) are private, nonprofit organizations that are members of the OPTN and certified by the Health Resources and Services Administration. Each OPO has its own board of directors and medical director, usually a transplant surgeon or physician. Procurement coordinators work for the OPO. They are highly trained professionals, often nurses, who coordinate each step of the transplant process.

The OPO's are involved in every step of a deceased-donor (cadaveric) organ transplant, from evaluating potential donors, to obtaining consent from the donor's family, placing the organs and traveling with the procurement team to obtain the organs. The OPO's other primary role is to promote organ donation within the community. They engage in public and professional education efforts in the community and in the hospitals they serve.

The OPO's have defined service areas designed to assure maximum effectiveness in organ procurement and equitable distribution of organs. There are currently 59 OPO's. The OPO's serve all the hospitals in their designated geographical areas. North Carolina is served by two OPO's. Carolina Donor Services serves 79 counties in North Carolina, and Danville, Virginia. LifeShare Of the Carolinas serves 23 counties in southwestern North Carolina and York County, South Carolina.[1,8,9]

LEGISLATIVE HISTORY

Uniform Anatomical Gift Act

The Uniform Anatomical Gift Act (UAGA), promulgated in 1968, established the legal framework for organ donation. A version of the UAGA was adopted in each state and the District of Columbia. The scope of the act is limited to organ procurement. It requires hospitals to establish affiliations with regional organ procurement organizations to coordinate the procurement of organs. The UAGA holds that all citizens aged 18 and over have the right to decide for themselves if they choose to be organ donors. It established the Uniform Organ Donor Card as a legal document. The law does not require the consent of next of kin for the procurement of organs from a brain dead patient with written documentation of intention to donate, such as a signed donor card or driver's license.[10] However, in practice, the OPOs require consent from the patient's family prior to organ donation. The law also establishes the order of priority in obtaining consent: spouse; adult son or daughter; parent; adult sibling; grandparent; and legal guardian.[1]

National Organ Transplantation Act

In 1984 Congress passed the National Organ Transplant Act (NOTA). This act established the Organ Procurement and Transplantation Network (OPTN). The OPTN has two primary goals: to increase the effectiveness and efficiency of organ sharing and equity in the national system of organ allocation; and, to increase the supply of donated organs available for transplantation.[1] NOTA also expressly forbids the buying or selling of organs.

The US Department of Health and Human Services, through the Health Resources and Services Administration, contracts with a private, nonprofit organization to operate the OPTN. Since 1986, the United Network for Organ Sharing (UNOS), based in Richmond, Virginia, has administered the OPTN. UNOS operates the national wait list.

Omnibus Budget Reconciliation Act

A 1986 amendment to the Social Security Act requires hospitals that receive Medicare or Medicaid funding to have written protocols for the identification of potential organ donors and notification of the local OPO. It also requires hospitals to make families aware of the option to donate or to decline to donate. Transplant hospitals are required to be members of the OPTN and abide by the Network's rules. Finally, it added limited coverage for immunosuppressive drugs for Medicare patients.[1,8]

Medicare ESRD Program

Prior to the 1960's, End-Stage Renal Disease (ESRD) was a certain death sentence. In that decade, two powerful treatment options emerged: dialysis and transplantation. Congress created the ESRD Program in 1972. It covers most medical care for almost all ESRD patients. When the program was created, there were 10,000 eligible patients. By 2000, there were over 323,000 patients receiving treatment for ESRD. This number is expected to continue to grow rapidly. Current estimates are that in 2010, there will be 651,000 ESRD patients.[11] For those patients for whom it is medically appropriate, transplantation is preferable to dialysis. It leads to longer life expectancy, better quality of life, and lower costs than dialysis.[12]

Other Legislation

In 1998, the US Department of Health and Human Services made changes to the Conditions of Participation for hospitals that receive Medicare and/or Medicaid funding in an attempt to increase organ donation. Hospitals are required to notify the local OPO of all deaths or imminent deaths. The individual who initiates family discussions about organ donation must be a representative of the local OPO or someone who has been specially trained to request organ donation.[8] This is not typically a physician. Decoupling the discussions about brain death and organ donation is thought to increase the consent rate. Requests for organ donation that come from someone specially trained, such as an OPO representative, are also thought to increase consent rates.

This year the Organ Donation and Recovery Improvement Act was introduced in the US Senate. If passed, it would fund a public education campaign and hospital organ donation coordination programs. It would also allow reimbursement to organ donor families for travel and subsistence expenses. However, the idea of providing reimbursement to donor families is controversial and in contradiction to the National Organ Transplantation Act.

North Carolina Legislation

The "Gift of Life Act," passed in 1997, requires hospitals to notify the local OPO of all cardiac deaths or impending brain deaths of patients up to age 75. It also designates OPOs as responsible for evaluating all referrals for potential donation and informing families of the option to donate.

THE PROCESS OF ORGAN DONATION AND TRANSPLANTATION

When a transplant center initially decides that a patient with end-stage disease is appropriate for transplant, the potential organ recipient's name and medical information are entered into a computer database at the UNOS Organ Center. At this point, the patient has been "listed" for transplant. The potential transplant recipient then waits on the list until a donor organ becomes available. As the waiting lists grow longer, so do the waiting times. Almost half of all transplant candidates in North Carolina who are waiting for kidney or heart transplants have been waiting more than two years. More than half of those waiting for liver, lung, and heart-lung transplants have been waiting more than two years.[1]

Brain Death

The donor process begins when a local OPO is contacted by a hospital caring for a patient with impending brain death. The vast majority of organs procured from deceased donors come from donors who have sustained brain death under circumstances that allow their respiration and circulation to continue to be supported by artificial means. The acceptance of organ procurement for transplantation depends on understanding the concept of brain death. Under the Uniform Determination of Death Act,[13] drafted in 1980 and adopted by 43 states, death is defined as either irreversible cessation of circulation and respiration, or irreversible cessation of all brain and brainstem function.[8] Prior to the declaration of brain death, several other diagnoses must be ruled out, including hypothermia, circulatory shock, drug intoxication, metabolic intoxication from kidney or liver failure, and the prolonged effects of neuromuscular blocking drugs.[14]

A physician must certify a patient as brain dead in order for that patient to be an organ donor. The criteria for diagnosing brain death vary from hospital to hospital, but they include some combination of physical exam and other tests. The usual tests include reflexes such as gag, cough and pupillary response to light. An apnea test is performed to determine that the patient cannot breathe without mechanical assistance. A cerebral blood flow test may also be performed to determine whether or not there is blood flowing to the brain.[8]

Brain death can be caused by any condition that interrupts oxygen delivery to the brain. Such conditions include trauma, stroke, intracranial bleed, drowning, carbon monoxide poisoning, drug overdose and others.[8] The most common causes of death for organ donors are head trauma, cerebrovascular accident (stroke), and anoxia (lack of oxygen supply to the brain).[1]

Potential organ donors undergo physiologic changes that require aggressive medical management prior to and after the declaration of brain death. Medical interventions are often required to maintain adequate intravascular volume and blood pressure; maintain body temperature; correct coagulopathy (bleeding disorders); avoid elevated intracranial pressures; and treat hormone imbalances such as diabetes insipidus. The most common complication, occurring in up to 91% of patients, is hypotension (low blood pressure) requiring invasive monitoring and/or support with vasopressors (medicines to increase blood pressure). Timely determination of brain death is important to protect the condition of the donor's organs. A rapid brain death determination protocol can reduce medical failures prior to organ donation and can increase consent rates for donation. It can also increase the number of organs procured per donor to a level well above the national average.[14]

Table 3.
Maximum Cold Ischemic Time

Organ	Preservation Time
Heart and Lungs	4-6 hours
Liver	12-24 hours
Kidney	48-72 hours
Pancreas	12-24 hours
Small Intestine	12 hours

Source: Adapted from www.lifesharecarolinas.org and Punch, JD.

Organ Allocation and Procurement

After the declaration of brain death, the donor OPO performs a medical evaluation and contacts the patient's family to discuss organ donation. Once the family agrees to donation, the procurement coordinator from the OPO takes over medical management of the donor. At the same time, the coordinator contacts the UNOS Organ Center to begin the process of organ placement.

Each time a donor organ becomes available, the UNOS computer compares characteristics of the donor with each individual waiting for that type of organ. The computer then generates a list of potential organ recipients, the "match-run" list, ranked in order based on characteristics such as blood type, body size, medical urgency, waiting time and location. Factors such as race, religion, gender and financial status do not enter into the equation.[8]

The allocation policy is somewhat different for each organ. In general, organs first are offered to patients awaiting transplant within the OPO in which the organs were donated. They are then offered regionally and nationally. Some organs are offered based on recipient distance (in air miles) from the donor hospital. This policy decreases organ preservation time, thus improving organ quality and recipient outcomes. It also reduces costs to the transplant patient and provides more equitable geographic access to transplantation.[1]

Once the match list is available, the procurement coordinator contacts the transplant team caring for the patient at the top of the list. The transplant surgeon determines whether or not the organ being offered is appropriate for that patient. If so, the organ procurement and transplant operations are scheduled. If not, the procurement coordinator moves to the next patient on the list, calls that patient's transplant team and offers the organ. This process continues until all the available organs from a given donor are placed with transplant recipients.[8]

The accepting transplant teams travel to the donor's hospital, where the procurement operation takes place. Transplant teams from widely separated centers can share organs from a common donor. Surgical techniques allow any combination of organs to be removed. Preserving solid organs depends on rapid intravascular cooling done in situ (in the body), followed by removal of the organs, storage of the organs in ice-cold preservation fluid and rapid transport to the recipients' hospitals.[2] The cold ischemic time is the length of time the organs are on ice, without blood flow. The maximum cold ischemic time limits the amount of time that can pass between organ recovery and the organ transplant.

UNOS functions as the middle-man between the donor OPO and the receiving OPO. The donor OPO receives the match-run list, but does not have access to information about other patients who are listed for transplant. The receiving OPO can access wait lists for the hospitals that they serve, but cannot see the match-run list. This system was put into place to prevent individual transplant centers from manipulating the donor system.[7]

From the time consent for organ donation is obtained, all costs incurred in the donation process are billed to the OPO.

INCREASING THE NUMBER OF ORGANS FOR TRANSPLANT

One of the biggest challenges facing the transplant community at this time is a stagnant number of deceased donors in the face of an ever-increasing need for donor organs.

A number of options for expanding the pool of available organs exist. Increasing the rate of consent by families of potential donors could expand the pool of deceased donors. Policy changes in consent for organ procurement may increase available organs. Increased use of living donors for kidney, liver and lung transplants is an attractive option, although this practice is debated as it exposes otherwise healthy people to risk of morbidity and mortality. Compensation to donor families, once taboo, is now being debated. Technical changes include expanded donor criteria and non-heartbeating donors. Biological research aimed at xenotransplantation (animal-to-human transplantation) is ongoing, but this is not currently a viable solution.

Table 4.
Patient Waiting List for Organ Transplants as of January 21, 2004

Organ Needed	Patients in US	Patients in NC
Kidney	56,519	1,945
Liver	17,283	687
Lung	3,915	220
Heart	3,542	73
Kidney-Pancreas	2,417	96
Pancreas	1,527	15
Heart-Lung	189	17
Intestine	171	1
Total	**83,570**	**2,965**

Source: www.optn.org

Missed Donors

Over the past 10 years, between five and six thousand organs were procured from deceased donors each year. However, it has been unclear how many potential donors are available but do not donate. Recently, the Association of Organ Procurement Organizations published a large study[15] that indicates 54% of those families asked to donate agreed to do so. Only 42% of potential donors actually became donors. From 1997-1999, it is estimated that about 13,500 potential donors were available each year; this appears to be a stable pool of potential donors. There were about 5,500 actual donors each year. The population base for this study was large, and it probably accurately represents what is happening nationwide. However, the OPOs in the Southeastern United States did not contribute any data to this study.

Increasing the consent rate among potential donor families is one way to significantly increase the number of organs available. In fact, if all potential donors became actual donors, there would be enough hearts and kidneys available to transplant each person added to the list in 2002.[15] This study offered important insight into how this goal might be accomplished. Families of brain dead patients were less likely to donate if the patient was older, non-white or died from a cause other than trauma. Moreover, 89% of potential donors and 91% of actual donors were cared for at hospitals with 150 or more beds; 88% of potential donors who did not ultimately donate were cared for at these larger hospitals. That indicates that efforts to increase donation should be concentrated at these larger hospitals.

In March of 2002, Carolina Donor Services surveyed residents in the counties that it serves in an attempt to better understand residents' attitudes and awareness concerning organ donation. They found that families, friends, medical providers and clergy were most likely to influence the intention to be an organ donor. While 97% agreed that "organ donors provide the gift of life" and 93% agreed that "people are dying because there aren't enough organs available," only 56% intend to donate their organs when they die. As compared to whites, African Americans are more likely to be unsure about donating (45% vs. 22%) and are more likely to be opposed to organ donation (21% vs. 12%).[8]

The main factors that motivate North Carolinians to be organ donors are a sense of altruism and practicality. The chance to help someone else or save a life motivates 65% of donors, while 29% say that they intend to be a donor because "I don't need organs when I die." The most commonly reported reason people decide not to be donors is that they think they are too old or unhealthy to donate (26%). Other common reasons are that they never thought about it (19%) or that they are uncomfortable with the idea (15%).[8] Carolina Donor Services used the results of this survey to plan educational interventions to increase organ donation.

Carolina Donor Services also found that only 63% of people know that major religious groups support organ donation. In fact, all major religions in the US support organ donation and transplantation.[8]

Consent Procedures

The current donor system depends on a patchwork of organ donor cards, driver's licenses, advanced directives, and durable power of attorney for healthcare statements as vehicles for citizens to state their wishes. This is an "opt-in" system; it depends on routine referral of all potentially medically eligible donors to the local organ procurement organization (OPO). Trained professionals from the OPO then initiate contact with the patient's family regarding potential donation. The OPO attempts to ascertain the patient's wishes from documentation and discussions with the family. Even if the potential donor indicated his or her wish to donate, consent is still obtained from the family.

Eighty two percent of Americans believe that the individual, rather than his/her family, should make the decision regarding organ donation. Unfortunately, the same study found that 58% of Americans were unsure about their plans to donate or not to donate after death (30% intended to donate and 12% intended not to donate) and only 38% had discussed their plans with their families.[16]

These numbers are important because, in practice, the OPOs place tremendous weight on the family's wishes when obtaining consent for organ donation. A survey of all OPO's found that 48% rank impact on the deceased's family as the most important factor when obtaining consent, while only 12% rank the deceased patient's wishes as the most important factor.[17]

Other Options for Consent

Some European countries approach consent for organ donation via an "opt-out" system. Citizens are presumed to consent to donation unless they explicitly state that they do not want to be donors. Spain, Austria, France, Portugal, and Belgium have presumed consent policies. The British Medical Association favors such a policy in the United Kingdom.

The Belgian system serves as an interesting example. It allows any citizen to register his objection to donation at the local town hall. A national database tracks those who have opted-out; less than two percent of Belgian citizens have done so. Doctors ask the patient's family to confirm the fact that the patient did not object, rather than asking the family to make the decision to consent to donation. The system also allows physicians to defer procurement for any valid reason. This system, enacted in 1986, led to an increase in the number of organ donors and an increase in the number of organs procured per donor.[18]

Mandated choice is a system that compels competent adults to decide whether or not they wish to be organ donors when they die. The decision could be required when obtaining a driver's license or filing a tax return. Under this system, each person must consider the issue and make a decision; the individual's decision is honored at the time of death.[16]

A Gallup poll conducted in 1993 provides the most recent evidence on public opinion regarding mandated choice. Thirty percent of those surveyed had signed organ donor cards. When asked if they would sign up to donate if mandated choice became law, 63% said yes.[16] Based on the results of this survey, mandated choice would increase the number of available organs. Given that 82% of people think that the individual rather than his family should make the decision about organ donation, and that under mandated choice the individual's decision would be binding, mandated choice could protect individual autonomy while also sparing the potential donor's family an important decision at a difficult time.

> *Some European countries approach consent for organ donation via an "opt-out" system. Citizens are presumed to consent to donation unless they explicitly state that they do not want to be donors.*

A more subtle finding in this study is that the more one thinks about organ donation, the more likely s/he is to donate. Of the 25% who previously gave organ donation serious thought, 76% decided to donate.[16] It appears that mandated choice could further increase organ donation simply by encouraging people to consider the issue on a regular basis. A recent online experiment supported this finding.[19]

The American Medical Association Council on Ethical and Judicial Affairs and the United Network for Organ Sharing both endorse mandated choice.

Living Donors

One viable option for increasing the number of organ donors is to increase reliance on living donors. In 2001, for the first time ever, there were more living kidney donors than deceased kidney donors. That trend continues. In addition to kidneys, livers, lungs, small intestines and pancreases are available from living donors. Living donors may be related, unrelated loved ones, or strangers. They are usually aged 18-60, physically fit and in good health. They must have a blood type that is compatible with the recipient.[1]

Living donation is handled at the transplant center doing the transplant, rather than through OPOs and UNOS.[1] If the recipient has private health insurance, the costs of living donation are usually covered. Medicare covers the costs of living donation for donors whose recipient is covered under the End-Stage Renal Disease program.

Living donation is common for kidneys. Portions of liver and lung are transplanted with increasing frequency, while living donor pancreas and small intestine transplants remain rare. Use of organs from living donors can be controversial because the process exposes an otherwise healthy person to the risks of a donor operation. For this reason, the evaluation and consent of living donors requires special care. In particular, the transplant center must ensure that the donor's decision is voluntary. The transplant center must disclose all potential risks and benefits to the donor and recipient, including information on medical uncertainties and any alternative treatments for the recipient.[20]

Prior to donating an organ, a potential donor should undergo psychosocial evaluation by a mental health professional with special training in transplantation. This evaluator should not be involved in caring for the potential recipient. The goals of psychosocial evaluation are to evaluate social and emotional stability, establish competence to give informed consent, and to ensure that the decision to donate is made without coercion.[20] With these safeguards in place, living donation is a good way to increase the number of organs available for transplant.

The vast majority of experience with living donors is in kidney transplant. Kidneys transplanted from living donors have better outcomes than kidneys transplanted from deceased donors. The organs function better and longer. In fact, the half-life (the time until half of all organs stop functioning) is 21.6 years for organs from living donors, as compared to 13.8 years for organs from deceased donors. Kidney donation has low rates of complications for the donor, with perioperative morbidity of 1-1.3% and mortality of 0-0.03%.[21]

The UNOS Board of Directors recently endorsed new initiatives to increase donation by living donors. These include coverage under the Family Medical Leave Act and a proposal to reimburse living donors for wages lost during the recovery period following transplantation.[1]

Compensation for Donors

The National Organ Transplant Act prohibits the sale of organs. For many years, the transplant community was uniformly opposed to the idea of compensating donors. Organ donation is seen as dependent on intangible benefits to the donor's family—a way to create some good from a personal tragedy, gain meaning from death, contribute to the good of society and honor a loved one's wishes.[22]

In recent years there has been a shift in perspective. The possibility of compensating organ donors is now frequently debated by medical professionals and ethicists. A UNOS telephone survey performed in 1990 found that the public was almost evenly split on whether or not organ donors should be compensated in some form. The state of Pennsylvania recently enacted a program whereby $300 is paid directly to the funeral home to help defray the costs to families of organ donors.[23] Perhaps efforts to increase the tangible benefits of organ donation could increase the rate of donation.

Other Options for Increasing Organ Supply

Expanded donor criteria refers to the use of organs from donors who previously have been considered medically unacceptable. Expanded criteria include using donors at extremes of age or those with underlying medical illnesses that make them suboptimal donors. It may also include using organs from donors with active infection or colonization, those who have been poisoned, or those who were transplant recipients prior to death. Organs from donors with hepatitis B or C infection can be transplanted into recipients with those infections.[24] As experience with donors previously thought to be unacceptable grows, what constitutes an "acceptable" donor continues to change.

Some technical factors can also contribute to increasing the number of organs available. Kidneys from donors less than five years of age have been considered unusable. However, if they are transplanted *en bloc*, giving two small kidneys to the recipient, outcomes are good. Sometimes a donor liver can be split, thus providing livers for two recipients from one donor organ.[21] Organs, especially kidneys, can be procured from non-heartbeating donors. This is also known as controlled donation after cardiac death. It is a more complicated procedure and outcomes are not as good as when organs are obtained from brain dead donors.[24]

Table 5.
Solid Organ Transplants in 2002

	Patients in US	Patients in NC
Patients who received transplants in 2002	24,897	701
Patients who died while waiting in 2002	6,391	210

Source: Adapted from www.carolinadonorservices.org

Xenotransplantation, the use of tissue from an animal donor, may one day provide a solution to the chronic shortage of donor organs. It is not yet a viable option because the human immune response to the animal organ cannot be well-controlled. Also, the potential risks of infectious disease transmission from the animal to the human are poorly understood. In the past, nonhuman primates have been used experimentally to provide organs. In the future, pigs seem most likely to supply organs for transplant because there are fewer ethical concerns than with primates and because they breed quickly. Laboratory research continues and clinical trials may begin soon.[25]

Conclusions

Efforts to increase organ donation continue. Carolina Donor Services recently partnered with UNC Hospitals and Pitt County Memorial Hospital to engage in an initiative by the US Department of Health and Human Services called the "Organ Donation Breakthrough Collaborative." The collaborative will apply best practices of organ donation processes to attempt to increase donation rates to 75%.[8]

Many people are hard at work developing ways to increase the number of organs available for transplantation. For the time being, education and policy efforts aimed at increasing the consent rate for deceased donation appear to offer the most hope. Consent to donate organs usually occurs in concert with an unexpected, tragic death. Organ donor cards and driver's license notations are an important part of organ donation policy. However, family discussions about organ donation prior to an unexpected tragedy are the best way to spare the family a difficult decision and insure that the patient's wishes are respected.

Transplantation is the best hope for many people with end-stage organ disease. And it works. Each year since 1988, the number of patients surviving more than one year after transplant has increased. The future of organ transplantation, and the future of those waiting for transplants, is limited only by a shortage of donor organs.

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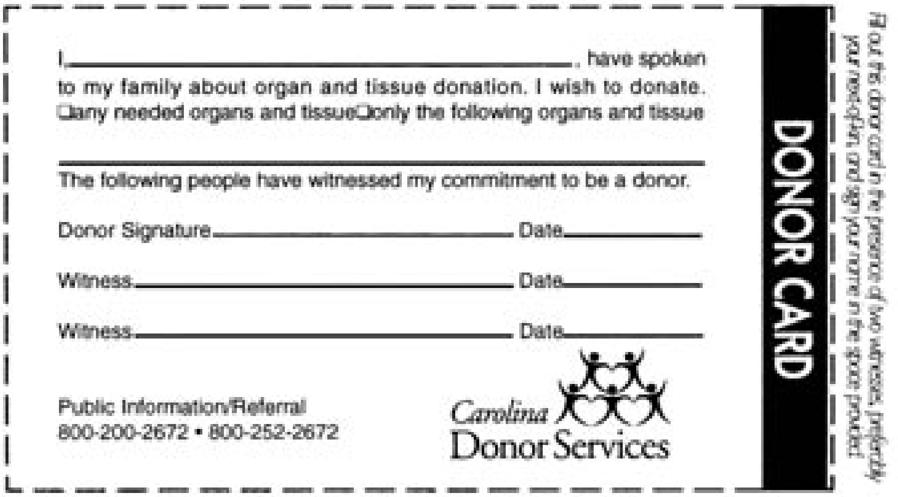
WEB RESOURCES

www.optn.org
www.unos.org
www.carolinadonorservices.org
www.lifesharecarolinas.org
www.organdonor.gov
www.shareyourlife.org



DONOR CARD

I,____________________________, have spoken to my family about organ and tissue donation. I wish to donate.
☐any needed organs and tissue☐only the following organs and tissue

____

The following people have witnessed my commitment to be a donor.

Donor Signature____________________ Date________

Witness____________________ Date________

Witness____________________ Date________

Public Information/Referral
800-200-2672 • 800-252-2672

Carolina Donor Services

Fill out this donor card in the presence of two witnesses, preferably your next-of-kin, and sign your name in the space provided.

Increasing Donation:
Key Factors to Save More Lives

Lloyd Jordan

In my role as Executive Director of Carolina Donor Services (CDS), the non-profit, federally-designated organ and tissue recovery agency for 78 counties of North Carolina and one Virginia county, I am blessed to know many people who have received the "gift of life" through organ and tissue donation. In fact, there are more than 200,000 Americans living with transplants, people who are alive today thanks to the donor who saved their life.

As glad as I am to know these remarkable recipients, it is even more rewarding to me when I meet donor families, those who have made the selfless decision to donate their loved one's organs or tissues in order to save another person's life. The enormous courage, faith and generosity that these people share remind me daily of why I have remained in the field of donation for almost 20 years.

Over the years, I have witnessed remarkable advances in the processes of organ and tissue recovery and transplantation. Advances in medicine, surgery and immunosuppressive drug development have provided us with the ability to help more people than ever before and yet we are limited by one very critical factor—the relatively few number of donors.

Desperate need for more donors

Sadly, the number of people who need transplants continues to grow steadily each year, reaching 83,000 people nationwide and almost 3,000 here in our state. At the same time, the number of deceased donors has remained almost the same, rising just three percent last year to 6,185 donors. This gap means that almost 17 Americans die each day while waiting for an organ transplant; four North Carolinians die each week before they get the heart, lung, liver, kidney, pancreas or intestine transplant that they need to survive.

Many of these lives could be saved if only more people chose to donate. Nationally, about half of families choose to donate their loved one's organs when faced with that decision, although the current consent rate is slightly higher in the area served by Carolina Donor Services. Research shows that the main reasons people chose not to donate are due to a general lack of understanding about donation, as well as misconceptions, such as thinking they are too old to donate (in reality, there is no age restriction for organ donation), believing their religion doesn't support donation (all major religions do), or an unfounded, but prevalent fear that doctors won't try to save their lives if they are known donors.

Strategies to increase the number of people willing to donate

Much of the misinformation and myths that exist can be addressed through public education, which is why our organization devotes so much time and energy to community education and awareness programs in high schools, colleges, churches/faith communities, workplaces, Division of Motor Vehicles offices, the media, and other places where people get information. But, much more needs to be done.

One development that is helping to address the shortage of donors is living donation. The number of living donors-people who give one of their kidneys, or a part of their liver or lung while they're still alive-has grown significantly, to 6,607 people in 2002. While that increase has certainly had a very positive impact, each living donor can usually save the life of one person, while a deceased donor can potentially save up to eight lives through organ donation and enhance the lives of 50 people through tissue donation. So, ways to increase the number of deceased donors must also be explored.

A number of programs are currently being considered and studied to see if they will impact donation rates in our country. Donor registries, financial incentives and presumed consent are among some of the most widely-discussed and debated issues right now. I should also point out that xenotransplantation (animal-to-human transplant) research, tissue engineering and artificial organ research may also play a role in addressing the shortage of organs,

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but these are developing technologies, rather than efforts to increase donation rates. Since our organization is committed to saving more lives by increasing donation, I will focus on efforts in this area.

there is no age restriction for organ donation

Donor Registry. Thirty-three states now have active donor registries, where a person can sign up to be an organ donor, either on line or via mail. In these states, an individual's donor information is maintained in a secure database that can only be accessed by certain healthcare professionals, including recovery coordinators. Organ, tissue and eye recovery personnel can access the registry information around-the-clock to determine if a person wanted to be a donor, enhancing their ability to ensure a person's wishes are followed. Studies are now underway to determine the effect that registries have on consent and donation rates.

Here in North Carolina, we do not yet have a donor registry, although we are working diligently to change that. State Senator Steve Metcalf (D-Buncombe) has introduced legislation (SB 852) that would allow the state's two organ procurement organizations and eyebank to access the donor records maintained by the Division of Motor Vehicles. The bill passed the Senate and is headed to the House for consideration in May 2004.

Financial incentives. Financial incentives for donation are also being considered as a possible way to encourage more deceased donors. Legislation has been introduced in Congress that would authorize the federal government to fund demonstration projects on offering incentives in return for donation. (Right now, the practice is illegal since the National Transplant Act of 1984 outlawed the sale of human organs and tissues). Different possible financial incentives are being discussed, including covering funeral expenses, providing a tax credit to the donor's estate, or a direct payment to the family. While the American Medical Association supports these studies, other groups are opposed due to the ethical dilemmas raised by any form of payment for organs.

Presumed consent. Presumed consent, or an "opt-out" system of consent, has also received a lot of attention lately as another possible solution to the donor shortage. In several European counties, including Austria, Belgium, France, Hungary, Poland, Portugal and Sweden, it is assumed that everyone is willing to be a donor, with family consent after death, unless there is written documentation otherwise. The donation rates in these counties are slightly higher than in counties with "opt-in" systems similar to our own.

An interesting study was done recently at Columbia University that seems to support the theory that a "presumed consent" system could potentially boost our nation's donation rates.[1] Three groups of people were involved in this study. The first group was told that they just moved to a new state where it was assumed they would be organ donors, but they were given the choice to confirm or change that status. Another group was told that they would not be considered donors unless they specified they wanted to be. The third group was told simply to choose whether or not they wanted to become a donor. The highest donation rate (82%) was found in the first group, among those who had to opt-out from being a donor. These findings seem to support the need for further study about the impact of presumed consent on donation rates, as well as research regarding how receptive the American public would be to such a change in our current system.

Improving hospital systems and public awareness. Ultimately, the key to increasing donation will likely be a combination of these efforts, along with a continued focus on improving systems that support donation in the hospital setting, as well as an ongoing commitment to public education and awareness activities. At CDS, we have recently begun two new programs that hold promise for the future. One, called the "Organ Donation Breakthrough Collaborative," is an effort being coordinated by the federal US Department of Health and Human Services. The other, called "A License to Give," is a new high school donation curriculum being offered to educators throughout our state.

The collaborative is intended to show that a dramatic increase in the number of lives saved through transplantation is possible. Nationwide, 105 hospitals and 46 organ procurement organizations are participating, including UNC Hospitals in Chapel Hill and Pitt County Memorial Hospital in Greenville. Multidisciplinary teams from each of these hospitals and Carolina Donor Services are working together to learn, adapt, redesign, implement, track and refine their organ donation processes to increase the donation rate to 75% over an eight-month period. If we're successful, we will be able to replicate the "best practices" established through this study in hospitals throughout the rest of the state and country.

The "License to Give" donation education kit, which was named by a ninth grade English class in Elkin, NC, was developed to assist teachers in introducing the topic of donation in a sensitive, engaging way. The free kits, which are available from Carolina Donor Services, as well as other organ/tissue/eye recovery agencies in the state, are just one way that we hope to reach today's youth and tomorrow's generations with life-saving donation information.

Conclusion

Although we have much more work before us, I am encouraged by the developments in organ/tissue donation and transplantation over the last 20 years. I look ahead with hope and optimism that someday our cumulative efforts will result in the end of the national organ transplant waiting list and thousands more lives saved each year, thanks to those who make the decision to donate.

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COMMENTARY

The Gift Relationship in Process:
From Donor to Recipient

Julie Landon, RN, CPTC

The diary below is a day and a half in my life as an organ donation coordinator at Carolina Donor Services. A nurse for almost 17 years, I have been an organ donation coordinator since June 1998. I recount my experiences with a recent organ donor with the hope that it will help others understand the complex emotional and clinical processes involved with donation.

Sunday

0730: I receive a referral from a local hospital about a 22-year-old female, J., who was admitted with an intracranial hemorrhage secondary to an aneurysm.

0815: I arrive at the hospital and talk with the staff and the physician concerning the history surrounding her admission. I obtain the patient's course of treatment since admission and inquired about the family and how they are coping. The staff informs me that a Cerebral Blood Flow study has been ordered and is scheduled to be performed at 10:00 a.m.

0830-1000: I review the patient's medical chart and recorded medications, blood pressures, heart rate, lab values, any blood products and I.V. fluids given and urine output. I also record any surgical procedures preformed. Then, I call the CDS Medical Director and obtain authorization to follow this patient as a potential organ donor.

1000-1200: The brain death exam has been completed (most hospitals use both clinical and apnea tests). The clinical exam consists of testing for the absence of pupillary response; no blink response when the eye is touched (corneal reflex), no cough or gag reflex and no response to painful stimulus. The apnea test confirms absent respirations, which is a mandatory finding to support brain death. The Cerebral Blood Flow study was used as a confirmatory test for brain death.

1200-1400: With the brain death exam complete, the physician notifies her husband and parents and explains that J. has died. He answers their questions and tells them the time of her death. The physician informs the family that there is someone available to talk with them about decisions they will have to make. *Note: Legally and medically, brain death and cardiac death are the same as far as pronouncement of death.*

1400-1500: The family has informed the nurse they are ready to speak with me. I find a quiet, private room where I can talk with the family about the opportunity to donate J.'s organs. I answer their questions, which include the steps in the recovery procedure, how long it will take, and whether they can still have an open casket funeral for her. After answering their questions, the family agrees to donation. J.'s husband, her parents, and her husband's parents are there for the conversation. I spend time talking with the family about J. They share with me that she had just been married for one year, that she has a deep religious commitment and that she was always helping other people. J.'s family also shares that she loved the outdoors. While talking with her family, I found it very interesting that they had had a conversation and knew that her wishes were to be an organ donor. The family completed the consent form that would allow for the donation of J.'s heart, lungs, liver, pancreas and kidneys. The family chose not to consent to tissue (e.g. bone, skin) and eye/cornea donation.

1500-1600: Family and friends gather at J.'s bedside to say their goodbyes.

1600-1800: I call the Medical Examiner to see if there will be any restrictions for donation. Depending on the cause of death, the M.E. can restrict certain or all organs for donation if s/he feels it will interfere with an investigation of the circumstances behind the death. In this case, no restrictions have been set, so the donation can move forward. I send blood for serologies, tissue typing (used for placing the kidneys and the pancreas), and values on patient's current organ function. I also begin initiation of standard orders to maintain the patient's organ functions.

1800-2200: I evaluate lab results and make adjustments to I.V. fluids and the ventilator to optimize organ function. Then I call the United Network for Organ Sharing (UNOS) and give them the information on the patient including the patient's height, weight, blood group, age, sex and race. UNOS has all the potential organ recipients listed for the entire country. They will then run a list of recipients that are the same blood group as the patient and close to her height and weight. They will be listed in priority order according to UNOS allocation policies, which vary by organ, with emphasis on placement with local recipients. All of the consults for cardiac and pulmonary function are completed. Next, I start placing organs according to the UNOS list.

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2200-2400: The serology and tissue typing results are reported. With these results, I place all the organs for transplantation during this time except the heart because of J.'s size; she was not a match for recipients at our local transplant centers.

Monday

2400-0200: I place both kidneys with UNOS for perfect matches (a perfect match is based on specific DNA tissue typing). The lungs, liver, and the pancreas are placed for recipients listed in North Carolina. I continue to try to place the heart. I call the operating room (OR) to inform them that we would like to go to the operating room around 0400 depending on who would accept the heart and how far they would be coming to recover. *Note: The coordinator is responsible for arranging pick-up and transport of the arriving recovery/transplant teams.*

0200-0300: I place the heart with a hospital in New York. The recipient is a 50-year-old male who was farther down on the list for transplant, but whose size most closely matches the donor's. I would imagine he is very excited. The heart team states that they can arrange a flight and will land at the airport at approximately 0400. I call the OR and arrange for a room for 0400. I call a local ambulance service to be waiting at the airport for the heart team from New York to land and bring them to the hospital. Then I call one of our CDS preservation coordinators responsible for flushing the organs during the case with the time he will need to be at the hospital.

0300-0500: UNOS calls me back to say the kidneys are accepted for two patients in New York pending the anatomy. I continue with donor management, making changes in I.V. fluids to make sure the organs continue to function optimally. I also find time to work on my paperwork and make copies of the chart, which include an official declaration of time of death, copy of the consent form for donation, and blood type information.

0400-0500: The local transplant teams arrive. We take the patient to the operating room. The heart transplant team from New York arrives. Everyone in the operating room introduces himself or herself to each other.

0425-1030: An incision is made from the top of the sternum to 2-3 inches below the umbilicus. The thoracic surgeons work in the chest cavity and visualize the heart and lungs. This takes 20-30 minutes, after which they will leave the operating room to find a place to rest. The abdominal surgeon will take from 2-3 hours to reach the point of being prepared to recover the organs. If the pancreas is being recovered, it will add 1-2 hrs to the surgical process. Once the abdominal surgeon is ready, the thoracic surgeons will return to the table. The coordinator will then ask the anesthesiologist to draw 120-200cc's of blood from the patient, which will be used by the transplant centers to test with their recipient's blood to make sure there will be no adverse reactions. After the blood is drawn, 30,000 to 40,000 units of heparin are given to thin the blood. Next, cannulas are inserted in the aorta above the heart, the pulmonary arteries, the descending aorta below the kidneys and the portal vein below the liver. These cannulas are then connected to cold bags of preservative solution called "UW." The circulation is then clamped off just above the heart and below the kidneys. The flush solution is then started so that all the organs that are to be transplanted are cleared of blood and replaced with the cold preservative. Once the flush is complete which takes 15-30 minutes the heart is then removed. The heart takes approximately 5-10 minutes to remove from the body. The heart should be transplanted within 4 hours after being recovered or there may be irreversible cell and organ damage, which is why most out-of-state heart recovery teams will use jet service to reach their destinations.

The lungs are removed next, which again takes 5-10 minutes. Lungs can remain out of the body for approximately 4-6 hours before possible organ damage develops. The thoracic teams will then place the organs in sterile bags surrounded by sterile ice and "UW."

The abdominal surgeon will take another 2-3 hours to recover the liver, pancreas and kidneys. These organs will also be placed in sterile bags, solution and ice. The surgical teams will take the recovered organs back with them to be transplanted. The kidneys that were accepted by New York will have transportation arranged by UNOS. Usually kidneys are transported by commercial airlines. The kidney can remain on ice for 24 hours before there is concern of damage to organ function. The liver should be transplanted within 8-12 hours and the pancreas within 12-16 hours.

1030-1100: The incision is sutured closed; the body is cleaned then taken to the hospital morgue. I call the family to tell them how the recovery went, since that is what they wanted. I also notify the nursing supervisor that the organ recovery is complete. Organ donation will not affect the family's decision to have an open casket or other funeral arrangements. *Note: If the family had consented to eye and tissue donation, this recovery would occur after the organ donation is complete. Tissue donation usually takes from 2-4 hours and eye donation typically takes 30-45 minutes. If the family is going to have an open casket funeral, some types of bone will not be removed. Eye donation does not affect having an open casket funeral. If the patient is a Medical Examiner's case, the M.E. will view the body after all recovery is complete and they will then release the body to the funeral home.*

1130-1230: I thank the hospital staff in the OR and on the inpatient unit for their cooperation, answer their questions, and gather my belongings.

1300: I go to the office to complete paperwork. After the paperwork is completed, I go home to get some sleep.

2-3 weeks after donation: I write a letter to the family informing them of what organs were recovered and transplanted, giving them some general (non-identifying) information about the organ recipients (e.g. their families, work, hobbies) and how well they are doing. With this donor, the heart, lungs, liver, pancreas, and kidneys were transplanted and are functioning well. Hopefully, this information will provide the family with some comfort in their time of grief.

Carolina Donor Services will remain in contact with the donor family for two years or longer, if the family wants to continue a relationship with us. Carolina Donor Services' Life Anew Program invites families to annual Services of Remembrance to honor their loved ones who were donors. The Life Anew Program also facilitates correspondence—and sometimes even face-to-face meetings if both sides request it—between donor families and recipients.

COMMENTARY

The Rapid Development of Solid Organ Transplantation in North Carolina

Michael R. Mill, MD

The first successful solid organ transplant between two individuals occurred in Boston in 1954 involving a living-related kidney transplant between twin brothers. The ensuing three decades were filled with dramatic stories of basic science and clinical research resulting in the successful performance of transplants, mostly with cadaver (brain dead) donors, involving the liver, pancreas, heart, heart-lung, and finally isolated lungs. Despite these successes, the overall survivals were largely measured in months and the procedures were only available in a select few transplant facilities. Clinical transplantation did not become a reliable therapy until the work to develop effective immunosuppressant medications resulted in the release of Cyclosporine in 1982. Thereafter, an explosion of activity occurred, with transplant centers opening at many major academic medical centers across the country. The clinical results achieved led transplantation to become standard therapy for end-organ disease of the organs noted above. At the present time, there are 260 transplant centers in the United States, which encompass a total of 835 individual transplant programs (Table 1).

Table 1.
Transplant Programs by Organ in the United States
Medical Centers with Transplant Programs – 260

Organ	Number of Programs
Kidney	245
Liver	122
Pancreas	169
Heart	141
Heart-Lung	82
Lung	76
Total	**835**

Source: Modified from UNOS Data (www.unos.org).

Transplantation in North Carolina

North Carolina followed the national trend with the development of transplantation programs at each of the academic medical centers. Duke University and the University of North Carolina at Chapel Hill led the way, establishing programs in all transplantable organs. Subsequently programs in selected solid organs have been developed at East Carolina University (kidney), Wake Forest University School of Medicine (kidney, pancreas, heart) and the Carolinas Medical Center in Charlotte (kidney, heart, liver and pancreas).

At the University of North Carolina School of Medicine-UNC Hospitals, solid organ transplantation began with kidney transplantation in 1968. The heart transplantation program was founded in 1986, and was followed in rapid succession by lung transplantation in 1990, heart-lung transplantation in 1991, liver transplantation in 1991 and pancreas transplantation in 1994. In addition, UNC has further developed the expertise to perform pediatric transplantation in each of the individual organ programs (Table 2).

The Effect of Transplantation on Medical Education

The rapid development of these programs has led to dramatic changes in the training of medical students, residents, and subspecialty fellows. Medical students now learn the basics of transplantation immunology

Table 2.
Numbers of Procedures by Transplant Programs at UNC Hospitals, 1968 – present.

Organ	Adult	Pediatric
Kidney	941	114
Heart	196	31
Heart-lung	10	3
Lung	225	24
Liver	457	85
Pancreas	3	3
Total	**1,832**	**260**

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during their basic science years and are exposed to clinical transplantation during their clerkships. Residency training programs in internal medicine, pediatrics and general surgery, at least at academic centers with transplant programs, now include education and experience with transplantation. In internal medicine and pediatrics, residents (and attending physicians) must learn to care for patients with end-stage organ disease, including when to refer patients for transplantation, and the basic care of these patients post-transplantation when they present with transplant complications (infections, renal failure, and malignancies), in addition to standard health maintenance for the common side-effects of the medications, including hypertension, hypercholesterolemia and diabetes mellitus. General surgery residencies at academic medical centers often include separate clinical services for abdominal transplantation through which the residents rotate.

At UNC-CH, Abdominal Transplantation is now a separate Division within the Department of Surgery with a separate clinical service, a full complement of residents assigned to the service, a transplant fellow, and four attending surgeons, all of whom have completed Abdominal Transplantation Fellowships. General surgery residents gain experience in thoracic transplantation when they rotate on the cardiothoracic surgery service. Our cardiothoracic surgery residents assume responsibility for the heart, heart-lung and lung transplant patients as part of their routine duties. Our faculty at UNC includes three cardiothoracic surgeons who have completed Thoracic Transplantation Fellowships.

Many of the common fellowships now must include experience in transplantation. Adult and pediatric cardiology, gastroenterology, nephrology, infectious diseases, oncology and many other fellowship training programs must now educate their fellows in the care of their specialty-related transplants. In addition, there are now subspecialty fellowship programs specifically in heart failure and cardiac transplantation, hepatology and liver transplantation, and renal transplantation. In surgical training, fellowships have been established in abdominal transplantation, covering liver, kidney, pancreas and most recently intestinal transplantation, and in thoracic transplantation covering heart, heart-lung and lung transplantation. Indeed, medical societies have been founded which focus specifically on transplant medicine. The most prominent are the American Society of Transplant Physicians, the American Society of Transplant Surgeons and the International Society of Heart and Lung Transplantation. In all, an entire new body of knowledge has been added to medical education, largely within the past decade.

Just as medical schools and post-graduate training programs have had to assimilate this new body of knowledge, hospitals have had to evolve as well. All major transplant hospitals must have the appropriate staff and laboratories, as well as the availability of operating rooms, anesthesiologists and trained operating room personnel to perform the transplants and care for the patients afterward. The individual transplant programs are required by Medicare and many insurance programs to ensure thorough evaluation of potential candidates in order to select patients who will be most likely to benefit from the scarce resource of donor organs and the expensive and complex therapy inherent in transplantation. These teams consist of social workers, psychologists, psychiatrists, nutritionists, physical therapists, financial counselors and transplant coordinators, in addition to the physicians and fellows involved in the program. The ability to perform routine laboratory examinations in addition to assays to measure levels of immunosuppressant medications, to perform microbiology cultures to rule out or identify infections and pathology services to interpret biopsy specimens to identify or rule out rejection, is mandatory. And of course, facilities and personnel must be available to perform the transplant procedures at any time, day or (usually) night. The nurses in the intensive care units and wards must develop the expertise to care for these patients. Many hospitals have developed separate transplant units to centralize and improve care for transplant recipients. In addition to academic medical centers, some larger private hospitals across the country, have developed transplantation programs. Overall, it is a huge investment in resources for hospitals to participate in solid organ transplantation.

Transplantation and the Non-Academic Community

In addition to the tremendous investment by physicians and hospitals to develop transplant programs, physicians all across the state and nation have had to learn about transplantation to care for the ever increasing proportion of their patients who need or have undergone transplant procedures. Like their counterparts in the academic medical centers, they have had to learn when to appropriately refer patients, and perhaps more importantly how to care for their patients' routine and potentially catastrophic post-transplant medical problems, including when to refer the patients back to the transplant center. Graduate medical education programs have helped disseminate this information, though perhaps the greatest source of information comes from the transplant centers, and more specifically the transplant coordinators. These highly trained and skilled individuals, usually nurses, nurse practitioners or physician assistants, are the patient's and their local physicians' lifeline for both routine care and emergency intervention. Our coordinators, as well as those at all centers, work very hard to be effective liaisons between the transplant center and the patients, their local physicians, hospitals and pharmacies. In reality, the entire process could not function without these dedicated individuals.

Conclusion

In the past two decades, solid organ transplantation has progressed from futuristic science fiction to life-saving procedures performed hundreds of times every day throughout the United States (over 23,000 transplants were performed in 2002). North Carolina has assumed its appropriate place in this scientific activity, providing its citizens and others from throughout the country, with these services. This activity has changed the practice and education of physicians, nurses and other medical personnel, and greatly impacted the hospital services both in the community and the academic medical centers. Given the successes of transplantation, as well as new advances in immunosuppression, potential new sources of donors (non-heart beating human donors and genetically altered animals for xenotransplantation), and other new therapies for end-stage disease (artificial livers and mechanical assist devices for heart failure), one can predict that 20 years from now, we will have even more sophisticated treatments that will have far reaching effects on medical practice and education, advances likely to eclipse even those of the past two decades.

Table 3.
Transplants by Donor Type and Center in NC Transplants Performed: January 1, 1988 - October 31, 2003

		All Donor Types	Deceased Donor	Living Donor
All North Carolina Centers	All Organs	7,911	6,248	1,663
	Kidney	4,414	2,818	1,596
	Liver	1,300	1,248	52
	Pancreas	59	59	0
	Kidney / Pancreas	329	329	0
	Heart	1,052	1,052	0
	Lung	719	704	15
	Heart / Lung	38	38	0
Wake Forsest University Baptist Medical Center	All Organs	957	689	268
	Kidney	835	567	268
	Pancreas	12	12	0
	Kidney / Pancreas	26	26	0
	Heart	82	82	0
	Lung*	2	2	0
Carolinas Medical Center	All Organs	1,709	1,426	283
	Kidney	1,068	785	283
	Liver	262	262	0
	Pancreas	7	7	0
	Kidney / Pancreas	68	68	0
	Heart	304	304	0
Duke University Medical Center	All Organs	2,791	2,390	401
	Kidney	1,119	730	389
	Liver	506	500	6
	Pancreas	37	37	0
	Kidney / Pancreas	197	197	0
	Heart	437	437	0
	Lung	470	464	6
	Heart / Lung	25	25	0
Durham VA Medical Center	All Organs	70	59	11
	Kidney	65	54	11
	Kidney / Pancreas	5	5	0
Pitt County Memorial Hospital	All Organs	617	286	331
	Kidney	596	265	331
	Pancreas	1	1	0
	Kidney / Pancreas	2	2	0
	Heart*	18	18	0
UNC Hospitals	All Organs	1,767	1,398	369
	Kidney	731	417	314
	Liver	532	486	46
	Pancreas	2	2	0
	Kidney / Pancreas	31	31	0
	Heart	211	211	0
	Lung	247	238	9
	Heart / Lung	13	13	0

*Source: Based on OPTN data as of January 23, 2004 (www.optn.org). * No longer performing this procedure.*

COMMENTARY

Building a Modern Transplant Center

J. Elizabeth Tuttle-Newhall, MD

Organ transplantation is currently the standard therapy for end-organ failure in those patients medically suitable for transplant. At present, there are over 80,000 patients listed for transplantation in the United States.[1] The United States organ transplant waiting list grows on average 16-20% per year. In the past 10 years, the number of registrants has increased from 23,901 to over 80,000. In contrast, the number of deceased organ donors available has increased from 4,526 in 1991 to 5,985 in 2001.[2] Overall mortality for all patients on the waiting list is 7.5% and continues to grow yearly.[1] The number of transplants performed in the United States has also increased from 12,626 in 1988 to over 22,000 in 2000.[2]

Currently, there are over 300 transplant centers in the United States. While the majority of transplant centers are in academic tertiary care facilities, there are several very successful programs in the private arena. In North Carolina there are three multi-abdominal transplant centers (liver, kidney and pancreas transplants) including Duke University Medical Center, Carolinas Medical Center in Charlotte and UNC Hospitals in Chapel Hill. Both Wake Forest University Baptist Medical Center and Pitt County Memorial Hospital with University Health Systems of Eastern Carolina have abdominal transplant programs that perform pancreas and kidney transplants.

The establishment and maintenance of abdominal transplant programs requires enormous planning and resources. Extensive negotiations must take place to ensure institutional and/or departmental commitments prior to initiation of any program. The recruitment and retention of an expert multidisciplinary team of physicians and nurses follows subsequently. Strategic planning is required to adequately deploy resources, lobby referring physicians, and recruit patients in order to achieve success.[3]

Infrastructural Support Requirements

Institutional support is paramount to the establishment and maintenance of a successful transplant program. Fiscal investment is required to establish adequate programmatic infrastructure. Infrastructure is required to not only meet regulatory requirements, but also provides the backbone for provision of excellent clinical care for complex patients. Programmatic infrastructure is required to manage the requirements of data collection and organization that is mandated by the United Network of Organ Sharing (UNOS). Information systems are necessary to capture and organize patient information that is analyzed to determine patient outcome, graft survival and programmatic performance. Required UNOS data are also used regionally and nationally to assess performance of UNOS allocation policies to ensure the best patient outcomes and effective utilization of limited resources. Individual programmatic data should be available to assess programmatic performance, not only in terms of clinical outcomes, but in the financial aspects of all phases of transplant as well. Support staff must include not only database managers but also patient contact personnel. Clinical systems must be available to assist in efficient patient access and easy physician referrals. These clinical systems must also facilitate patient throughput once the patient is in the system at the specific transplant center.

Institutional support is paramount to the establishment and maintenance of a successful transplant program.

Institutions must invest in space and equipment for care of the complex organ failure patient in all of the phases of transplant (pre-operative, peri-operative and post-operative). Clinic space and adequate time in that space must be available for the medical and surgical specialist to see the volume of pre-operative patients necessary to establish a program and assist in the multi-disciplinary management of the post-operative patients. Operating room equipment must be available, and personnel

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must be trained. Call teams should be established for specialized transplant procedures that require a specific level of nursing expertise. Intensive care unit resources must also be available with appropriately trained staff to care for the post-operative and often critically ill transplant recipient. Investment in the clinical enterprise required to support a transplant program can only occur at the institutional level. The incentives for the institution are not only fulfillment of the academic center's mission to provide tertiary levels of care, but also financial gain if the program can achieve a profitable clinical volume.

Personnel Requirements

Personnel recruitment and retention are of foremost importance to achieving success in any transplant program. Medical, surgical and nursing expertise in transplant are required. For example, a kidney transplant program requires a transplant nephrologist, a transplant surgeon, and several nurse coordinators who have specific interest and expertise in the work-up and management of kidney transplant patients. A kidney transplant program also requires a histocompatibility lab, a lab director and lab personnel to support the transplant program. Social work, medical psychology, financial support staff must all be available to assist those patients who may require evaluation prior to transplant and support during all phases of the transplant process. All of these individuals maintain a pivotal role in the daily management of their particular program. Likewise, liver transplant programs require a transplant hepatologist, a specialized anesthesiologist, critical care specialists, transplant infectious disease specialists, radiologists with experience in transplantation, pathologists and nursing personnel that are familiar with care of the transplant patient. If the transplant center is associated with a medical school and academic center, lab support and time must be made available to the involved physicians who have an interest in research and/or clinical teaching in order to support the academic and educational missions of their individual institutions. Transplantation requires the development of a multi-disciplinary team of experts who are dedicated to providing excellent clinical care for those patients with organ failure.

Relationships with Recipient's Referring Physicians

Finally, in order to assure the success of any program, involvement and recruitment of referring physicians and their patients must occur. While transplant patients are specialized in many aspects of their care, their primary and referring physicians are still involved during all phases of transplant. Resources must be available and deployed to ensure adequate communication between the transplant center and the referring physicians in order to ensure the best possible patient care. Ease of communication and exchange of up-to-date information between physicians ensure excellent patient care and patient outcomes. Access for the patients to the transplant centers must be simple and timely in order to expedite work-up and as is of the patient. If the patient is not a candidate for transplant, an alternative care plan can be quickly developed.

In summary, development of a transplant program requires fiscal investment, recruitment and retention of personnel with clinical expertise and the ability to assess and evaluate resources and their outcomes to deliver the best possible quality of care to those patients most in need.

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COMMENTARY

Some of the Challenges of Encouraging Organ Donation Among Minority Populations

Lynt B. Johnson, MD, FACS

Organ donation and organ allocation remain important issues for patients awaiting transplantation in the United States. The disparity between the number of deceased donors and the number of patients awaiting transplantation continues to widen each year. The number of deceased donors in the United States has remained stagnant at approximately 5,000 donors per year, while the waiting list for organs in 2004 exceeds 80,000 individuals. Each day in the United States 15 patients die while awaiting life-saving transplants. The method of allocation of these precious gifts is of importance to all patients, but is of particular importance to minorities. Although minorities are represented in all end-stage organ diseases, end-stage renal disease has by far the greatest impact on minorities. Diseases such as hypertension and diabetes, which can lead to end-stage renal disease and the need for transplantation, disproportionately affect minorities. Several key questions should be openly discussed and debated in regard to transplantation policy and minorities. Some of these questions might be: Is there proportionate representation of minorities on organ waiting lists? Does race impact organ availability? What are the reasons that waiting time is longer for minorities awaiting kidney transplantation? How can we increase organ availability for minorities? What should be the guiding principles of organ rationing?

> *In some areas of the country, African Americans account for over 70% of the patients awaiting kidney transplantation.*

For many highly specialized procedures in the United States, racial differences in access to effective medical procedures persist. Minorities are far less represented than their majority counterparts, even when adjustments are made for economic status and education. Coronary artery bypass surgery, total knee and hip replacement, cataract surgery, screening colonoscopy and mammography are examples of such procedures where disparities exist. Access remains a critical issue.

Two significant risk factors for renal disease, hypertension and diabetes, disproportionately affect African Americans. It is estimated that more 30% of adult African Americans are hypertensive, compared to a 20% incidence in the majority population. More importantly the age of onset in African Americans is earlier, resulting in higher age-adjusted hypertension prevalence. This early onset subsequently leads to more target organ damage and greater overall mortality burden when compared with the majority white population. Although the difference is not as drastic with the incidence of diabetes, the risk of end-stage renal disease in African Americans with diabetes is three times as great as that of the majority population.

Due to the greater burden of disease, the incidence of end-stage renal disease is much higher in African Americans. Thirty-five percent of all patients awaiting kidney transplantation in the United States are African American. In some areas of the country, African Americans account for over 70% of the patients awaiting kidney transplantation. Thus, issues of organ allocation are of paramount importance to understand. Organ allocation begins with timely referral to transplant centers. In a study by Ayanian et al., they showed that despite equivalent desire for transplant, the number of patients referred for evaluation and the number of patients placed on the waiting list were significantly less for African Americans than for their majority white counterparts.[1] One recent proposal to level the playing field is for patients to be assigned waiting time from their initial diagnosis of renal dialysis and not with their referral to the transplant center. This proposal, if implemented, may allow for those patients with less access to the referral process to gain a more equitable footing. However, there remains some opposition to this proposal in the transplant community. Not only must we provide better access to transplantation, but the method of allocation has great importance

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since the demand far outweighs the supply of deceased donor organs. For patients listed in 1997, African Americans waited an average of two-and-a-half years longer than their white counterparts on the waiting list. This disparity is most notably accounted for by the limited supply of genetically closely matched organs, and to some extent by the continued use of tissue type matching in the algorithm for kidney allocation. Traditionally it has been shown that in the prior era of immunosuppressant drugs, tissue type matching played a role in the longevity of functioning kidney transplants. As the immunosuppression drugs have improved, these differences have been lessened. Certain tissue types are much more common in the majority of white populations than in minority populations. Since the majority of deceased donors are Caucasian, this limits opportunities for closely matched organs in some instances. Over the years the preference given to tissue type matching has been reduced. The question remains: should we eliminate tissue type matching altogether and apply severity of illness and waiting time as the only factors for recipient selection in kidney transplant allocation? Previous studies have shown that the impact of elimination of tissue type matching reduces long-term kidney survival.[3] It is my belief that this difference may be mitigated by utilizing different immunosupressive strategies for African Americans than for their majority white counterparts.

Other issues of importance include increasing organ donation, especially in the minority population. The African American deceased organ donor consent rate is far less than it is in the white population. Boulware, et al. recently studied racial and gender issues relating to donation in a Baltimore community.[2] Their results suggest that mistrust of hospitals and concerns about racial discrimination in hospitals accounted for the significant differences in willingness to donate between non-Hispanic blacks and whites. Black males were particularly resistant to organ donation. White males were most likely to identify themselves as organ donors on a driver's license (65%), compared to white females (60%), black females (38%). Only 19% of black males indicated their willingness to donate. Ironically in the year 2003, in the service area of the greater metropolitan Washington, DC area, the percentages of actual deceased organ donation show great similarity to the data provided by Boulware and her colleagues. Of eligible African American families that were approached concerning organ donation the consent rate was 25%, compared to 60% for the Caucasian population.[2]

Targeted education in the minority community will likely provide greatest benefit to increasing organ donation in the minority population. Central figures of trust within minority communities can be used as advocates for dissemination of this critical information. Dissemination of information regarding the need for organ donation in the minority community will be more effective if simultaneous education about disease prevention occurs, especially in relation to hypertension and diabetes, which ravage our community. The future looks grim with almost 20% of minority group children facing obesity. More often than not, they will carry this problem into adulthood leading to a greater incidence of hypertension and diabetes. We must confront these lifestyle issues now by targeting exercise, nutrition and disease prevention in our children. These and other issues must get on the agenda in our organizations, community and political debates. We need to not only emphasize the needs of end-stage organ disease patients, but also preventive strategies for our communities.

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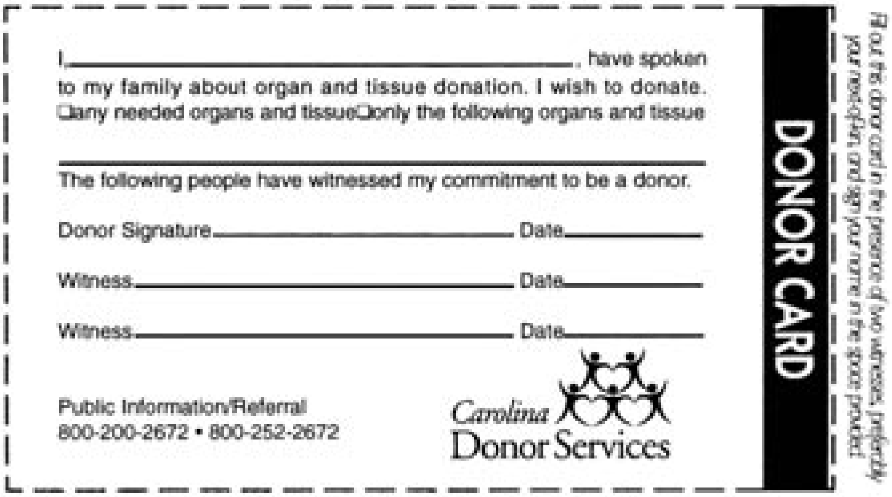

I,______________________________, have spoken to my family about organ and tissue donation. I wish to donate.

☐any needed organs and tissue☐only the following organs and tissue

____

The following people have witnessed my commitment to be a donor.

Donor Signature______________________ Date__________

Witness______________________ Date__________

Witness______________________ Date__________

Public Information/Referral
800-200-2672 • 800-252-2672

Carolina Donor Services

DONOR CARD

Fill out this donor card in the presence of two witnesses, preferably your next-of-kin, and sign your name in the space provided.

A Minority Perspective
The State of Minority Donation in North Carolina

Debbie Mann Gibbs

Derrick Floyd will celebrate a big birthday, his 40th, in March. There will be the usual ice cream, cake and presents. What will really make the day special, however, is what will be missing. This year Derrick won't be tethered to a dialysis machine—the piece of equipment that artificially replaced his failing kidneys for three and a half years.

Thanks to the generosity of a donor family, Derrick received a kidney transplant last summer at Carolinas Medical Center in Charlotte. Hello to new-found energy, dark-colored soft drinks and time on the basketball court with son, DJ. Goodbye to shunts, loss of work and family time.

Table 1.
Organ by Ethnicity: Current NC Waiting List

	All Organs	Kidney	Liver	Pancreas	Kidney/ Pancreas	Heart	Lung	Heart/ Lung	Intestine
All Ethnicities	3,065	1,965	684	15	91	73	220	16	1
White	1,521	638	563	13	66	49	181	10	1
Black	1,445	1,261	95	2	25	22	34	6	0
Hispanic	36	24	9	0	0	1	2	0	0
Asian	35	24	10	0	0	0	1	0	0
Other	28	18	7	0	0	1	2	0	0

Derrick was lucky. His transplant came exactly six months after his mother died of the same kidney disease, focal segmental glomerulosclerosis. Like many African Americans in desperate need of a kidney transplant, the call to tell her a kidney was available did not come in time.

The Statistics are Startling

According to figures from the United Network for Organ Sharing (UNOS), the organization that maintains the nation's database of waiting-list candidates, 220 North Carolinians died in 2002 (the last full year for which statistics are available) before a compatible organ was found. Ninety-six of them were African American.

There are more than 3,000 people in North Carolina on the waiting list for an organ transplant—1,965 need a kidney transplant. The situation is critical for minorities, particularly African Americans.

As of January 14, 2004, there were 1,257 African Americans on North Carolina's kidney waiting list or 64%—a staggering figure considering 21.5% of North Carolina's population is African American.

Minorities represent over half of those on the national kidney waiting list with African Americans comprising 35% and Hispanics, 16%.

The reason for the disparity is simple. African Americans and Hispanics are four times more likely to suffer from hypertension and diabetes, both of which lead to end-stage renal disease. Despite advances in medicine and technology, demand for organs continues to far outpace supply. As a result, minorities are at higher risk for longer waiting times on transplant waiting lists and ultimately, death.

There were 220 people who died in North Carolina in 2002 as a result of the critical shortage of donors. There were 112 whites, compared to 96 African Americans and three Hispanics.

Because of the genetic matching of antigens, minorities have a better chance of receiving a kidney transplant if the donor is

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from the same ethnic background. The common perception that minorities do not donate is not borne out by the statistics.

National Studies Reflect State Trends

UNOS data indicate that nationwide the proportion of white donors has decreased over a 10-year period while the proportion of minority donors has increased. A study by the Association of Organ Procurement Organizations (AOPO) of death record reviews from 30 organ procurement organizations showed that when African Americans do refuse to donate, the reason is not always the result of a family saying no. In some instances, the potential donor was never referred by the hospital nor was the family ever approached.[1]

Meanwhile in North Carolina, the trend for minority donation is on the upswing. Out of 551 deceased donors in the state in 2002, 143 (or about 25%) were minorities (92 African Americans and 42 Hispanics). Meanwhile, out of 701 citizens who received various types of transplants in 2002, minorities received only 206 of them.

The *Journal of the National Medical Association* published a national study[2] in January of 2002 which showed that the gap between the number of whites and minority groups that received organ transplants actually widened during the 1990's. While the rates for all groups were similar in 1988, almost 10 years later in 1997:

- Heart transplantation rates for Caucasians were more than five times greater than for African Americans.
- Kidney transplant rates were nearly nine times higher for whites than for other ethnic groups.

No data were collected separately for North Carolina in that study. That, however, has not stopped LifeShare Of The Carolinas and Carolina Donor Services (CDS), the state's two organ procurement organizations, from developing various programs to increase donation rates among the state's minority populations.

LifeShare has formed strategic collaborations with black physicians and lawyer's groups in Charlotte to distribute information on organ and tissue donation to the African American community. The organization has also partnered with the Links, Inc., a black women's civic organization, on a two-year grass-roots project that targets black churches among other groups. CDS received a $373,000 federal grant from the Health Resources and Services Administration (HRSA) for a three-year study. The project is a campus-wide intervention to increase intent to donate among African American students at four of the state's historically black colleges and universities.

Table 2.
Deceased Donors Recovered in NC by Donor Ethnicity

	To Date	2003	2002	2001	2000	1999	1998	1997	1996	1995	1994	1993	1992	1991	1990	1989	1988
All Ethnicities	2,077	157	161	155	167	147	170	142	138	133	139	109	108	100	101	72	78
White	1,634	123	120	123	124	118	133	104	104	101	113	86	85	81	90	61	68
Black	365	21	28	23	38	27	31	32	31	27	20	22	21	15	9	10	10
Hispanic	52	8	9	4	4	1	5	5	3	3	3	1	1	3	1	1	0
Asian	11	2	2	3	0	0	1	0	0	1	2	0	0	0	0	0	0
Other	13	2	1	2	1	1	0	1	0	1	1	0	1	1	1	0	0
Non-Hispanic Multiracial	2	1	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0

Donors Recovered: January 1, 1988 - November 30, 2003

Table 3.
Transplants in NC by Recipient Ethnicity

	To Date	2003	2002	2001	2000	1999	1998	1997	1996	1995	1994	1993	1992	1991	1990	1989	1988
All Ethnicities	7,969	685	701	693	673	606	633	573	525	483	527	347	349	361	311	245	257
White	5,385	436	495	465	453	412	431	375	343	347	362	242	230	250	225	151	168
Black	2,355	221	186	211	196	183	182	185	167	125	143	96	112	100	76	89	83
Hispanic	85	15	6	8	7	5	3	5	4	5	10	3	3	5	3	1	2
Asian	62	4	5	3	9	4	9	4	4	4	6	1	3	1	2	1	2
Other	81	9	8	6	8	2	8	4	7	2	6	5	1	5	5	3	2
Non-Hispanic Multiracial	1	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0

Transplants Performed: January 1, 1988 - November 30, 2003

Ad Campaigns Respond to Crisis

Both LifeShare and CDS support national advertising campaigns developed by the national Coalition on Donation. Two of the campaigns consist of a series of print, broadcast and out-of-home public service ads targeted at African American and Hispanic consumers. They have been a good investment of time and effort. To date, they have been played 2,337 times on North Carolina radio and television stations, generating over $229,000 in donated media time.

The ads are the first to be created as part of national campaigns that are based on research. Focus groups convened among the target groups in several cities across the country, including the southeast, had several similarities. African American and Hispanic participants revealed several barriers to donation including:

- Concern about the fairness of the system
- Lack of available information
- Mistrust of the medical community and fear of being declared dead prematurely

Loletha, a Charlotte transplant recipient, is featured in the African American brochure and on the Coalition's web site at www.donatelife.net. Loletha received a kidney transplant at Carolinas Medical Center in 1993. Like Derrick, she also waited over three years on the transplant waiting list. Since then, she has continued a prosperous career in banking and even more significant, given birth to a daughter, two things she wasn't sure she would ever be able to achieve.

LifeShare and CDS are active members of the North Carolina Coalition on Donation, a local affiliate of the national Coalition on Donation. The Coalition is a not-for-profit alliance of national organizations and local coalitions dedicated to inspiring all people to donate life through organ and tissue donation. Since 1992, the Coalition has developed several ad campaigns and national projects which have been implemented at the local level in North Carolina.

Derrick and his son are featured in a new general market brochure developed by the Coalition coined "Empowering Testimonials." He is one of seven transplant recipients depicted and the only African American. His profile can be found in the newest Coalition brochure.

You Can Help

How can the public help? There are several ways. Minority transplant recipients and donor family members are available to share their stories with church, school or civic groups. The presentations are free and may be arranged by contacting LifeShare at 800-932-GIVE(4483) or CDS at 800-200-2672.

North Carolina residents are encouraged to get a donor card, sign it and carry it in their wallet. More importantly, everyone is encouraged to share their wishes on organ and tissue donation with their families. In North Carolina, a driver's license is not legally binding. A signed donor card is. A donor card can be obtained by calling either of the OPO's or by downloading one from the LifeShare web site at www.lifesharecarolinas.org.

Life is full of decisions. Paper or plastic? Cash, check or charge? All it takes to save the lives of ALL patients in North Carolina who need a transplant is for more people to decide to become donors, to share their organs when they no longer need them.

To borrow a line from the Coalition's African American ad campaign, "When you do nothing, everybody loses."

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Thank You Letter from Derrick to His Donor's Family

Dear Guardian Angel,

How do you begin to thank someone for giving you your life back? I am in constant thanks for your gift of life.

I would like to extend great sorrow and compassion for the loss of your family member. I know that the pain of such loss can be unbearable, as I lost my Mother of the same disease that I suffer just six months prior to receiving the kidney.

Your gift has made a tremendous change in my life and in the lives of my family. I can now do simple things without the feeling of fatigue or dizziness. I can play catch with my son and attend his football game while standing the entire time. I know that these tasks sound simple, but they were major challenges before you gave me my life back.

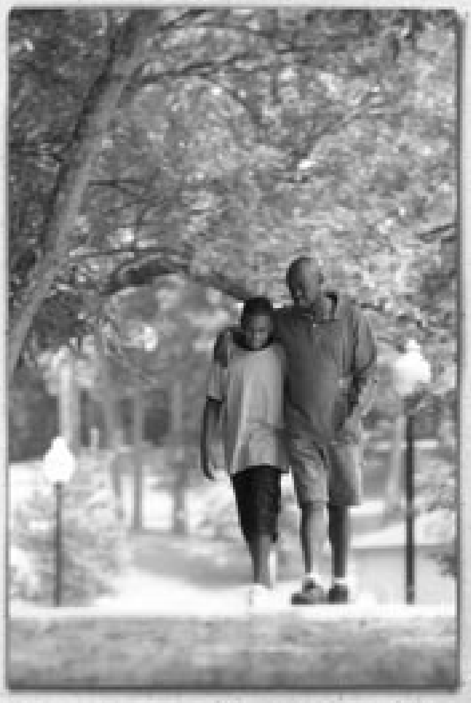
I thought you might find this poem comforting. As my mother was losing her battle to this disease, she told me that I would receive a kidney and you made it possible. I would like to share one of her favorite poems with you:

If I Knew

If I knew if would be the last time that I'd see you fall asleep, I would tuck you in more tightly and pray the Lord, your soul to keep. If I knew it would be the last time I would see you walk out the door, I would give you a hug and a kiss and call you back for one more. If I knew it would be the last time I'd hear your voice lifted up in praise, I would video tape each action and word so I could play it back, day after day. If I knew it would be the last time I could spare an extra minute to stop and say, "I love you" instead of assuming you would KNOW I do. Take time to say "I'm sorry," "Please forgive me, "Thank You" or "It's okay,'" And if tomorrow never comes, you'll have no regrets about today.

I hope that you find some comfort in those words. I thank God for you and your family daily and we as a family will continue to pray for you. By the way, my family and I would love to meet you.

May God Bless You and Keep You.



COMMENTARY

“What’s in your wallet?”

Will Your Intentions Be Known?

Betsy J. Walsh, JD, MPH, and Judy Jones Tisdale, PhD

Think that little heart on your NC driver’s license makes you an organ donor? Think again! In North Carolina, only a valid donor card is recognized as a legal document for organ donation. The intent on a driver’s license is not enough. This often comes as news to both medical professionals and laypersons alike. “But I already am an organ donor,” most say as they whip out their driver’s license. As the number of organs available continues to fall behind the number of North Carolinians in need, we must dispel this misconception.

The American Medical Association (AMA) encourages healthcare professionals to promote organ donation awareness. In fact, in 1998, the AMA started the “Live and Then Give” program to educate physicians about this issue and to encourage them to promote donor awareness in their communities.[1] While physicians are uniquely positioned to talk with patients about donation, they are not the only ones who can make an impact on the increasing shortage of needed organs. Whether you are a healthcare professional or an interested layperson, you can help—share this message with family, friends, clients, patients, and colleagues.

Guarantee Your Right to Be an Organ Donor

To guarantee your wishes about organ donation are honored, do the following:

1. **Carry a signed, witnessed donor card.** You can print one off the Internet at Carolina Donor Services (www.carolinadonorservices.org), LifeShare Of The Carolinas (www.lifesharecarolinas.org), or the Coalition on Donation (www.donatelife.net/become.asp). The AMA also has a downloadable card on its web site (www.ama-assn.org) on the Organ and Tissue Donation page. Sign the card in front of two individuals (not related to you) so that they can serve as witnesses. You can even specify on the card, if you choose, which organ(s) you want to donate. This card is THE legal document in North Carolina to indicate your desire to be a donor.
2. **Tell your family members.** Let your family know that you want to be a donor so that they do not have to make that decision for you. They will have enough decisions to make if you are ever in a position to donate; make this one for them. Healthcare providers are, understandably, hesitant to act against the wishes of family members in these situations, so ensure your family knows what you want. The decision to donate at the time of death can be heart-breaking if family members do not know their loved one’s wishes about donation. Make a decision about this issue well before this point and share your choice with family members.
3. **Show your decision on your driver’s license.** When renewing your license, say “yes” to the organ donation question. Although the license is not a binding legal document for donation purposes, it does indicate your intent and encourage healthcare providers to begin the dialogue with your family.

Healthcare Professionals Should Give Patients and the Public the Facts to Make an Informed Choice

Did you know before reading this commentary that the NC driver’s license is not a legally binding document for donation purposes? If not, that is a good place to start the conversation with patients and the public alike. If you did know this fact, you will be surprised at how many people do not know-and many of them are people who want to be donors.

The AMA publishes “Organ Donation Tips for Patient Education” to guide healthcare professionals in this important education effort.[2] One suggestion, for example, is that physicians choose a non-crisis office visit, such as a check-up, to initiate a conversation about donation. And if staff members talk with patients, they should be clear that they are discussing this topic with all patients at the physician’s request. Of course, if patients

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are not receptive to talking about donation, physicians and staff should not pursue the topic. Organ donation is a "gift of life," and individuals should decide what is right for them. However, more than likely, patients will have questions. Share your knowledge as a healthcare professional to help them make an informed decision about being a donor.

For other healthcare professionals and laypeople, there are plenty of additional resources to help you get involved in raising organ donation awareness. The Coalition on Donation provides several easy-to-implement suggestions to promote donation education (www.donatelife.net/promote.html). This site offers a downloadable web banner, an e-card to send to friends and family, and a presentation kit. The United Network for Organ Sharing (UNOS) offers ideas on its web site for individuals to promote donation in their local areas, as well as a reminder about the Workplace Partnership for Life initiative sponsored by the US Department of Health and Human Services. This campaign encourages US businesses to share information about organ donation in the workplace and encourages workers to sign up as donors. To learn more, simply go to the UNOS web site (www.unos.org) and click on the "Help Save a Life" link. Carolina Donor Services provides helpful information for teachers, clergy, minority interests, and employers; click on the "Special Interests" link on the home page (www.carolinadonorservices.org). And LifeShare Of The Carolinas invites interested people to contact them for speakers and to learn more about the Workplace Initiative. Additionally LifeShare has a web page dedicated to educating children about donation issues (www.lifesharecarolinas.org/kids/index.html).

Answering Patient's Common Questions About Organ Donation

Here are the most common questions or concerns that you will be asked about organ donation-and facts you can use in responding:[3]

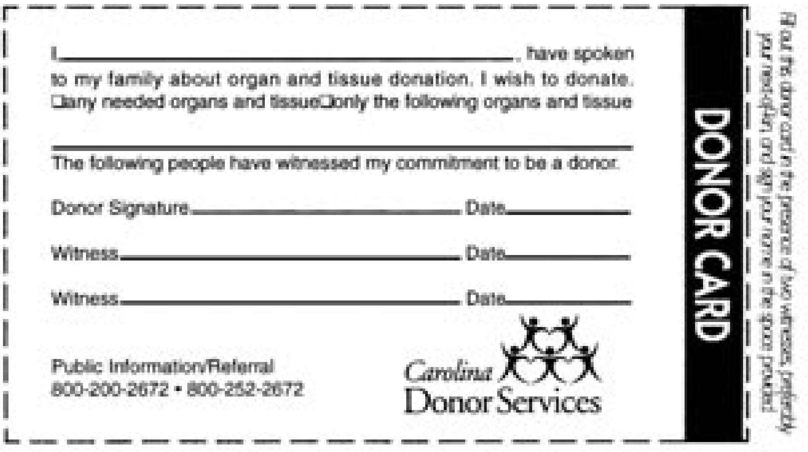
- "I'm afraid that the doctors may not try hard enough to save me if they think my organs will fit someone who needs them." FACT—healthcare providers will do whatever is necessary to try to save lives. Individuals are eligible to be donors only after they have been declared brain dead.
- "I might want an open casket funeral." FACT—individuals can still have an open casket funeral if they choose to donate organs. Donating does not affect how an individual looks in an open casket.
- "How much money will it cost my family?" FACT—the answer is $0. Once a decision is made to donate, the deceased's family bears no financial costs from that point forward.
- "What if they take my organs before I'm dead?" FACT—before being eligible for donation, several tests must be made to determine if an individual is brain dead. Only once someone is declared brain dead can that person be eligible to be a donor.
- "I don't think my religion approves." FACT—most religions either support donation or make no statement, instead supporting individual choice. Want to look up a particular religion's stance on donation? Check out Carolina Donor Services' web page (www.carolinadonorservices.org), click on "Get the Facts," and then on "Religious Views."
- "What about family members in other states?" FACT—states have different laws governing donation. Visit the Coalition on Donation web site (www.donatelife.net/) to learn more about each state's laws.

After you answer such questions and provide facts, some people may elect to sign a donor card; some may want to review printed material before making a decision, and some may decide against being a donor.[4] Even if individuals elect not to be an organ donor, you have at least provided them with information to make an informed choice.

Call to Action

At the end of November 2003, 2,976 North Carolinians were on waiting lists hoping for a call to a better life. Healthcare professionals and laypeople alike can save lives. Offer family, friends, colleagues, clients, and patients the same chance by asking them "What's in your wallet?"

The opinions in this commentary are those of the authors as individuals and not as representatives of any employer or organization.



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REFERENCES

1. Source: www.ama-assn.org. Accessed Jan. 15, 2004.
2. Source: www.ama-assn.org. Accessed Jan. 15, 2004.
3. The sources for these questions and responses (as well as others) can be found on the Carolina Donor Services web site, the AMA web site, and the Coalition on Donation web site (http://www.donatelife.net/facts.html).
4. You can order or download educational materials and donor cards from UNOS, Carolina Donor Services, LifeShare of the Carolinas, the AMA, and the Coalition on Donation.

SPECIAL ARTICLE

Giving and Receiving When Vital Organs Fail

Donald L. Madison, MD (with Andrew, Jim and Susan Pike)

Andrew Pike is 25 years old. He lives in Chapel Hill. Seventeen years ago, when he was eight, Andrew received a heart transplant. He received a kidney transplant on June 24, 2003. The donor of the heart was an unknown child. Andrew's father, Jim, donated the kidney.

Seventeen years is a long time for a heart recipient to remain free of life threatening complications (although kidney failure was in fact a complication of one of the immunosuppressive drugs that was administered following the heart transplant). Andrew Pike is not yet setting the bar, but he is approaching it. The longest survival for a first heart transplant in a child that Dr. Michael Mill (who heads the heart and lung transplant team at UNC Hospitals) knows of is 25 years.

Andrew's mother, Susan Pike, had been the donor of choice for his new kidney, but she failed to pass muster during the workup.

SUSAN: My kidney was fine, but the blood vessels weren't. Instead of being straight and having regular thickness of the walls, mine were curved and had overgrowth of some kind. So the doctor did not want those blood vessels because you must take part of the vessels along with the kidney to transplant. And they thought that it was not going to be good for me to have only one kidney.

JIM: They had a name for that condition.

SUSAN: Dysplasia. Some kind of dysplasia. It's nice that we've forgotten.

DLM: Dysplasia means shaped wrongly.

SUSAN: That's me alright.

DLM: Actually, it means that something developed wrong. That's pretty common in and around the kidney.

Jim and Susan have another son, Ben, who is six years older than Andrew. Ben lives near Chicago and might also have qualified as a donor except for his high blood pressure. But beyond that physical disqualifier was another, social one: Ben is the recent father of triplets.

When Andrew was born, on the second day of 1979, the Pikes were living in Wilmette, Illinois, a suburb just north of Chicago, not far from the lake.

ANDREW: I was born between two of the worst blizzards. I've only heard stories about it. I guess it was the day after I was born that they noticed that I had transposition of the great vessels.

DLM: I imagine that it doesn't take long to notice.

Susan, Jim and Andrew Pike

ANDREW: I think it was my dad who looked in on me when I was lying in the isolette, and he noticed that I was breathing twice as fast as the other babies. And I was turning blue. After that the cardiologists came in to figure out what was what. I'm a little fuzzy on all the details. But between then and my ninth birthday I had, I think, five open heart operations, with physical therapy, I suppose, after each one, and probably hundreds of tests and procedures. And when I was eight years old I had my heart transplant. I was in the

Note: For help with this article I wish to thank the Pike family, Erika Rager, MD, Michael Mill, MD, Romulo Colindres, MD, and Jonathan Oberlander, PhD.

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hospital for seven weeks. Finally, I think it was on Christmas Eve, I was released from the hospital.

It was a struggle to get used to everything after that. I had to relearn a lot of things, because I had a stroke during the procedure.

DLM: While you were on the operating table?

ANDREW: I think that's the way it happened. And after that the right side of my body was pretty much paralyzed for a while. I had to relearn how to use my right hand, which still has a lot of weakness—a lot of physical therapy after that, speech therapy, too. But it was also a time to celebrate even while I was going through so much hardship. I would have to make sure I wasn't around people with germs, because after an organ transplant—any organ transplant—you have to take anti-rejection medicine, and a side effect of that is that you are immune-suppressed. Well, actually, that's not a side effect; it's the main purpose of it.

It was difficult for me, being at such a young age, to understand why this was all happening to me. I would see my friends, who would be leading normal lives, going to school, playing outside and all that, and they didn't have to deal with any of this. That was probably the most challenging part for me—not having the slightest idea why this should happen to me and not somebody else. I've been on medication since, I guess, day one. My nickname when I was in the hospital used to be Human Pin Cushion, because I had to get so many shots. By now I'd guess it's probably been 2,000 or so. I'm used to it. After the transplant I had to have heart biopsies done, I guess twice a week to start out with, and then every week, and then every other week and so on. Now it's every couple of years.

DLM: What are they looking for?

ANDREW: A biopsy is the surest way to check to see whether or not I'm experiencing rejection. They take a catheter, which is really a long, thin wire, and insert it into a vein, thread it up to my heart, and take a sample of tissue and then look at it under a microscope to determine if there is rejection. That was probably the most difficult thing for me as a kid in terms of dealing with pain. I would wake up sometimes maybe 10 or 15 minutes before the whole thing was over, and they would have to hold gauze with pressure against the site. I remember that as the most painful thing.

DLM: And there has been no sign of rejection?

ANDREW: So far, no. Most people experience rejection or coronary artery disease after about 10 years. To go this long without experiencing either of those is—not unheard of, but it's unusual.

Jim and Susan Pike met in Madison, Wisconsin. Susan was a graduate student in Spanish at the University of Wisconsin; and she attended the church where Jim came as Associate Pastor following his graduation from divinity school at Colgate Rochester (in Rochester, New York) and his ordination in the American Baptist clergy.

Susan's roots are in North Carolina and Tennessee. She was born in Elizabeth City and attended school in Lexington and Raleigh before moving to Nashville, where she finished high school and attended college at Vanderbilt. Her father was a Southern Baptist minister who became editor of a Sunday School periodical and other church literature for young people.

Jim grew up in Terre Haute, Indiana. After high school he attended his hometown college, Indiana State. Both of his parents were high school teachers: his mother taught Latin, and his father was a football and basketball coach whose most illustrious pupil—probably—was the Terre Haute Terror, future inductee into the Basketball Hall of Fame, future teammate of both Dean Smith and Bill Russell and, eventually, the most physically imposing one-term sheriff in the history of Vigo County, Indiana. (I think I impressed Jim by knowing that Clyde Lovellette was from Terre Haute.)

After graduate school, Susan taught for five years. She and Jim married and moved to Chicago, where he became Pastor of the Community Church of Wilmette. They lived in Wilmette for 22 years and during that time raised their two boys.

Eight years ago the family came to North Carolina when Jim accepted a call to become Pastor of the Olin T. Binkley Memorial Baptist Church in Chapel Hill.

On the day after he was born Andrew underwent his first heart operation. His congenital malformation included transposition of the great arteries (the aorta emerged from the wrong ventricle and so did the pulmonary artery) with stenosis of the pulmonary valve, along with a faulty tricuspid valve, and a defect of the septum between the two atria (a hole in the wall that separates them) and also of the septum between the two ventricles. Transposition of the great arteries means that the stronger left ventricle is pumping blood into the lungs (instead of out into the body) and that this oxygenated blood when it returns from the lungs comes back to the same side of the heart, only to be pumped through the lungs again and again. At the same time, the right side of the heart is pumping blood out into the body, and this blood returns to the right side of the heart, bypassing the lungs altogether. The entire circulation looks like a figure 8, except that the two loops of the 8 don't connect. One loop has oxygenated blood; the other one doesn't. The only way that any oxygenated blood from the lungs can reach the rest of the body is through the defect: The small hole in the septum between the two atria allows mixing of oxygenated blood from the left heart with deoxygenated blood from the right heart. This mixing allows *some* oxygen—though not enough—to reach the rest of the body. But the greater amount of blood that is being forced into the lungs by the stronger left ventricle causes pulmonary hypertension; and the extra work placed on the weaker right ventricle (which now has to pump against the much greater resistance put up by the circulatory system of the entire body) causes heart failure. So if the defect (hole) between the atria can be enlarged by performing a balloon septostomy, which was Andrew's first operation, more of the blood can be mixed and therefore oxygenated, and the heart failure can be slowed, temporarily.

The balloon septostomy didn't require opening Andrew's chest, but later operations did. When he was 18 months old, he underwent a Mustard Procedure. During this operation (no longer performed in the U.S.) the surgeons actually used the pericardium (the sack that surrounds the heart) to construct a baffle inside the atrium that then forced more of the oxygenated blood returning from the lungs to pass down into the right ventricle, which in transposition of the great arteries is the pumping ventricle for the aorta and the rest of the body. At the same time the surgeons also repaired Andrew's ventricular septal defect, the stenosis of the pulmonary artery, and the tricuspid valve. But during the post-operative course Andrew developed a complication—an infection beneath the sternum, which required a second, clean-up operation.

Three years later, Andrew's heart was again opened, this time because his tricuspid valve was failing. The surgeons then put in a new, artificial St. Jude valve.

DLM: When you were very young, before the heart transplant, could you exert yourself at all? What kind of shape were you in physically?

ANDREW: I wanted to be active—run, climb, jump—I wanted to do everything, which made it all the more difficult for my mother and father to prevent me from going against the doctors' instructions and what not.

JIM: When he was a baby Susan had to check his heart rate every two hours. Once, we were on vacation, and I can still picture her putting him on the hood of the car and counting his heart rate. It was a pretty constant thing.

Andrew at seven months with his mother, Susan.

SUSAN: Later, the doctor had to say things like, "Well, I don't want you to become a couch potato, but..." and asked him not to play quite so hard. Before he was ready for the transplant he won two blue ribbons in the Cub Scout Olympics, which involved foot races, throwing a basketball and the like. And the next week he was in the hospital with congestive heart failure.

Physical activity mixed with a taste for high adventure has been a theme of Andrew's life both as a child and adult. But his active life came to an abrupt deceleration at about age seven.

SUSAN: When Andrew experienced a TIA (transient ischemic attack)—I'm going to say he was six and a half—the doctor said, no, he should not use his skateboard anymore, should not ride a bicycle, should not climb trees. And that was hard.

JIM: That's when we talked with him about having a heart transplant and asked him whether he wanted to do it. And he said, "Will I be able to climb a tree again?" And I said, "Yes, you will." "Then I want to do it," he said.

Andrew's heart failure progressed from that point. In September of 1987 he underwent yet another heart operation, an attempt to reverse the earlier Mustard Procedure and take greater advantage of the stronger of the two ventricles' capacity to pump blood to his body. The surgeons referred to this as a "last ditch" operation. Susan remembers that Andrew did show some modest improvement afterward, but only for about two weeks. It was clear that he would need a heart transplant to survive.

In 1987 only three centers—Stanford, the University of Minnesota and Childrens Hospital of Pittsburgh—were performing heart transplants in children. Michael Mill was, at that time, the transplant fellow in cardiac surgery at Stanford; he recalls that in those days hearts were "relatively plentiful, mainly because so few centers were performing transplants, and we could establish direct personal relationships with other hospitals that would often put us in touch with a donor." The national organ procurement regulations were still in the future. Today, instead of three hospitals performing heart transplants in children, somewhere between 60 and 70 hospitals have pediatric heart transplant programs. Altogether, the United States now has 141 heart transplant programs (adult and children) and 245 kidney transplant programs. In the year 2000 these centers performed a total of 2,246 heart transplants and 14,283 kidney transplants.

In the summer and fall of 1987 eight-year-old Andrew Pike was in severe congestive heart failure. He needed a transplant; but there was a problem.

JIM: We were told that the scars from Andy's previous heart surgeries would keep him from having a transplant. They told us that he wasn't going to make it.

Then our cardiologist—her name was Theresa Berry—went to New Orleans to a heart convention, and she talked to the people from Pittsburgh, and they said that they'd like to see Andy and maybe consider him, but that it would be an exception.

I remember that weekend was Halloween. I had carried him out trick-or-treating, because he couldn't walk at that point; he just didn't have the strength. The next week he was on an "Angel Flight" to Pittsburgh, and a week later he had a new heart.

(NOTE: "Angel Flight" is an umbrella organization of regional associations of volunteer pilots who provide free emergency transportation for medical purposes such as this one.)

DLM: So you went to Pittsburgh for evaluation?

ANDREW: Well, before the transplant I think everyone had decided that it was going to happen. Right?

SUSAN: Well, you had to be evaluated. And the surgeons pointed out that there were risks, including the risk of stroke.

Disney World, July 1987. Suffering from severe congestive heart failure, eight-year-old Andrew would have a new heart four months later.

JIM: But they determined after a couple of days that he was a candidate. And the last few days we were just waiting.

SUSAN: It just happened that a heart was available after a week. The same donor who gave Andrew a heart also gave a liver and two kidneys.

DLM: Do you know anything about the donor or the circumstances of the donor's death?

SUSAN: At that time they did not introduce donor families. But it was a good heart, they said. The doctor would not tell Andrew the gender of the donor. We did understand that an auto accident caused the other person to lose his/her life. And the person was older than Andrew—I think 13—so the heart was a little bigger than what he normally would have had.

DLM: When you say that at that time they did not introduce donors' families to recipients and that the doctor wouldn't tell you the donor's gender, it suggests how terribly important it was that the identity of the donor be kept confidential.

ANDREW: Yes, and even now, the only way I could meet the family is if I wrote a letter to the organ procurement organization of North Carolina—they have people there who would evaluate the letter and decide whether or not it was possible and appropriate to contact the family. If it was they would make contact and ask them how they felt about this. And if the family wanted to meet with me then that agency would help set it up.

DLM: It sounds like you've looked into this.

ANDREW: I have, and there was one time about three years ago when I thought seriously about going to see them or at least getting in touch. So I did learn then about how it was done; but in the end I decided that my life just wasn't where I wanted it to be, and I wanted to be at my best when I did that. It's really important to me that I be at least somewhat successful and independent and on my own before I meet them.

DLM: So it's still something that you have on your agenda, long term?

ANDREW: Yes, it is.

JIM: At the time of the transplant we did write a letter to the family, anonymously, and the hospital saw that they received it. We did not hear from them.

DLM: After the heart transplant, your main medical problem, besides the need for immunosuppression, must have been rehabilitation from stroke.

ANDREW: Yes, the stroke was a main issue. I was in the hospital for seven weeks after the transplant. I did have to take third grade over again. I had missed 117 days of school that year. That was difficult getting stuck back a year away from my friends. How long after the operation did I have to stay there (in Pittsburgh)?

JIM: We rented an apartment not too far from the hospital with the help of the social work department there, and Susan and Andy stayed there almost until the middle of February, and then they came home for a few days and then had to go back. Because Andy had to have these biopsies every week or so for so long, it was well into April before we gave up that apartment. But his care was not transferred to Chicago until that summer. So we continued to make trips to Pittsburgh until June or July.

SUSAN: Andrew had to deal with the stroke, of course, but

The summer after the heart transplant.

there were other problems. He always had strong side effects from the medications. Cyclosporin and his body were just not compatible. Not only did he have overgrowth of hair, and darker hair—he did not look like his old self. One of his friends told him: "You're not Andy." And by junior high and the onset of puberty, he was having terrible headaches that would cause him to miss school. Or he'd get to school and then call me and say, "I'm in the nurse's office." They tried to play around with the medication to alter it or do something that would help. And he took Neurontin for a long time—to be sure there were no seizures. We finally sought help from a man who was both a neurologist and knew acupuncture. He was about the only one who could get the headaches to stop.

JIM: It turned out that they were Cyclosporin headaches. It took a while for them to decide that. We thought they were migraines.

SUSAN: Andrew's older brother had headaches, so we were predisposed to think that Andrew was getting the same kind. I don't think they knew then that Cyclosporin in some people caused these severe, debilitating headaches.

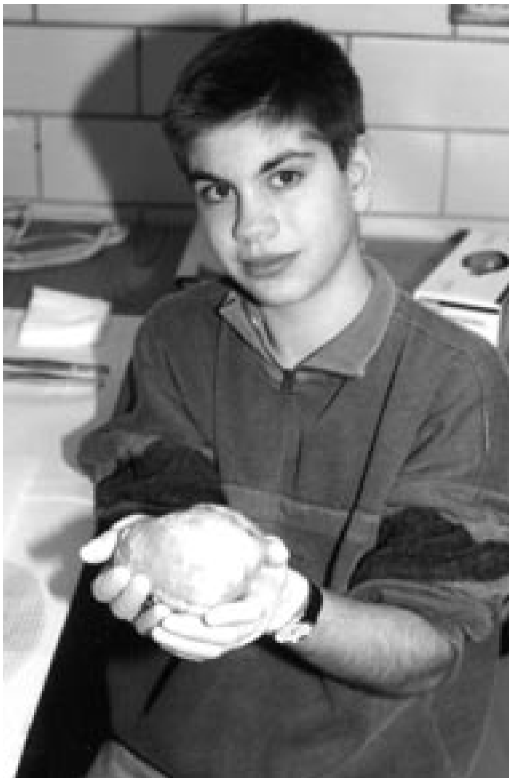
JIM: One of the immunosuppression problems is warts. Remember that horrible wart, two inches wide, on your foot, the year after the transplant? You were on crutches for a long time.

ANDREW: I remember that. It was right on the bottom of my foot, and it hurt. It was not fun.

SUSAN: He couldn't do gymnastics because of it. One of the other patients in Pittsburgh, a little Canadian girl, had little tiny warts all over the bottoms of both feet. She had also had a stroke, but hers was such that she had to learn to write with her left hand. And the Make-A-Wish Foundation gave her a computer so that she could do her work that way.

Andrew is reminded of the part in his story played by the Make-A-Wish Foundation, an organization that took on the important responsibility of providing a pleasurable episode at a painful time.

ANDREW: They came into my hospital room—some representatives of the Make-A-Wish Foundation. They asked me what I wanted and, as I remember, the first thing I wanted to do was go skydiving. I'd seen it on TV and I thought it was what I wanted to do. The doctors thought that would be a little too risky for someone who has just had a heart transplant, so that was out. Then I thought about maybe meeting Arnold Schwarzenegger, because he was my hero at



Andrew at 10 years of age. He is holding his "old" heart, which he wanted to see after being told that it was in a repository (of congenitally malformed hearts) at Children's Memorial Hospital in Chicago.

the time, the big action hero in the movies, and I loved all that stuff. I wanted to be in a movie with him. But then I realized that it would be just meeting and talking to him for maybe 15 minutes and it would be over. Eventually I decided I wanted my own tree house. So the Make-A-Wish Foundation paid for a builder to come to our home and build this two-story tree house with rope ladder, bridge, monkey bars, trap doors, and a slide and a pole and all this fun stuff. It was pretty much the biggest news in our neighborhood. All the kids were really impressed. It was the coolest thing in the world. My brother was disappointed, though. He wanted to go to Hawaii. But he couldn't convince me of that.

Apart from dealing and coming to terms with the side effects of Cyclosporin and Prednisone, Andrew was soon able to lead a more active life than he had ever been able to before.

JIM: The summer after the transplant we were at Ben's Little League baseball game. Ben is our older son. And we couldn't find Andrew anywhere. We finally did. He was at the next diamond, and he'd climbed up the backstop and was perched on the top.

I asked Andrew when it first became apparent that kidney failure had progressed to the point that he might need a kidney transplant.

ANDREW: Well, the kidney failure started when I was born. It came from the heart failure. And then the anti-rejection medication (Cyclosporin) after the heart transplant caused the progression of the kidney failure. So, pretty much that's been going on my whole life. They said that my Creatinine level was OK where it was and as long as it didn't go any higher... But it continued to go higher, little by little. And then ...

SUSAN: Wait. When he was in high school, just before we left Illinois, Andrew got a kidney infection. He had to go to Children's Hospital and have a kidney biopsy. And at that point they said that he was 50% below normal functioning. I would say he had more fatigue after that, but it did not become more than that until this past year.

JIM: I remember that when we were still in Chicago, and I had just accepted the job at Binkley (in Chapel Hill) and we went to see the doctor, who told us that Andrew had glomerulosclerosis and might need a kidney transplant. I know that's when it was because I said, "How can I go to a new church and have this facing us?" It wouldn't be fair to the new congregation; that was my fear. I remember that Andy and I went for a walk and talked about it, and he encouraged me to do it. I thought—and maybe I said it then: "Well, it feels like God is in this, so it must be alright."

Andrew also remembers the Pike family's decision to move to Chapel Hill, but he recalls a different "sign."

ANDREW: Actually, this is the way it was: There was a program by all the singing groups at my high school; all the groups were there. And the very first song that these 400 or 500 kids sang at that concert was "Nothing could be finer than to be in Carolina in the Morning." That was the sign that it was time to go.

JIM: When we got to North Carolina one of the first things we did was to get Andrew connected with a neurologist, a cardiologist, and a nephrologist.

DLM: No primary care physician?

SUSAN: Oh, yes, Dr. Allen Daugird. And he's done a good job, not only with the ordinary medical things that happen, but also things like helping Andrew get a driver's license.

ANDREW: Every couple of years I have to have a form filled out that says that I'm taking all my medications and doing what the doctor says, and so on, and that I can drive a car safely.

JIM: Well, after we got here Andrew went to see the nephrologist, Dr. Ronald Falk, and he said that most of the deterioration of the kidneys had probably occurred before the heart transplant. And he weaned Andrew off of the Prednisone he'd been on, which required biopsies once a month for about four or five months to assure that there was no rejection. Prednisone is a mean drug that causes a lot of side effects. Andrew was much better after that for quite a while.

During this time Andrew graduated from Chapel Hill High School, took some classes at Durham Tech, and got a job at Blockbuster Video. He also, finally, indulged his long-held wish to try skydiving.

ANDREW: Even today being active is very important to me. And when my kidneys prevented me from doing that, it was really hard. But when I was 19 I wanted to try skydiving. We knew someone in our church whose son did it, and so I got together with them, and I got to do it for the very first time. I remember going up in the airplane and thinking, "I can't believe I'm going to do this." But I was also so excited that it took the fear away. I remember getting to the door of the plane—I was doing a tandem jump so I was actually attached to someone behind me, the expert, who was wearing the parachute. Anyway, I remember kneeling down at the door, looking down 13,500 feet, and thinking this is the most exciting thing I've ever done, this is just awesome! And the next thing I know I'm given a little shove, and I go out, and the first three seconds my stomach did ten or twelve flips. But after that we got into neutral position, which is just hands raised like you are surrendering to the police or something. It was just incredible. We were falling at 120 or 125 miles per hour. It was so fast, and the wind... It was very windy, let's put it that way. And then when he pulled the cord we went from 120 miles an hour to 20 in just a split second. It's just like going from total, complete, amazing exhilaration to the most peaceful experience —because you're just floating down like a bird. I did it seven more times. The next four were tandem (you have to do five tandem) and then I did a few solo. But it eventually became

> too expensive. It was about $150 per jump. But it really taught me something: my limits were not as much as I thought they might be.

So, for much of the time between age eight, when he had his heart transplant and age 24, when he had the kidney transplant, Andrew was an active boy and young man who liked to push his limits and was sometimes able to. Then, last January a year ago he had a scheduled heart biopsy. At the same time the doctors ordered a Creatinine level—he hadn't had that particular blood test (a test of kidney function) for about a year. His serum Creatinine was elevated significantly and alarmingly. The test was repeated every other week, and the level continued to rise until by the end of April it was at seven and a half. By then Andrew was starting to be "...not incoherent, but fuzzyheaded." He was showing the signs of kidney failure.

Graduation day, Spring of 1998. Andrew, posing here with Ben, is 18 years old.

> **ANDREW:** I was feeling a lot of disorientation and dizziness, confusion, and a lot of fatigue.

This is when the testing for a donor began, testing that Susan eventually failed and Jim eventually passed. But Andrew's advanced kidney failure signaled that he could not wait for a transplant. He began hemodialysis. I asked him to describe it.

ANDREW: Imagine all of your energy being drained out of your body completely. That's what it was like. I didn't have all that much energy to begin with by then. But it made me feel so miserable. I was tired all the time. The only hope I had of getting better was the transplant.

DLM: What was your schedule for the dialysis?

ANDREW: Three days a week for two and a half to three hours.

DLM: And did you feel different afterward?

ANDREW: I felt more disoriented afterward. And very weak. I just think that being on dialysis means that you don't have a life anymore. You're alive, but there's nothing good about it.

JIM: My observation was that the day of the dialysis you felt horrible, the next day was not quite as horrible, and the next day you were back in dialysis. On the day off you seemed to feel a little better. But let me go back. Andrew had a temporary port for his dialysis. And when Susan couldn't be a donor Dr. Falk arranged for him to have whatever the next stage is to get started, because this temporary port did not function as well as another kind of dialysis would do—the abdominal kind. What's that called?

DLM: Peritoneal.

JIM: Yes. Andrew chose that. And he was scheduled to begin it two or three days after I was approved, so they cancelled it. And the surgery was performed a little more than a week later, on June 24. They began testing on Susan in early April and that went on for four or five weeks. And when she was disqualified, they started on me, and I was at the hospital two or three days a week for three weeks just going through the tests. We were both so thoroughly examined it was incredible. I think that at one time I counted that there were 27 different tests that they did on me, including adding tests like colonoscopy. It was so thorough that you wonder how anybody could qualify after all those tests. That I did is a miracle.

DLM: You may qualify more easily, though, if you have health insurance.

JIM: That's true. Before any of this started they verified that our insurance company would cover all of it, including our testing.

SUSAN: However, the insurance will only pay for testing one potential donor at a time. I had to finish before Jim could begin.

DLM: Then, I suppose, at some point they said to you, "You pass."

JIM: Yes, my blood pressure and cholesterol and lipids were all at acceptable levels. Which was amazing. They told me that if my blood pressure were too high I would be disqualified, or if my cholesterol or lipids were too high. So the testing was not just to see if I were qualified to give a kidney to Andrew, it was also to see whether I would be healthy enough, whether my health might be compromised by making this donation. And they determined that I was fit, physically. And then we had meetings with the social worker, financial consultant, and an interview with the psychologist to make sure that I was doing this for appropriate reasons. Those were all appointments required by the hospital—in addition to all the medical things. But we had wonderful experiences with all of the staff at the hospital. We're very grateful.

DLM: Who does the surgery? It must take two different surgeons.

SUSAN: Yes. There are four on staff who do kidney transplants. One was in Afghanistan with the Army. And so they had to schedule it among the other three. Otherwise they could have done it sooner.

DLM: What was the post-operative course like for both of you?

SUSAN: They told us ahead of time that it would be easier for Andrew than for Jim. The donor would have a harder time because the surgeons would be doing more traumatic things inside—in order to take the kidney out whole. In the recipient they just need a place to put it in. They don't have to twist things around so much.

JIM: They did not take out either of Andy's kidneys. So he now has three. But, of course, two of them don't work. They needed a place to put in just one kidney. With me the surgery was more extensive, but we both had quite a time.

ANDREW: I remember thinking before the operation that with dialysis I don't have a life. So it was a choice between not having a life and having a life, and if that meant having a transplant.... On the day of the operation they took me in and on the operating table, and before they put me to sleep I thought, "Well, here we go," and, "I hope it works." And when I woke up there were maybe four or five nurses screaming at me, telling me to wake up. I was having a really hard time waking up. I don't know if they were afraid that I was never going to wake up or what, but it seemed like they were screaming their heads off. Finally I did wake up, and as I remember, they put me in a hospital bed, and they brought my dad alongside me on another hospital bed, and we just looked at each other and said, "We did it."

DLM: What was the screaming to wake up about? Do you know?

ANDREW: I have no idea. Maybe the anesthesia was... I've always had trouble waking up.

JIM: Even without anesthesia!

ANDREW: Anyway, during the course of the next week I experienced severe cramps and lots of sharp pains where the incision was made, just like everybody. But it was easier for me to deal with being in the hospital and all the tests and people coming in and out, because I was so used to it. They did say to me that it would be a lot easier for me in terms of the surgery and recuperating from it because I had already been through so many of them. But for my dad it was all very new.

Assuming the "neutral position."

JIM: And the transplant was easier for you than for many other recipients because you were already immunosuppressed.

SUSAN: And the kidney started working very soon after the operation. So Andy felt better.

JIM: The hardest part of the whole thing for me was the fear that I might not be able to do it, that I might be disqualified and that Andrew might have to continue the dialysis, which was so hard. So we were elated when we learned that it could happen, and we went in with a sense of celebration, even though they were very clear that it was going to be a difficult recovery.

They told me to plan to take eight weeks off work, which I did. I think they said, "You'll be able to function after eight weeks off work." But they didn't tell me very vividly how I would feel after that. I found that I needed lots of rest and was very weak and tired. But as for the surgery itself, I just woke up in the room and it was all over and the worst part afterwards was gas pain. They did it laparoscopically—made a four-inch incision and then two other incisions for camera and lights and all. I haven't really noticed any difference in terms of kidney function or urinary function. But regaining my energy level has taken a long time, much longer than I thought. I had mistakenly thought that after eight weeks I would be ready to go back full steam, and that was definitely not the case.

ANDREW: After the procedure was done—I don't remember why it happened—I became diabetic.

SUSAN: Many people after this surgery become diabetic, and Andrew did, too.

JIM: Because of the additional Prednisone.

ANDREW: Because of the Prednisone, that's right. And just like anybody with diabetes I had to check my blood sugar levels with the machine, four times a day to start with. And it wasn't until I got out of the hospital, the very first day, that I took it and it was down.

DLM: This was an additional dose of Prednisone to guard against rejection of the new kidney?

ANDREW: Yes.

DLM: With your new kidney do you have to have biopsies or something else that's analogous to the way you still have to test your heart—to see if there's rejection?

ANDREW: Luckily, the only thing I have to do now is blood work. It's much easier. I go in once every couple of weeks now, for blood work and to see that all of my medications are where they need to be.

JIM: And they're continuing to lower Andrew's medications, like Prednisone, over a period of time, so that he will be taking much less medication after a year.

DLM: But transplant recipients must continue to receive some level of immunosuppression medication for their lifetime, isn't that right?

ANDREW: Yes, absolutely. Anytime you have an organ transplant there's a foreign object in your body and the immune system's going to think it's not supposed to be there. So it's going to try to kill it. So you have to take immunosuppression to make sure that the immune system won't be strong enough to (do that).

JIM: One thing that was very helpful in terms of recovery time was home healthcare. For the first three weeks home, a nurse came here every other day, the first week almost every day. Andrew's wound was open, so it needed to be dressed and packed for about six weeks. And they came to do the blood work for several weeks. It meant that we didn't have to take Andrew and get over to the hospital ourselves. We were very grateful for that service; it made a lot of difference.

SUSAN: We also took care of the wound, but being rank amateurs we needed the home healthcare here to get us started. I should point out, too, how very helpful friends and church members were, especially to bring food from church. And then Jim's twin sister, and my sister came; our other son came, and Jim's brother and sister-in-law and niece also came for a couple of days right after the surgery. So we were well supported, and it was good to have them here. So many people have helped, both then and earlier. Andrew's third grade teacher taught him to write again after the stroke. The community where we lived then began a fund to help on their own accord when he needed the heart transplant. They sent letters and a videotape and all kinds of things to the hospital when we had to leave Chicago and go to Pittsburgh, which back then was a place of last resort for kids with severe problems, when transplants weren't done very frequently.

DLM: Is Andrew eligible for Medicare?

JIM: Well, that just took effect, what was it, two months ago? We did not apply until after the kidney transplant, although Dr. Daugird had suggested it two years ago.

DLM: He would have been eligible then as someone who had end-stage renal disease.

JIM: With end-stage renal disease you're automatically qualified for Medicare. But if you get a transplant then the assumption by the government is that you're going to be fine and be back in the workforce. So Medicare coverage lasts for only three years following the transplant. But Andrew is on Medicaid now. And we have yet to experience how that's going to function. I don't know whether Medicaid would have supported a transplant or not. We've been trying to reach someone who will talk to us about questions like that. Of course, I would like to know the facts before we take Andrew off of my private insurance. Which is going to have to happen when I retire, but right now it doesn't. That's one of the big worries of transplant families.

SUSAN: How to pay for the medicine.

JIM: I have piled up here probably three or four hundred letters from UNC Hospitals that have come in the mail since June 24th. Literally—and the cost of the mailing from the hospital must be enormous. And for every one we get from them we get another letter from the insurance company. It's just bizarre. I need a full-time accountant here.

SUSAN: When Andrew was quite small, I could recite by heart all of his medications. I had them on the tip of my tongue. In the process of his growing up and taking over his own care, I don't now have all the facts at my fingertips. And I don't have to do it the same way. But it makes me extremely anxious when we start talking about it, because I'm thinking that some of the facts may not be right or that we may not have them straight.

The volume of clinical information that Andrew's father and mother—and now Andrew himself—have had to remember is enormous. Each of the many first-doctor-visits over 25 years in two different communities (three, counting Pittsburgh) involves taking a new history. Finally, the family has gotten in the habit of taking along a four- or five-page synopsis of the history and handing it to the doctor. But, says Jim, "They don't pay attention to that, they still want to hear it all verbally."

DLM: I'm wondering, is there a support group, locally, for organ transplant recipients?

ANDREW: Well, not long ago I got a letter from a person who had had a heart transplant and a kidney transplant, and who just wanted to get together some people who had had these experiences, to meet casually and talk, and that sort of thing. And I'm planning on getting together with that group, which is just now starting. I don't know much more about it yet.

Brother Ben feeding Andrew's three nephews.

Twice a recipient, Andrew Pike is now an advocate and campaigner for organ donations.

He referred to his own experience when he spoke briefly at church on the occasion of National Organ Tissue Donor Sabbath.

"It marks a chance for you to become a true hero," he told the assembled congregants, mentioning also that one of his own heroes, Michael Jordan, was the Organ and Tissue Donor Spokesperson.

Andrew then told the story of the family that invited him to visit with their ten-year old son, who was in the hospital awaiting a heart transplant. A week after the visit, still waiting for a heart to arrive, the boy died.

A year and a half ago Andrew wrote of the reason the pleasures of his own life had been his. It was "because of the good faith and kindness of one family... whom I have never met..."

Become a donor, he says, "if you are looking for a chance to show God's love. Give the gift of life."

Letters to the Editor

Mental Health Reform

To The Editor:

Congratulations on your September/October, 2003 issue focusing on Mental Health Reform, a masterpiece of diplomacy. Unfortunately it left out input from, or representation of programs which have been closed, staff who have been discharged or have left and patients who have been informed they will no longer be provided services. Reform is needed, but we need to reform the current implementation. We need to reform the reform.

Doctors Swartz and Morrissey refer to the "mental health care system" as having lagged behind the rest of the nation. In fact the initial development of what was to become the mental health system was a model for the nation in the early 1970s but has remained a "nonsystem". In his book, *People, Patients and Politics*, Clark Cahow, reviewing the history of North Carolina mental hospitals from 1848 to 1960, cites the need to "comprehend the complex interplay in the roles of the Governor, the Commissioner [now the Director of the Division of Mental Health, Developmental Disabilities, and Substance Abuse Services (MH/DD/SAS)], the Legislature and the medical centers." Further he states "future leaders must remain aware of the continual necessity to sell the concept of this relationship to the ever-changing political community." Unfortunately, Mental Health has suffered from a lack of leadership from the Governor's office, administration, the Legislature and the medical centers, since the reorganization of state government at the tail end of Governor Bob Scott's tenure.

The current implementation of "Reform" is in the process of creating a new bureaucracy in the form of Local Management Entities which will not provide direct services. Moreover it has made divestiture and privatization primary goals, supplanting quality direct patient care and invites corruption in place of what at times may have been misguided efforts to provide services in a few area programs. Doctor Visingardi's article is brief and cryptic, and refers to "managers of public policy," "divesting public service," as activities operant in moving forward. He closes with a question: "Have we positively contributed to the lives of people with disabilities and their families?" The answer to that at present is not only NO, but we have contributed negatively. His propensity to issuing multipage memoranda, stifling employee input, and issuing invitations to state-level meetings take the place of a process of interaction with the people to be served and serving.

> *a lack of accountability among the local area authorities and the state's excessive reliance on our state institutions. Both in fact, are failings of state-level leadership.*

Representative Insko reminds us that the Auditor's report related to two major issues, a lack of accountability among the local area authorities and the state's excessive reliance on our state institutions. Both, in fact, are failings of state-level leadership. If the benign neglect of the past continues, the only thing that will come of these efforts will be increased chaos. Perhaps in our more urban areas where political, professional and consumer and public leadership is substantial, what is good will be salvaged. Mr. Campbell (State Auditor) clearly identifies problems of "no funding to create programs" and the fact that "mental health programs had been underfunded for years." He emphasizes "the local structure for providing services must be in place this time as we shift care back to the community." However, reform implementation proceeds without funds and alternative services in place. Ms. Flamino provides clarity regarding the separateness of the nonsystem of mental health, homelessness and criminal justice, a dynamic sure to continue to obscure the true needs.

Dr. Bridges, the long-term optimist, neglects to say that the program of Vance, Granville, Warren and Franklin Counties where he served for over 20 years has been dismantled and the staff discharged without adequate alternative services, only one example of program closures. "A Parent's Tale" provides ample substance and argument for the fact that state/local funded and operated services will always be necessary and the unfortunate likelihood is that those individuals affected by mental illness, developmental disabilities and substance abuse will continue to be the lowest priority of leadership. In view of this it seems that parsimony when it comes to the elaboration of bureaucracy and preservation of current staff and services must assume primary roles.

Finally, it is no coincidence that the golden years of the early 1960s to the mid-1970s saw the Division of MH/DD/SAS led by a number of highly respected licensed medical doctors. The deterioration of the nonsystem occurred parallel to the systematic removal of physician positions. The current reform has been without a physician at the state level until recently, when, after relenting to pressures from the NC Medical Society and NC Psychiatric Association along with that of consumers, one position has been adverised. Consistent with this policy to abolish medical doctors from leadership in programs which are medical, the entire Division continues without a physician director which the General Statutes still called for the last time I looked.

— Nicholas E. Stratas, MD
DLFAPA

The Cost of Prescription Drugs

To The Editor:

I have been reading your latest issue (Vol. 64, No. 6), which is a nice job. I liked the Ingram, Hooker Odom, and Millstein pieces in particular. I disliked Marks, whose European perspective shines through as smug superiority; I don't recall any acknowledgment of the Europe-as-free-rider hypothesis.

The Oberlander piece oversimplifies some things. For example, I don't quite accept the parallel between the original enactment of Medicare and the new drug benefit. To be sure, Congress in 1965 did appease the medical/hospital monopoly and leave costs for future attention. The new bill, however, instead of leaving the cost issue completely unaddressed, tries to provide some competitive alternatives to price controls on drugs. Original Medicare left the BCBS models in place, and made no provision for competition, which entered the picture only with the HMO Act, the antitrust initiative, and the Reagan administration's attempt to bring HMOs into the program. The new law certainly will hasten the coming train wreck, because there is nowhere near enough money to pay for the entire entitlement package for all who will be entitled to it. Inviting a crisis may not be a bad idea, however, since no one wants to reform Medicare until they have no option. Oberlander may be right that the Democrats will eventually impose drug price controls (he might at least have acknowledged that there's a downside to squeezing industry profits), but it's more likely that the crisis will be of such a magnitude that the whole entitlement philosophy will finally have to be rethought, with a shift to defined contributions—the obvious solution.

In general, the problems with drugs, especially the high cost of promoting them and their inefficient use, lies in the professional paradigm, which says that doctors should make all the choices (perhaps with some input from non-cost-conscious patients) and that health plans should be limited to pleading from the sidelines. Most all of our problems lie ultimately, of course, in a payment system in which health plans are barred from acting as purchasing agents and must be simply payers (at negotiated prices, perhaps) for whatever professionals deem necessary to protect our health.

— Clark Havighurst, JD
William Neal Reynolds Professor Emeritus of Law
Duke University

The new law certainly will hasten the coming train wreck, because there is nowhere near enough money to pay for the entire entitlement package for all who will be entitled to it.

The North Carolina Institute of Medicine

Since January 2002,
Publisher of The *North Carolina Medical Journal*

In 1983 the North Carolina General Assembly chartered the North Carolina Institute of Medicine as an independent, nonprofit organization to serve as a non-political source of analysis and advice on issues of relevance to the health of North Carolina's population. The Institute is a convenor of persons and organizations with health-relevant expertise, a provider of carefully conducted studies of complex and often controversial health and healthcare issues, and a source of advice regarding available options for problem solution. The principal mode of addressing such issues is through the convening of task forces consisting of some of the state's leading professionals, policy makers and interest group representatives to undertake detailed analyses of the various dimensions of such issues and to identify a range of possible options for addressing them.

Members of the NC Institute of Medicine are appointed for five-year terms by the Governor, and each task force convened by the Institute typically includes at least one-third of its membership from among the appointed members. Topics to be addressed through task force efforts are chosen following requests from the Governor, the General Assembly or agencies of state government. In some cases, topics are selected on the basis of requests from a number of stakeholder organizations across the state where this type of analytical process is considered to have potential value.

The NC Institute of Medicine assumed the role of publisher of the *North Carolina Medical Journal* in January 2002 when the North Carolina Medical Society reached the decision to cease support for its publication. The Institute views the *North Carolina Medical Journal* as an extension of its mission. The *Journal* provides a forum for stakeholders, healthcare professionals, and policy makers and shapers to study and discuss the most salient health policy issues facing our state. Like many states, North Carolina is grappling with issues such as an increasing number of uninsured, the unmet health needs of the growing Latino population, a critical shortage of nursing personnel, the health risks of tobacco and obesity, rising prescription drugs costs, mental health system reform, the increasing societal burden of chronic illness care, the threat of bioterrorism and the necessity of assuring adequate public health preparedness—all in the midst of an economic downturn. Each of these issues presents unique challenges to healthcare providers and state policy makers. Yet, a fully implemented task force to consider each of these sets of issues is not feasible. The *Journal* makes it possible to present an organized and balanced overview of some of these issues, six times per year, and allows interested persons the opportunity to engage in the ongoing discussion of these issues throughout the year. The Institute hopes that our readers of the *Journal* will, in this way, become involved in the continuing debate about the most promising avenues for assuring the highest standards of health and healthcare for all North Carolinians.

health policy

North Carolina Institute of Medicine

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Running the Numbers

A Periodic Feature to Inform North Carolina Healthcare Professionals
About Current Topics in Health Statistics

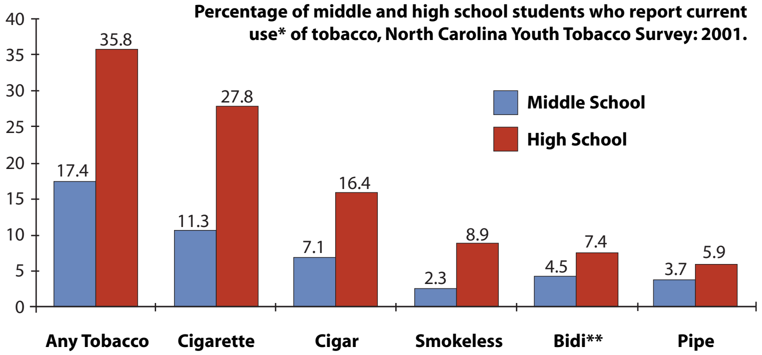
From the State Center for Health Statistics, North Carolina Department of Health and Human Services
www.schs.state.nc.us/SCHS

Youth Tobacco Use in North Carolina

Tobacco is the leading cause of preventable death in the nation and the state.[1] Many negative health outcomes are associated with tobacco use, most notably lung cancer and cardiovascular diseases.[2] More than 80% of tobacco use starts before the age of 19; therefore prevention efforts among youth are an important opportunity to curb use. Healthcare professionals play a critical role in youth tobacco prevention. Even brief clinical efforts to "ask and advise" lead to a reduction in use or ever starting.

The North Carolina Youth Tobacco Survey (NC YTS) is the largest, most comprehensive source of data on youth tobacco use, behaviors, and attitudes in the state. The NC YTS is conducted in coordination with the North Carolina Department of Public Instruction and the Centers for Disease Control and Prevention. In 2001, more than 10,000 middle and high school students from across the state participated in the survey. The overall survey response rate was 71%. The survey data were weighted to be representative of the entire population of middle and high school students in North Carolina.

Results from the 2001 NC YTS indicate that an estimated 36% of high school and 17% of middle school students had used some type of tobacco on one or more of the past 30 days. There is a marked difference between use by middle (6th - 8th grade) and high school (9th - 12th grade) students for each type of tobacco. Cigarette smoking accounted for the majority of tobacco used in both middle and high school students followed by cigars, smokeless tobacco, bidis, and pipe tobacco. Some students reported using more than one of these types of tobacco during the past 30 days. Most of these percentages are slightly higher than national rates of tobacco use among middle and high school students.


Percentage of middle and high school students who report current use* of tobacco, North Carolina Youth Tobacco Survey: 2001.

Note: * Current use of cigarettes, cigars, smokeless tobacco, pipes, or bidis on 1 or more of the 30 days preceding the survey.
** Bidis are small round hand-wrapped cigarettes typically from India.

Based on data from the NC YTS, the state allocated $18.6 million to address teen tobacco use through the Health and Wellness Trust Fund, created as part of the multi-state Master Settlement Agreement with the tobacco companies. It is hoped that school and community interventions will decrease youth consumption and reduce North Carolina's tobacco-related morbidity and mortality.

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1. McGinnis JM, Foege WH. Mortality and morbidity attributable to the use of addictive substances in the United States. Proceedings from the American Association of American Physicians 1999; 111: 109-118.
2. U.S. Department of Health and Human Services. Surgeon General report: the health consequences of smoking. Atlanta, GA: USDHHS, CDC, Office on Smoking and Health, 1981.

Contributed by Scott Proescholdbell, MPH
Tobacco Prevention and Control Branch, North Carolina Division of Public Health

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Herbert G. Garrison, MD, MPH
Scientific Editor, North Carolina Medical Journal

North Carolina is blessed with some of the finest medical research institutions in the world. The work of the medical scientists that labor in our research facilities becomes complete (in many ways) and public when it is published in peer-reviewed journals.

While medical researchers in North Carolina have many journals to which they can submit their manuscripts, we want them to consider keeping their work here at home. To be more specific, we invite the authors of our state to submit their papers to the *North Carolina Medical Journal*.

The *Journal* seeks papers that convey the results of original research. We are especially interested in publishing research papers that have relevance to the health of the people of our state.

An editor reviews all papers received and those of sufficient quality are peer-reviewed. As with any journal of merit, only papers of high quality will be published. Papers printed in the Journal are indexed in the National Library of Medicine's MEDLINE public database.

The *North Carolina Medical Journal* is published six times a year. It is distributed free of charge to the members of the North Carolina Medical Society, the North Carolina Hospital Association, the North Carolina College of Internal Medicine, the North Carolina Academy of Physician Assistants, the North Carolina Board of Pharmacy, the North Carolina Association of Pharmacists, the North Carolina Division of Public Health, the North Carolina Association of Health Plans, and the Medical Review of North Carolina. The *Journal* is available by subscription to others.

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Given the sluggish economy and job losses, free clinics face greater challenges than ever. Most clinics are forced to turn away more patients than they are able to see.

To help address this need, the Blue Cross and Blue Shield of North Carolina Foundation is providing a grant of $10 million to the North Carolina Association of Free Clinics over the next five years. The grant's goal is to double the number of people that free clinics and pharmacies can serve and to provide statewide access to these facilities. The grant is expected to result in a 50 percent increase in the number of free clinics and pharmacies across our state.

Meeting these ambitious goals will continue to require the commitment of dedicated volunteers. While this grant will provide the impetus for the creation of new clinics, establishing clinics also requires the involvement of community leaders, medical professionals and other volunteers willing to organize and sustain such an effort.

No one entity can solve the problem of the uninsured. However, by continuing to work together, we can all make a big difference.

For more information about free clinics, we would invite you to check out the Web site of the N.C. Association of Free Clinics, at **www.ncfreeclinics.org**.

You can learn more about the BCBSNC Foundation at **www.bcbsnc.com/foundation**.

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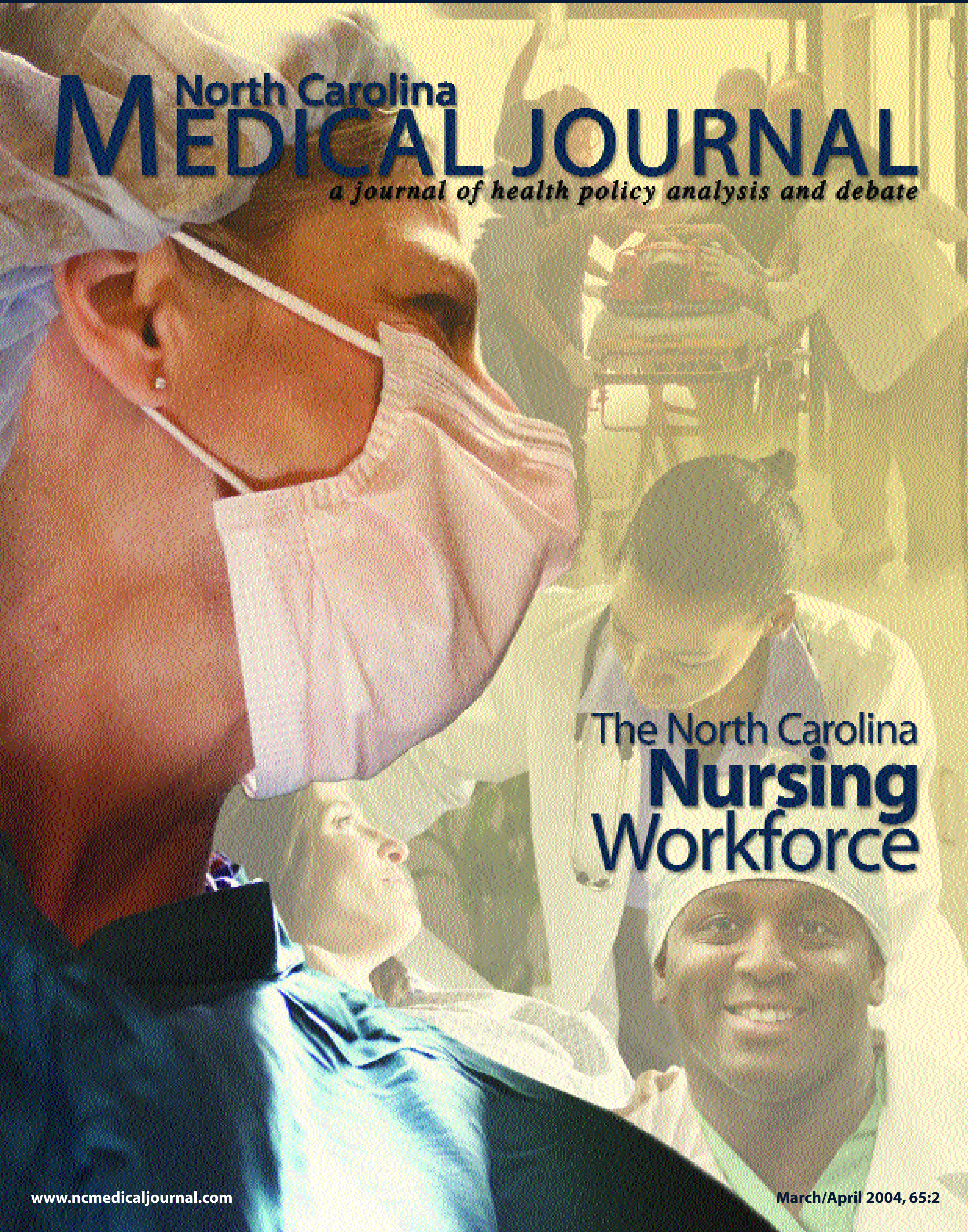

The North Carolina **Nursing** Workforce

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Be Active North Carolina is offering a free brochure that physicians can use to prescribe healthier lifestyles for their patients. This tool highlights simple yet effective ways to become more active everyday such as taking the stairs instead of the elevator and a checklist of activities for physicians to prescribe to their patients.

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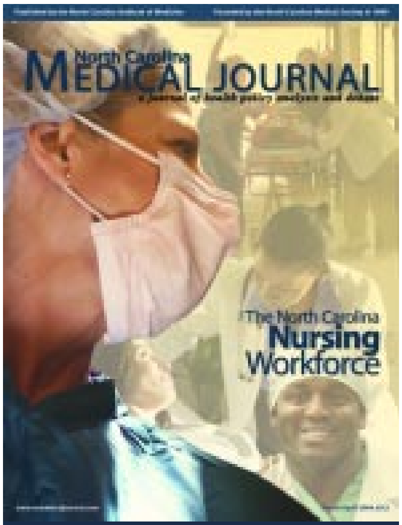

North Carolina
MEDICAL JOURNAL
a journal of health policy analysis and debate

March/April 2004, Volume 65, Number 2 **Published by the North Carolina Institute of Medicine**

POLICY FORUM: *The North Carolina Nursing Workforce*

"It is our collective responsibility to do what we can to ensure that we have an excellent nursing workforce in 2004, and for many years to come."

COMMENTARIES

DEPARTMENTS

Universal Childhood Vaccine Distribution Program: North Carolina's Strategy to Ensure All Children are Age-Appropriately Immunized

As one of the greatest public health achievements of the twentieth century, immunizations have been described as both cost-efficient—saving $15 for each $1 spent—and effective in reducing incidences of disease throughout the world.

North Carolina's immunization program was developed to prevent and control transmission of vaccine-preventable diseases, with emphasis on accelerating interventions to improve the immunization coverage rates of children under two years of age. In 1994, the North Carolina Department of Health and Human Services, Division of Public Health, Immunization Branch, instituted the Universal Childhood Vaccine Distribution Program (UCVDP) to keep children in their medical homes and remove cost as a barrier to age-appropriate immunizations.

The UCVDP program provides all of the required childhood vaccines—at no charge—for any child present in the state of North Carolina from birth through 18 years of age. More than 97 percent of providers who administer immunizations in North Carolina (more than 4,200 physicians) have signed up for the UCVDP program. Because of the success of this program, North Carolina ranks fifth in the nation, with an immunization coverage rate of 85.6 percent.

The benefits of the UCVDP program for health care providers are numerous and include:

- ✓ one-stop shopping for ordering vaccines;
- ✓ reduction of risk of paying for vaccines for which payment may not be collected;
- ✓ vaccine consultation;
- ✓ elimination of the need to keep two sets of vaccine supplies for most vaccines;
- ✓ health care provider 'friendly' program; and
- ✓ minimal paperwork.

For information about becoming a participant in the UCVDP program, call the North Carolina Immunization Branch at 1-800-344-0569 or visit the Branch online at **www.immunizenc.com**.

FORWARD

Policy Forum:
The North Carolina Nursing Workforce

Recently, a family member was in a local hospital for an extended period. The experience reminded me once again that, in the midst of all of the wonderful miracles and technology at our disposal in today's modern hospitals, nurses are still of critical importance in the process of caring for patients. My family's inevitable questions (What is happening? What should we expect? Where is something located? What hours is a service available?) were all directed to the nurse of the hour. And the nurse invariably could calm the anxious patient and the family with professionalism and expertise. Such is the expectation that our society places on the nursing profession.

Yet, those of us who work in healthcare recognize the challenges that are before the profession today. These challenges are enumerated in detail in the report of the Task Force on the NC Nursing Workforce, summarized in this issue of the *North Carolina Medical Journal*. This important and timely report includes some suggestions and recommendations for improvements and modifications in the way nurses are recruited to the profession, trained, and practice in North Carolina. Some of the subjects discussed have been with us for decades; others are ever-changing and call for new and clear thinking about the possibilities for the future.

The Duke Endowment, as one foundation, has long supported projects to address some of these challenges. However, at a meeting of our Board of Trustees in May 2002, there was a lively conversation about how we might best support a statewide discussion of the issues that could lead to a consensus for new actions. The North Carolina Institute of Medicine gave wonderful leadership by developing the format of such a process, and provided the all-important neutral voice in the discussions needed to arrive at the printed recommendations that appear in this report. The members of the Task Force were indispensable. They came to the meetings with enthusiasm, interest, and high ideals for the future of nursing in North Carolina. The final product would not have been nearly as valuable without their participation and contributions.

We believe the groundwork for the future is being laid by this report. Already, work has begun to assist foundations like the Endowment as we strive to understand where we can maximize our investments to address nursing workforce issues. We encourage your thoughtful consideration of the information and recommendations contained in these pages. And we encourage lively and constructive discussions of the actions that will lead North Carolina toward a more healthy future.

In hospitals, in nursing facilities, in home visitation, in public health, in school health centers, in rural health centers, in nursing education classrooms, and in many other locations, nursing is vital to the care that we all wish to receive—for ourselves and for our communities. It is our collective responsibility to do what we can to ensure that we have an excellent nursing workforce in 2004, and for many years to come.

Please join with us in moving these dreams to reality.

Eugene W. Cochrane, Jr.
Executive Vice President
and President-Elect
The Duke Endowment

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ISSUE BRIEF

North Carolina Institute of Medicine Task Force on the North Carolina Nursing Workforce (2004)

Cynthia M. Freund, RN, PhD, FAAN, Joseph D. Crocker, Pam C. Silberman, JD, DrPH, Kristie K. Weisner, MA, and Gordon H. DeFriese, PhD

Background and Purpose of the Task Force

By 2002, several states were reporting severe nursing shortages. At the same time, some North Carolina employers were reporting difficulties filling nursing positions. Whether there is currently a nursing workforce "shortage" or "crisis" in North Carolina is open to debate. Yet, there is little question that, without some intervention, North Carolina is likely to experience a severe nursing shortage in the coming decade due to the combination of an aging population and an aging nursing workforce. Long-range forecasts of registered nurse (RN) supply and demand in North Carolina predict a shortage of anywhere from 9,000 nurses in 2015 to almost 18,000 by 2020.

Rather than wait until North Carolina is in the midst of a full-blown nursing crisis, the North Carolina Institute of Medicine (NC IOM), in partnership with and at the request of the NC Nurses Association, the NC Center for Nursing, the NC Area Health Education Centers Program, the NC Board of Nursing, and the NC Hospital Association, decided to act proactively to prevent a future nursing shortage. In the fall of 2002 the NC IOM created the Task Force on the North Carolina Nursing Workforce to undertake a major study of issues surrounding the present and future supply of and demand for nursing personnel in this state. Co-Chairs of the Task Force were Cynthia M. Freund, RN, PhD, FAAN, Dean Emerita of the School of Nursing at the University of North Carolina at Chapel Hill, and Joseph D. Crocker, Senior Vice President, Wachovia and Manager of Community Affairs of The Carolinas Bank in Winston-Salem.[1] The 55-member Task Force included representatives of all levels of licensed nursing personnel, the NC Board of Nursing, NC Division of Facility Services (charged with registration of nursing aides), professional nursing associations, the NC Center for Nursing, the University of North Carolina System, the NC Community College System, the NC Independent Colleges and Universities, the NC Hospital Association, the NC Healthcare Facilities Association, home health and assisted living services providers, the NC Area Health Education Centers Program, school health nurses, and mental health nurses. The work of the Task Force was supported by a grant from The Duke Endowment.

The Task Force examined the current and projected demand for nursing professionals and paraprofessionals in all segments of the North Carolina healthcare industry. The Task Force also studied the degree to which current and developing educational and in-service educational programs are meeting, and are likely to meet, these demands. In addition, the Task Force examined school-to-work transitions, as well as the work environment for nursing personnel and methods to recruit and retain nurses. The Task Force tried to examine these issues for the full range of nursing personnel, including nurse aides, Licensed Practical Nurses (LPNs), Registered Nurses (RNs), Advanced Practice Registered Nurses (APRNs), as well as other registered nurses with graduate degrees at the master's and doctoral-levels. However, most of the Task Force's attention focused on Registered Nurses, who make up approximately 82% of the state's licensed nursing workforce.

Cynthia M. Freund, RN, PhD, FAAN, is Professor and Dean Emerita at the University of North Carolina at Chapel Hill School of Nursing and co-chair of the Task Force on the NC Nursing Workforce. Dr. Freund has had extensive experience in all aspects of nursing education and is herself a nurse practitioner who has practiced in North Carolina.

Joseph D. Crocker is Senior Vice President for Wachovia and Manager of Community Affairs of The Carolinas Bank in Winston-Salem, NC and co-chair of the Task Force on the NC Nursing Workforce. Mr. Crocker is an experienced hospital trustee, member of the North Carolina Medical Care Commission, Chair of the Board of Trustees of Western Carolina University.

Pam C. Silberman, JD, DrPH, is Vice President of the NC Institute of Medicine and helped staff the Task Force on the NC Nursing Workforce.

Kristie K. Weisner, MA, is Assistant Vice President of the NC Institute of Medicine and helped staff the Task Force on the NC Nursing Workforce.

Gordon H. DeFriese, PhD, is President and CEO of the NC Institute of Medicine and helped staff the Task Force on the NC Nursing Workforce. The authors can be reached at gordon_defriese@nciom.org or at 5501 Fortunes Ridge Drive, Suite E, Durham, NC 27713. Telephone: 919-401-6599 ext. 27.

The Current and Future North Carolina Nursing Workforce

Determining the exact number of nurses that will be needed in North Carolina in the future is difficult, as both the supply of nurses and the demand for nurses are constantly changing. But there are good reasons to believe that without some intervention, North Carolina will experience a shortage of registered nurses and other nursing assistive personnel over the next two decades. North Carolina's population continues to grow at a rapid pace and the age groups most likely to use healthcare services (those aged 65 and older) are among the fastest growing age groups. The nursing workforce in North Carolina is aging at an even faster rate. The average age of the North Carolina workforce in general grew from 37.7 (1984) to 40.4 (2001),[1] but the average age of RNs increased from 38.3 in 1983 to 43.6 (2001), and the average age of LPNs increased from 40.5 (1983) to 44.9 (2001). Traditionally, registered nurses move out of full-time employment rapidly after the age of 55. In 2001 about 14% of the RN workforce and 18% of the LPN workforce was age 55 or older. Another 31% of RNs and 32% of LPNs was between the ages of 45 and 54. These two factors, along with others, will exert enormous pressure on the balance between supply and demand for nurses in North Carolina over the next ten to 20 years.

As the general population ages, the use of healthcare services will increase. But this is not the only factor that drives demand for nursing services. Demand is driven by the number of people needing services, the acuity level of patients, healthcare technological and informatics changes, medical advances, labor productivity, regulatory and market changes, and advances designed to improve quality of care (including required nurse staffing levels). The current and future *supply* of nurses in North Carolina is also affected by a variety of other factors, including: the rate at which North Carolina can enroll and graduate new professionals from our educational institutions, the capacity of our educational system to expand or contract to meet market demands, the rate at which nurses move out of or into our state from other states or other countries (in- and out-migration), new and expanding career options for women and people with nursing degrees, demographic trends that affect the size and age of the labor force now and in the future, and workplace issues such as wage levels and working conditions that affect people's willingness to work in certain environments.

An obvious solution to a pending nursing shortage is simply to produce more nurses. However, before encouraging more people to enter the nursing profession, it will be necessary to expand the capacity of the state's nursing education programs to accommodate new students.

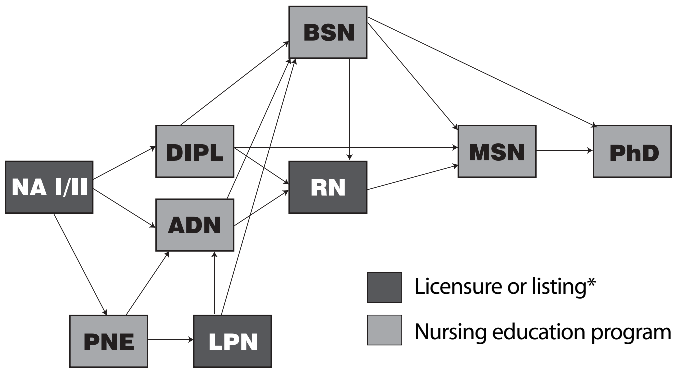
The state should also take additional steps to attract a more diverse workforce into nursing, as the characteristics of North Carolina nurses do not reflect the diversity of the state's population. For example, only about 6% of the RN workforce and about 5% of the LPN workforce is composed of men, compared to 52.8% of the state's workforce in general.[1] Twelve percent of RNs and 26% of LPNs represented racial or ethnic minority groups in 2001. In contrast, racial or ethnic minorities account for 28% of the state's population. These statistics are not inconsistent with national profiles of the US nursing workforce.

While the nursing workforce situation in North Carolina has not yet reached "crisis" proportions, the projected loss of our most experienced nurses due to aging and retirement, at a time when demand for nurses will be increasing, will undoubtedly lead to a severe shortage of nursing personnel by the end of the decade unless remedial steps are taken. The Task Force recommendations are aimed at attenuating what many have anticipated will be a "crisis" in regard to our state's nursing workforce.

Educating the Future Nursing Workforce

The entry-level credential for nursing practice is the basic license as a Registered Nurse (RN) or Licensed Practical Nurse (LPN). Nurses obtain their RN or LPN licensure by completing a basic course of study from a baccalaureate (BSN), associate degree (ADN), hospital-based diploma, or practical nursing education (PNE) program and passing the National Council Licensure Examination (NCLEX-RN or NCLEX-PN). Once licensed, there are also multiple routes to obtain advanced professional education (Figure 1).

Figure 1.
Possible Educational Pathways in Nursing



There were 64 nursing education programs in North Carolina offering credentials for entry-level RN licensure (BSN/ADN/Diploma) in 2004 (Figure 2). Among states in the Southeastern Region (i.e., those states served by the Southern Regional Education Board or SREB), only Texas has more nursing education programs than North Carolina. Moreover, North Carolina has the lowest proportion of BSN programs in relation to ADN and hospital diploma programs of any of the SREB states.

While we have many geographically dispersed educational programs to educate nurses and nursing assistive personnel, our educational system lacks the necessary infrastructure to significantly

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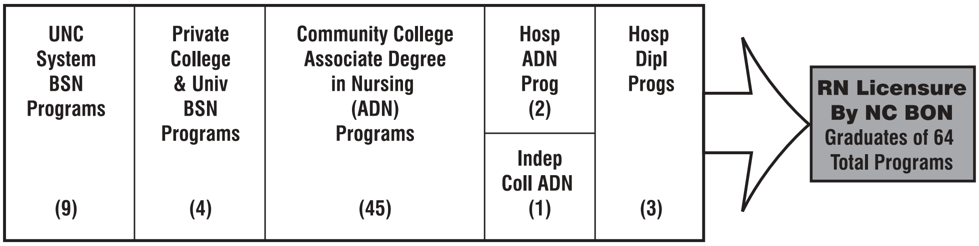
* North Carolina does not "certify" nurse aides. These personnel are "listed" after successfully completing the required training and competency evaluation program of the Nurse Aide I or Nurse Aide II Registry.

Figure 2.
North Carolina Nursing Education Programs Preparing Graduates for Entry-Level RN Licensure, 2003



An additional BSN program is in the second phase of development as of February 2004.

increase the number of new nursing students at this time. Increased funding for faculty positions, faculty recruitment and retention and securing appropriate clinical sites for nursing education are key components affecting the capacity of these nursing education programs to educate students. Our problem is not one of needing to attract more young people into nursing. Each year we are turning away hundreds of applicants who meet entry requirements from our North Carolina nursing programs. Altogether more than 5,446 potential new RNs and 1,707 potential new LPNs were denied admission to North Carolina nursing education programs last year because these programs were unable to add more faculty, more clinical practice sites, and/or more space for students, due largely to budget constraints. Once admitted to nursing education programs, tuition support and student support services (such as academic and educational financial counseling) are critical to the success of nursing education programs.

North Carolina must increase the number of nurses in every category (LPN, ADN, BSN, Diploma, MSN and PhD), and expand education programs that have demonstrated acceptable levels of quality, accessibility, effectiveness and efficiency. However, the issue isn't just the numbers of new nurses produced, but the mix of nurses with a range of educational credentials. In the future, with changes in medical technology and acuity levels of patients seen in certain inpatient or institutional settings, North Carolina is likely to need not just an increased number of new nurses, but nurses who have enhanced educational preparation. For example, there is growing evidence that hospitals that have smaller staff-to-patient ratios and more staff with higher levels of nursing education, also have decreased mortality rates, fewer medical errors and nursing practice violations, and better patient outcomes.[2,3,4,5,6]

Regardless of how nurses enter the profession, they should be offered opportunities to enhance their educational preparation for nursing practice. By greatly expanding the opportunities to pursue education at higher levels, the overall educational level of North Carolina nursing care will increase, and, in turn, provide a variety of nursing career options to a broad spectrum of North Carolina citizens. By expanding prelicensure BSN, RN-to-BSN, and accelerated BSN programs, the Task Force envisioned that the current ratio of 60% ADN/Diploma and 40% BSN nurses could gradually change over the next 10-15 years to 40% ADN/Diploma and 60% BSN. This ratio change is also important because it will increase the number of nurses qualified for graduate programs that prepare nursing faculty.

School-to-Work Transitions

Unlike the experience of other professionals, nurses are often expected to practice fully in a relatively short time span after licensure. However, studies have shown that new nurses often have difficulties translating their educational experience into practice, particularly as it relates to skills in recognizing abnormal findings, assessing the effectiveness of treatments and supervising care provided by others.[7] This, in turn, causes new graduates to feel insecure in their job responsibilities and be less satisfied in their jobs. To better prepare nursing students for the transition into the workplace, students should be given a more intensive clinical experience during their final semester of school, followed by a more intensive orientation or internship opportunity once the new nurse begins practice. Once employed, new graduates should be provided supervised on-the-job skills training, along with a system of peer support. Ensuring an adequate school-to-work transition will help new nurses understand their job responsibilities and obtain the confidence and skills necessary to provide higher quality care.

The Work Environments of North Carolina Nursing Personnel

Nurses report lower job satisfaction than other professionals. This is problematic because job satisfaction is strongly correlated with turnover and retention. In North Carolina, only about half of all nurses report being happy with their jobs; close to one-fifth of all nurses report being unhappy with their work situations (19.9% of staff RNs and 17.7% of staff LPNs), and the rest are neutral.[8] The aspects of job satisfaction vary among work settings, with nurses in hospitals and long-term care settings being least satisfied with their jobs; and those in community settings much more satisfied. Job dissatisfaction in nursing often results in low morale, absenteeism, turnover, and poor job performance.

When nurses are dissatisfied at work, they are more likely to change jobs. Not only does staff turnover reduce the number of experienced staff who are familiar with the organization, it brings added expense to employers. Some North Carolina nursing employers reported significant financial outlays to recruit and train new nursing staff. A recent study suggested that the cost of turnover for one hospital nurse ranges between $62,000-$68,000.[9]

In addition to affecting turnover and performance in a particular job, job satisfaction can also affect satisfaction with nursing as a career. Nurses, especially those working in inpatient hospital settings, were less willing to recommend nursing as a career to other people. Only 40% of hospital inpatient RNs, and 50% of inpatient LPNs reported that they would encourage others to become a nurse.

The Task Force considered the role of nurses in different workplace settings in North Carolina, including institutional settings (e.g., hospitals, psychiatric institutions), long-term care facilities (nursing homes and assisted living facilities) and community-based settings (home health and hospice, public health and school nursing). There are several critical elements for a successful nursing work environment that cut across workplace settings. These include: management support and skilled nurse managers; an environment that promotes positive team relationships with coworkers; orientation and mentoring programs; the involvement of nurses and nurse aides in policy and decision making at both the institutional and unit level; competitive salaries and benefits; reasonable work loads; a safe working environment; career ladders and opportunities for advancement; minimizing paperwork and administrative burdens; flexible scheduling; supporting nurses in their role as patient care integrators; and professionalism and process standards in all departments with accountability.

Advanced Practice Nursing

There are four types of advanced practice registered nurses (APRNs) practicing in North Carolina: nurse practitioners (NPs), certified nurse midwives (CNMs), clinical nurse specialists (CNSs), and certified registered nurse anesthetists (CRNAs). All APRNs are licensed registered nurses, have advanced academic preparation and many categories of APRNs are nationally certified. The Task Force heard testimony that advanced practice registered nurses in North Carolina are not currently permitted to practice to the full extent of their educational preparation. Although the education and certification requirements for each APRN group are similar across the country, the allowable scope of practice for each type of APRN varies depending on the state in which they practice. The Task Force was unable to fully explore these issues, but recommended further study of APRN practice issues.

Summary of Recommendations and a Blueprint for Action

The Task Force built upon these findings to formulate a series of recommendations to prevent a future nursing workforce crisis. These recommendations were grouped into seven areas: (1) nursing faculty recruitment and retention, (2) nursing education programs, (3) transition from school to work, (4) nursing work environments, (5) Advanced Practice Nursing, (6) building an interest in nursing as a career, and (7) cross-cutting issues. Absent new faculty, the state may be unable to expand the production of new nurses, and absent the production of new nurses, North Carolina may have insufficient nurses to meet the demands of the nurse workforce environment. In addition, efforts need to be made to smooth the transition from school-to-work, so that nurses are better prepared to assume clinical responsibilities. Finally, the Task Force recognized that North Carolina needs to address workplace issues in order to retain nurses in their jobs and the profession.

In total, the Task Force made 47 recommendations, which, if implemented, would expand the numbers, educational level, and retention of nursing personnel. The 16 *highest priority* recommendations are identified in shaded cells. Recommendations that require legislative action are separately noted, as are those that can be addressed through educational institutions, employers, foundations, the NC Board of Nursing or other organizations. The full text of all recommendations can be found in the corresponding chapter listed after the summary recommendation (for example, Rec. #4.1 refers to the first recommendation in Chapter 4). We hope that segmenting the Task Force recommendations in this way will facilitate a more systematic response to the findings and recommended actions discussed throughout this report.

	ACTION TO BE TAKEN BY ORGANIZATION, INSTITUTION OR GROUP						
RECOMMENDATIONS	**Legislature**	**Educational Institutions or AHEC**	**Employers**	**Nursing Community**	**Foundations**	**Board of Nursing**	**Other**
Nursing Faculty Recruitment/Retention							
Priority Recommendation:							
The Faculty Fellows Program (as proposed in House Bill 808 in last session of NC General Assembly) be enacted and funded to support the effort of BSN nurses who wish to pursue MSN degrees in preparation for nursing faculty careers. (Rec. # 3.25)	✓				✓		
Other Recommendations:							
The NC General Assembly should increase funding to the NC AHEC to offer off-campus RN-to-BSN and MSN nursing programs using a competitive grant approach which is available to both public and private institutions statewide. (Rec. # 3.20)	✓	✓			✓		
Nursing doctoral programs should be expanded. (Rec. # 3.21)	✓	✓			✓		

	ACTION TO BE TAKEN BY ORGANIZATION, INSTITUTION OR GROUP						
RECOMMENDATIONS	**Legislature**	**Educational Institutions or AHEC**	**Employers**	**Nursing Community**	**Foundations**	**Board of Nursing**	**Other**
RN Education Programs							
Priority Recommendations:							
Production of prelicensure RNs should be increased by 25% from the 2002-2003 graduation levels by 2007-08. The NC Community College System (NCCCS), UNC System, private colleges and universities, and hospital-based programs affected by these goals should develop a plan for how they will meet this increased production need and report to the NC General Assembly in the 2005 session. Greater priority should be placed on increasing production of BSN-educated nurses in order to achieve the overall Task Force goal of developing a nursing workforce with a ratio of 60% BSN: 40% ADN/hospital diploma graduates. (Rec. # 3.1a-c)	✓	✓				✓	
Nursing education programs in the community colleges should be reclassified as “high cost” (therefore increasing per capita funding of these programs). (Rec. # 3.6)	✓						
The NC General Assembly and/or private philanthropies should invest funds to enable NC community colleges to employ student support counselors specifically for nursing students and to provide emergency funds to reduce the risk of attrition for students in ADN and PNE programs. (Rec. # 3.8)	✓				✓		
The NC General Assembly should restore and increase appropriations to enable UNC System institutions to expand enrollments in their prelicensure BSN programs above current levels. These funds should be earmarked for nursing program support and funneled to university programs through the Office of the President of the UNC System. Funds should be allocated on the basis of performance standards related to graduation rates, faculty resources, and NCLEX-RN exam pass rates. (Rec. # 3.15)	✓						
The NC General Assembly and private foundations are encouraged to explore new scholarship support for nursing students in NC’s schools of nursing. (Rec. # 3.19)	✓				✓		
Nurse Scholars Program should be expanded, per-student loans increased and new categories of eligible students added (as specified in Chapter 3). (Rec. # 3.24a-f)	✓						
Private institutions offering the BSN degree should be encouraged to expand their enrollments. (Rec. # 3.17)		✓		✓			
NC residents with a baccalaureate degree who enroll in an accelerated BSN or MSN program at a NC private college of nursing should be eligible for state tuition support equivalent to students in these institutions pursuing the initial undergraduate degree. (Rec. # 3.18)	✓						
The Comprehensive Articulation Agreement between community colleges and UNC System campuses should be further refined and implemented fully. a. Associate Degree nursing curricula should include non-nursing courses that are part of the Comprehensive Articulation Agreement (CAA) between the NCCCS and the UNC System. b. The UNC System and Independent Colleges and Universities offering the BSN degree should establish (and accept for admission purposes, UNC System-wide) General Education and Nursing Education Core Requirements for the RN-to-BSN students who completed their nursing education in a NC community college or hospital-based program after 1999. (Rec. # 3.28a-b)		✓					

	ACTION TO BE TAKEN BY ORGANIZATION, INSTITUTION OR GROUP						
RECOMMENDATIONS	**Legislature**	**Educational Institutions or AHEC**	**Employers**	**Nursing Community**	**Foundations**	**Board of Nursing**	**Other**
Other recommendations:							
Approval for (and funding to support) enrollment growth should be limited to those nursing education programs where attrition (failure to complete) rates are lower than the three-year average attrition rate for that category of education program (BSN, ADN, or PNE) and the pass rates on the NCLEX-RN or NCLEX-PN examination exceed 80%.) (Rec. # 3.2)		✓			✓	✓	
NC BON-approved "slots" should be realigned with current enrollment in NC nursing education programs by 2006. (Rec. # 3.3)		✓				✓	
Clinical facilities, in collaboration with local/regional nursing education programs, should identify and make available more clinical training sites for nursing education. (Rec. # 3.4)		✓	✓				
Nursing education programs and clinical agencies should work together to develop creative partnerships to enhance/expand nursing education programs and help ensure the availability and accessibility of sufficient clinical sites: a. AHEC should convene regional meetings of nursing educational programs and clinical agencies to develop creative educational opportunities for *clinical* nursing experiences. b. Nursing education programs of all types at every level should work together to develop creative educational collaborations with clinical facilities and programs that promote educational quality, efficiency and effectiveness. (Rec. # 3.5)		✓	✓				
An alternative method of financing the expansion of community college-based nursing programs should be considered by the NC General Assembly (instead of the dependence on external resources for such expansions). (Rec. # 3.7)	✓						
Funding should be made available to enable every nursing education program to apply for and attain national accreditation by 2015. (Rec. # 3.9)	✓	✓					
The Community College System should include in the comprehensive data and information system being developed data on nursing student applications, admissions, retention and graduation. (Rec. # 3.10)	✓	✓					
A consistent definition of “retention” (or “attrition”) should be developed by the Community College System and used in every community college. (Rec. # 3.11)		✓				✓	
A consistent standard should be developed and used within the Community College System for the evaluation of retention-specific performance criteria for each nursing education program. (Rec. # 3.12)		✓				✓	
The NC General Assembly or private philanthropies should fund the Community College System to undertake a systematic study of the relationship between competitive, merit-based admission policies and graduation/attrition rates. (Rec. # 3.13)	✓	✓					
Admission criteria in community college nursing programs should be coupled with competitive, merit-based admission procedures in all community college-based nursing education programs. (Rec. # 3.14)		✓					
The UNC Office of the President, utilizing data provided by the NC Board of Nursing, should examine the percentage of first-time takers of the NCLEX-RN exam who are BSN, ADN and hospital-based school of nursing graduates. If necessary, the UNC Office of the President should convene the UNC System deans/directors of nursing for baccalaureate and higher degree programs to plan for increases in funding to support enrollment that will assure, at a minimum, a 40% or greater ratio of BSN prelicensure		✓					

	ACTION TO BE TAKEN BY ORGANIZATION, INSTITUTION OR GROUP						
RECOMMENDATIONS	**Legislature**	**Educational Institutions or AHEC**	**Employers**	**Nursing Community**	**Foundations**	**Board of Nursing**	**Other**
graduates (in relation to ADN and hospital graduates) and, where possible, a gradual increase in the BSN ratio over the next decade. These ratio increases should take into consideration increases in prelicensure BSN program enrollment, as well as ADN-to-BSN and accelerated BSN program productivity. (Rec. # 3.16)							
Hospitals and other nursing employers are encouraged to consider tuition remission programs to encourage their nursing employees to pursue LPN-RN, RN-BSN, MSN or PhD degrees. (Rec. # 3.27)			✓				
An RN-to-BSN statewide consortium should be established to promote accessibility, cost-effectiveness and consistency for these programs. (Rec. # 3.29)		✓					
PN Education Programs							
Priority recommendation:							
Production of prelicensure LPNs should be increased by 8% from the 2002-2003 graduation levels by 2007-08. NCCCS and private institutions affected by this goal should develop a plan for how they will meet these increases. NCCCS should convene this planning group, including representatives of private institutions offering these nursing programs, and a plan should be reported to the NC General Assembly in the 2005 session. Each year thereafter, the PNE programs should provide a status report to the NC General Assembly showing the extent to which they are meeting these goals; and whether production needs should be modified based on job availability for new graduates, changes in in-migration, retention or overall changes in demand for nurses in NC. (Rec. # 3.1d-e)	✓	✓				✓	
Other recommendations:							
All NC BSN and ADN nursing education programs should explore creative LPN-to-ADN and LPN-to-BSN pathways to facilitate career advancement and avoid unnecessary duplication of content in these curricula. (Rec. # 3.30)		✓					
The State Board of Education and the NCCCS should promote dual enrollment programs for PNE programs in high schools. (Rec. # 3.31)	✓	✓				✓	
All PNE programs in NC should seek and attain national accreditation by 2015 with adequate funding provided for faculty resources, student support services, and NLN accreditation application fees. (Rec. # 3.32)	✓	✓					
Nursing Assistant (Nurse Aide) Education Programs							
NC DHHS should develop special designation for licensed healthcare organizations providing LTC services that choose to meet enhanced workplace environmental and quality assurance standards. (Rec. # 4.5)			✓				✓ NC DHHS
The NC General Assembly should appropriate funds to be used as a wage pass-through to enhance the salaries of nursing assistants, especially within LTC facilities that have chosen to enhance workplace and quality assurance standards. (Rec. # 4.9)	✓		✓				
Efforts of NC DHHS, NC BON and NCCCS to create “medication aide” and “geriatric aide” classifications should be encouraged and supported. (Rec. # 3.33)				✓			✓ NC DHHS
NC Division of Facility Services in conjunction with the NC BON should develop a standardized Nurse Aide I competency evaluation program, to include a standardized exam and skills demonstration process. (Rec. # 3.34)		✓					✓ NC DHHS

RECOMMENDATIONS	ACTION TO BE TAKEN BY ORGANIZATION, INSTITUTION OR GROUP						
	Legislature	Educational Institutions or AHEC	Employers	Nursing Community	Foundations	Board of Nursing	Other
Transitions from Nursing School to Nursing Practice							
Priority recommendation:							
NC BON should convene a group to study options to improve school-to-work transitions, including: ■ intensive clinical experience in direct patient care during the final semester of study for nursing students, and ■ a supervised/mentored clinical internship experience either pre- or post-licensure. (Rec. # 4.3)		✓	✓	✓		✓	✓
Nursing Work Environments							
Priority recommendations:							
Employers should take steps to create "positive work environments" (meeting several defining criteria). (Rec. # 4.1)			✓		✓		
AHEC and the professional nursing schools should offer educational opportunities for leadership development, conflict resolution and communication skills training, interdisciplinary team building, and preceptor training. (Rec. # 4.2)		✓	✓				
NC BON and Division of Facility Services should implement regulations to prohibit nurses from providing direct patient care more than 12 hours in a 24 hour time period, or 60 hours in a 7 day time period. (Rec. # 4.10)						✓	✓ NC DHHS
Other recommendations:							
NC nursing organization leaders and healthcare trade associations should develop model programs and best practices (e.g., Magnet Hospital principles) for statewide dissemination. (Rec. # 4.4)			✓	✓	✓		✓
Trade associations, AHEC and private philanthropies should take the lead in disseminating best practices that help create a positive workplace culture for nursing personnel. (Rec. # 4.6)		✓	✓		✓		✓
NC Nurses Association should promote consumer advocacy efforts toward a well-educated, adequately staffed healthcare system in the interest of higher quality of care. (Rec. # 4.7)				✓			✓
Philanthropic organizations should support the provision of technical assistance to healthcare organizations as they attempt to make the changes necessary to improve the nursing workforce environment and enhance the quality of patient care. Financial assistance should be targeted to those facilities that would be unable to make these changes without financial assistance. (Rec. # 4.8)					✓		
Advanced Practice Registered Nurses							
The NC IOM should convene a workgroup to study issues specific to the practice of APRNs. (Rec. # 5.1)				✓		✓	✓ NC IOM
Trade and professional associations in NC should initiate an aggressive statewide effort to effect changes in federal and state legislation and regulations that affect Medicare, Medicaid and commercial managed care reimbursement in order to promote the full utilization of APRNs in long-term care and in other healthcare arenas. (Rec. # 5.2)			✓	✓			✓

	ACTION TO BE TAKEN BY ORGANIZATION, INSTITUTION OR GROUP						
RECOMMENDATIONS	**Legislature**	**Educational Institutions or AHEC**	**Employers**	**Nursing Community**	**Foundations**	**Board of Nursing**	**Other**
Building an Interest in Nursing as a Career							
Priority recommendation:							
Existing programs via AHEC, the health science programs in community colleges, universities and colleges, the NC Center for Nursing, and employers that target a diverse mix of middle and high school students to encourage them to consider health careers and prepare them for entry into programs of higher learning need to be strengthened and expanded. (Rec. # 3.22a-d)	✓	✓	✓	✓	✓		
Other recommendation:							
High school and college-level guidance counselors should receive additional training in the requirements of NC's nursing education programs, with counselors designated to provide nursing-specific advice to interested students. (Rec. # 3.23)		✓					
Additional Cross-Cutting Recommendations							
Employers of nurses (RN and LPN) who hold licenses in compact states other than NC should be required to report annually the names, states in which licensed, and period of employment of these nurses working in their facilities and programs. (Rec. #2.1)	✓		✓				✓
Any NC resident enrolled in a public or private nursing education program should receive a state income tax credit to offset their nursing education expenses. (Rec. # 3.26)	✓						

Summary

North Carolina is indeed fortunate to have avoided many of the extreme shortages of nurses reported in other states. Yet, there are important developments on the horizon that have the potential to cause such shortages. Taking action today to expand the production of new nurses, enhance their education, augment school-to-work transitions, and improve the nursing workplace environment can help reduce the likelihood of a future nursing workforce crisis. Some steps will require new financial commitments either from public or private sources. Others will require a renewed commitment on the part of employers, educators, regulators and the nursing community. However, these steps are necessary if we are to recruit and retain well-prepared and motivated nurses who are needed to meet our healthcare needs now and in the future. Nursing, especially nursing at the bedside in hospitals and in long-term care, requires increasingly sophisticated technical skills and continues to demand intellectual, physical and emotional energy beyond what would be required in many other professions and occupations.

It is hoped that the recommendations offered here will help focus the efforts of legislators, educators, employers, the nursing community, trade associations, foundations and the public at large to ensure an adequate supply of well-trained nursing personnel for the future. **NCMJ**

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COMMENTARY

Why is Nursing Important?

Susan F. Pierce, PhD, RN

As defined by the American Nurses Association, nursing is the protection, promotion and optimization of health and abilities, the prevention of illness and injury, and the alleviation of suffering.[1] Nursing has its historical roots in the poorhouses, the battlefields, and the industrial revolutions in Europe and America. Nurses cared for the sick in their homes, the wounded on battlefields and the suffering in institutions. While tending to the needs of their patients, nurses also observed their patients' progress or lack thereof, and the environments that either promoted or impeded their recovery.

This is not work that can be "outsourced." This is not work that can be "moved overseas." This is not work that can be performed by robots. Rather, this is hands-on, human-to-human, intimate work that all persons will need at some point in their lives. It is work that is intellectually challenging, physically demanding and spiritually enriching. Nurses bear witness to birth, death, and the many joys and sufferings in between. Nurses are not only providers of direct care, but are also designers, managers and coordinators of care.

As Virginia Henderson said in an excerpt from *Principles and Practice of Nursing (6th edition)*,[2] "Nursing is helping people in the performance of those activities that they would perform unaided if they had the necessary strength, will or knowledge." Thus, nurses are helping people at their most vulnerable, dependent times—when they need help the most. At every working moment, nurses are responsible for the lives of the patients in their charge and the peace of mind of their anxious visitors. While providing this complex care, nurses are also advocates and educators of these patients and their families.

> *"...this is hands-on, human-to-human, intimate work that all persons will need at some point in their lives."*

To succeed in all of these roles, professional nurses have been taught a set of core values which they continue to embrace: altruism, respect for human dignity, integrity, and social justice. Nurses have been the eyes, ears, hands and minds of those in need for over 100 years. About 2.7 million registered nurses in the United States (75,000 in North Carolina) go to work each day and accomplish just that. And according to repeated Gallop polls, people have come to know, respect, expect and trust that nurses will continue to do so.

Why the Task Force Report on the NC Nursing Workforce Is Important

The provision of nursing services is in crisis—both nationally and in North Carolina. The demand for more nurses is increasing faster than the supply, and those in the profession are nearing retirement at a faster pace than they are being replaced. The institutional work environment is not always supportive to the work the nurse is trying to accomplish, making retention of nurses at the bedside a critical problem.

North Carolina has a rich history of taking a leadership role in providing nurses and expert nursing care. In 1903, North Carolina was the first state to establish a Nursing Practice Act that created a Board of Nursing to safeguard the health of the public and provided for the legal registration of women (initially) as nurses based on their education and practice experience.

This hallmark event occurred over 100 years ago, but the tradition of "firsts" continued. In 1989, at the recommendation of the General Assembly's Task Force on the Nursing Shortage, the legislature established and funded the first Nursing Scholars Program in the country. Nursing students were given the opportunity to participate in a scholarship/loan program leading not only to initial licensure but to advanced education in this increasingly demanding field. Two years later, the General Assembly passed legislation that created and funded the North

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Carolina Center for Nursing to monitor supply, demand and utilization of nurses. Another Task Force initiative was to provide funding to the NC Area Health Education Centers (AHEC) Program for recruitment and educational mobility initiatives and grants to institutions to stimulate improvement in nurses' work environments. All of these approaches helped keep North Carolina from experiencing the effects of nursing shortages... until now. After twelve years, it is time to act again.

For the last 14 months, the Task Force established by the North Carolina Institute of Medicine has brought together the best minds in North Carolina. These minds have carefully crafted a 21st Century plan to provide our citizens with the continued high quality nursing services they deserve. The solutions to a potentially devastating nursing shortage are in this report. Hence, it is critical that the recommendations in the report come to fruition. The time for study is over. The time for debate has closed. The time for action is at hand if the health and well being of our citizens is to be protected. **NCMJ**

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COMMENTARY

Employers and the Nursing Workforce:
Seeking Local Solutions to a National Problem

J. Luckey Welsh, Jr., FACHE

The nation's healthcare industry is under stress—driven by an increased demand for services from a sicker, poorer and older population, coupled with reimbursement that does not keep up with the cost of caring. At the same time, we are on the precipice of the greatest shortage of healthcare workers in the state and nation's history. Leading this wave of shortages are registered nurses of the "baby boomer" generation who will be retiring or leaving the workforce in great numbers within the next 10 years. Patients are admitted to hospitals, long-term care facilities, and substance abuse centers because physicians determine that 24-hour nursing care is required. The simple fact is quality patient care cannot be provided without the required number of professionally educated and competent nurses.

There are many employers of nurses in the healthcare industry including hospitals, long-term care facilities, home health agencies, hospices, schools, public health departments, colleges, universities, and physicians. As an employer of approximately 500 nurses in a regional hospital in rural southeastern North Carolina, I appreciate and applaud the role that nurses play. Nurses are there to:

- Provide care to the poor,
- Help make our sick children well,
- Provide comfort and healing to our elderly mothers and fathers,
- Help bring new life into the world, and
- Be there to provide compassion and love to our dying patients.

Much has been written about the impending shortage of nurses in our state and in our nation. I applaud the efforts of the NC Institute of Medicine (NC IOM) for convening a task force with the assistance of The Duke Endowment to study and to develop recommendations toward the resolution of this problem. Many of our state's leading authorities in nursing and nursing education worked side by side with nursing employers and the NC IOM staff to address this most important issue facing the healthcare industry.

It has often been said, "Like politics, healthcare is a local issue." Whether you define "local" as state, a region within a state, a county or a community, that is where healthcare is delivered and where the shortage of nurses will be felt. I, therefore, believe many of the solutions to this problem should be developed and implemented at the local level. Every employer must take ownership of this problem and, more importantly, take ownership of the solutions in their own locale. The work of the NC IOM Task Force on the NC Nursing Workforce provided recommendations that employers of nurses should embrace and commit their time and resources toward implementating. Several of the recommendations that employers can have direct and meaningful impact on are as follows:

- Encourage the youth of our state to consider health careers with a special emphasis on nursing,
- Provide scholarships and loans to beginning students and those seeking to advance their level of educational attainment,
- Support and expand nursing education programs,
- Implement nursing recruitment and retention strategies,
- Provide a positive nursing work environment,
- Advocate collaboratively with state nursing leaders and trade associations for the NC IOM Task Force recommendations to the NC General Assembly.

Promote Healthcare Careers

Employers should begin initiatives to recruit the youth of our state and our nation into the healthcare professions. Employers should meet and develop strategies with public and private schools to expose and encourage young people to consider health as a career. Many examples across our state have already begun to develop, including the establishment of school academies, scouting explorer posts and school partnerships with community colleges, public schools and healthcare institutions. These programs allow middle and high school students to enter the nurses' places of employment to learn firsthand of

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this most rewarding profession. Bringing young people face-to-face with practicing nurses enables them to make a conscious choice in choosing their future area of study.

Provide Scholarships and Loans

Employers of nurses will find it advantageous to help with the educational costs of training new nurses. Employers can provide scholarships and/or loans to students who meet the admission criteria of their educational institutions. Employers can also encourage community foundations to fund these scholarships. "Growing your own" by helping to fund training of local people who have roots in the community is often more successful and less expensive than trying to recruit nurses from other regions or from abroad.

For those nurses already working in your facility, the employer will want to find innovative ways to help them advance in their field through further education and training. The employer can offer support through scholarships, loans and flexible work schedules to accommodate classroom schedules. This kind of support enables NAs to advance to LPN status and LPNs to earn an ADN degree. RNs need support as they work toward their BSN degrees and advance training for careers as CRNAs or NPs.

Support and Help Expand Educational Programs

Employers must proactively support and help to expand nursing education programs in their communities, whether at the community college or university level. For years, hospitals have served as clinical training sites, and we must continue to do so. It is also imperative that we take a look at our clinical site training and re-focus on how we can improve it. Employers with the resources may want to fund a faculty position at a local nursing school for a limited time in order to jump-start the expansion of that program. Finally, we, as employers, can advocate for our legislators to increase funding for nursing education programs throughout the state.

Develop Nursing Recruitment and Retention Strategies

Of course, employers will want to review regularly their pay and benefits for nurses to make sure that these are keeping pace with the state and region. Some hospitals have had success in recruiting nurses from abroad as a short-term measure that can supplement current staffing levels until other long-term efforts, such as those mentioned above, produce results.

One of the best retention strategies is the establishment of a mentorship program wherein a new nurse is paired with a more experienced mentor during the first year of work. This school-to-work transition is proving to be invaluable for the beginning professional, who needs orientation and guidance during the initial phase of employment.

Provide a Positive Nursing Work Environment

Improving the work environment for nurses is an important responsibility for employers. Hospitals, home health agencies, physician offices and other facilities can do many things to increase job satisfaction despite the fact that only about half of NC nurses report satisfaction with their current jobs and about the same percentage would recommend nursing as a career to others. In turn, improved job satisfaction could reduce soaring turnover rates and save the employer resources by cutting down on the burden of costly recruitment of new nurses.

Hospitals, especially, report lower levels of satisfaction among their nurses than in community settings. As employers, we must find ways to address the stress and other work patterns that raise turnover rates and increase the recruiting of new nursing staff. For example, we must develop work assignments that promote a balance between work and home life for the nurse.

Our nurse managers are key players in improving the work environment for staff nurses. Employers must make sure that these managers have the leadership training and support of management to make the workplace both challenging and rewarding for their staff. Employers should invest in new technologies that can cut paperwork and other administrative tasks so that nurses can do what they entered their profession to do—take care of patients. This emphasis on support and collaboration should filter through all levels of the workplace, from administration to other healthcare professionals, including physicians and allied health personnel. Furthermore, employers should familiarize themselves with the principles of the Magnet Hospital and adopt similar strategies for their workplaces.

Advocate Collaboratively

While we work locally to solve nursing workforce challenges, we must also remember that we, as employers, must advocate for statewide and national solutions to the nursing shortage. We can do this by proactively bringing these issues to the attention of the members of the NC General Assembly and the US Congress. We must not leave the solution of these problems to our trade associations or to the state nursing leadership. Although local solutions must be developed and implemented to counter nursing workforce issues, the employer must also take ownership of the grassroots effort to solve this problem through advocacy at both the state and national levels.

Employers of nurses can choose to sit idly by and expect Washington, Raleigh or our educational system to solve the nursing shortage. Or we can choose to implement many of the recommendations of the NC IOM Task Force and to participate actively in the resolution of the nursing workforce challenges we face. The choice is ours! **NCMJ**

The Long-Term Care Nursing Workforce:

Who Will Take Care of Our Rapidly Growing Aging Population?

Polly Godwin Welsh, RN, C

Nursing in Long-Term Care Facilities Is Complex

Approximately 40,000 North Carolinians reside in skilled nursing facilities. These patients are often medically complex and functionally frail. The acuity level continues to rise and many patients require intensive nursing rehabilitative services in addition to close medical and nursing supervision. Multiple diagnoses, co-morbidities and confounding complications are common. Nurses employed in nursing facilities work with the highest degree of independence and skill.

> *"This nurse must bring the patient and his/her family into the "team" and lead the team in making decisions to face the challenges ahead."*

Unlike hospital settings, long-term care nurses work without the continuous presence of physicians, emergency teams and advanced practice clinicians. These nurses must thoroughly assess patients who are likely to have communication deficits or some degree of dementia, and then communicate their findings to attending physicians, initiate nursing care plans, and respond to acute changes in patients whose conditions are unstable.

Not only are the keenest of clinical skills required to meet the needs of a medically complex patient population, the nurse working in a skilled nursing facility must utilize exceptional communication skills and navigate artfully through the emotions of patients and families. Patients and families are often overwhelmed by a recent catastrophic health event, immediate need for placement in a nursing facility and the stress of the many decisions to be made. Placement in a nursing facility is a major life event.

The guilt families may feel, along with the new responsibilities they face often render them somewhat in the care of the nurse as well. Nurses in skilled nursing facilities must ease the adjustment to this new phase in life for their patients and families. This nurse must bring the patient and his/her family into the "team" and lead the team in making decisions to face the challenges ahead. Extreme demands are placed on the emotions of the nurse who forges deep and important relationships that endure far beyond rendering immediate care. Nurses in skilled nursing facilities are there for the patient and family over the long term.

Patients in nursing facilities require extensive assistance with activities of daily living such as bathing, grooming, toileting and mobility. Statewide, over 20,000 nursing assistants are employed by facilities to assist with this care. Like the professional nurses with whom they work, they must possess special skills and caring hearts. The professional nurse must interact with these indispensable paraprofessionals with honed delegation and supervisory skills while functioning as the cornerstone for multi-disciplinary teamwork.

A metamorphosis has begun in skilled nursing facilities. The patients traditionally served comprise one facet of needs and expectations. Skilled nursing facilities have begun to see a new generation of customers emerge with a new generation of needs and expectations. Because of this emergence, North Carolina's nursing facilities will be facing an explosion in the demand for services. Not only are adequate numbers of professional nurses essential, but appropriate educational preparation and an assessment of models of care for the future are crucial.

Factors Affecting the Supply of Nurses and Nurse Aides Prepared to Work in Long-Term Care

To embrace these future demographics we must carefully examine the current external and internal factors relevant to the

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supply and demand for nurses. Among the external factors specific to nursing facilities operating in every county:

- Regional access to nursing education
- Bias against long-term care in the academic settings
- Utilization of "slots" in approved nurse aide training programs for nursing students as a prerequisite for nursing programs, thereby greatly limiting the availability of classes for nursing assistants
- Limited supply of experienced faculty with geriatric training and experience
- Uniqueness of the medically complex and frail elderly patient population
- Age-related pharmacological issues

These factors result in few graduates interested in or possessing adequate preparation for the unique challenges demanded by the long-term care healthcare environment. The complexity of the regulatory environment not only limits the skilled nursing facility's access to registered nurses, but also to Family and Geriatric Nurse Practitioners and Clinical Nurse Specialists. There is little research to identify efficacious staffing models for skilled nursing facilities. Even so, there is strong evidence that the presence of advanced practice nurses improve care outcomes. Many barriers make it difficult to infuse these types of practitioners into long-term care.

Where Will Long-Term Care Facilities Find More Nurses?

In response to the deficits in the preparation of a nursing workforce adequate in numbers to meet the needs of a frail geriatric population, nursing facilities have, for a long time, "grown their own" by indoctrination of new employees to skilled nursing care, by promoting from within, and educating nursing personnel on an on-going basis through their own resources and their professional associations. This pattern will soon escalate and expand through the development of technically trained workers in areas such as dementia, mobility and medication administration.

At a time when the nursing workforce in North Carolina is being analyzed, skilled nursing facilities must be at the forefront of the discussion. The world is preparing to welcome the aging baby-boomer to its rightful place in society, the new "up and coming" senior. Nursing academia must capture the exciting opportunity to join the evolution of healthcare by focusing on the change and challenge of the very population that will demand so much of the expanding field of nursing. **NCMJ**

COMMENTARY

Our Future Nursing Workforce:
A Regulatory Perspective

Polly Johnson, RN, MSN

Our History

North Carolina has the distinction of being the first state in the country, and second jurisdiction in the world, to pass laws in 1903 related to the practice of nursing—to register nurses who had completed formal education programs. Beginning in 1905, nurses also had to successfully complete a licensing exam in order to be registered. In those early years, formal nursing education took place in hospitals scattered across the state. By the mid-20th Century, practical nurse (PN) education programs were developed and registered nursing (RN) education moved beyond the hospitals, first into universities and then into the Community College System.

During this period of nursing education development and expansion, major regulatory emphasis was placed on standardizing and strengthening nursing education in the state—requiring all programs to meet a set of minimum standards for preparing new graduates to provide safe, effective nursing care to the citizens of our state. These standards focused on administrative structure of programs, resources, faculty preparation, curriculum including didactic and clinical learning opportunities, student services and minimum standards for passing licensure examinations. The NC Board of Nursing continues to set standards and approve nursing education programs as we move into the 21st Century. Today, there are close to 100 approved RN and PN education programs across our state.

> "North Carolina (is)...the first state... to (license) nurses who had completed formal education programs."

In addition to authorizing the Board of Nursing to set regulatory standards for the approval of nursing education programs, by the early 1920s the Nursing Practice Act began defining the scope (or components) of practice for RNs, expanding to include LPN scope of practice by the mid-20th Century, and then scopes of practice for advanced practice registered nurses (APRNs) by the last quarter of the 20th Century. Through the years, the NC Board of Nursing has worked diligently to assure that these regulatory standards not only meet our mandate for public protection, but also facilitate the evolution of nursing practice within an increasingly complex healthcare environment. Beginning in 2000, North Carolina entered the new age of multi-state nursing regulation through the enactment of the Nurse Licensure Compact-an agreement among states enabling licensees of one state to have the multi-state privilege to practice in other compact states according to the states' practice requirements, but without obtaining a license in those states.

Regulatory Challenges in Our Current and Future Healthcare Environment

Today, we face not only the demands for nursing care in a high tech, high touch, fast-paced acute care environment, but also the demands for care by an aging population and others with multiple chronic care needs. As the NC Institute of Medicine Task Force concludes its study of and makes recommendations to address a nursing workforce that is both aging and declining in number, the NC Board of Nursing is also addressing how best to assure that this future nursing workforce is not only adequately prepared to provide safe, effective care, but also remains competent as practice evolves and expands. Equally important is the regulatory imperative to assure that providers are permitted to practice to the fullest extent of their educational preparation and competence. As a regulatory board whose mandate is to protect the public, we are committed to removing unnecessary barriers that deny full utilization of our nursing workforce in order for our citizens to have access to a full range of appropriately qualified healthcare providers. The Board of Nursing continues to be committed to helping create the appropriate regulatory frame-

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work that provides for the utilization of advanced practice registered nurses to the fullest extent of their preparation without binding them to unnecessary oversight. We look forward to working with the NC Institute of Medicine in expanding this initiative.

Assuring Competence among Healthcare Providers

Following the release of the reports *To Err Is Human* (1999) and *Crossing the Quality Chasm* (2001) by the Institute of Medicine (IOM) of the National Academies[1,2] regulatory and accrediting bodies involved in health professions education and healthcare delivery systems are being challenged to establish standards that will improve patient safety and dramatically enhance the quality of healthcare in this country. Consistent with these initiatives, the NC Board of Nursing has reframed our overall approach to assuring the on-going competence of the North Carolina nursing workforce. Within a quality improvement framework, the Board is committed to supporting individual practitioners with deficits in their knowledge, skills and abilities by keeping them in the work setting while further enhancing their competence to practice safely. To this end, we are piloting a non-punitive, collaborative early intervention program that addresses concerns which have been raised about competency of individual licensees by several hospitals and long-term care facilities across our state. Through mutual agreement with the employer, the licensee and the Board of Nursing, we are offering remedial education and monitored practice to enhance the individual's competence while at the same time addressing mechanisms within delivery systems that could be changed to better support the delivery of safe care. The Board hopes to offer this program statewide within the next few years. More information about this innovative approach to enhancing the delivery of safe patient care can be found on the Citizen Advocacy Center's website www.4patientsafety.net.

As we plan for our future workforce, the Board is also addressing the need to assure the public that licensees maintain competence throughout their careers. Rather than requiring licensees to obtain a certain number of continuing education hours on an annual or biannual basis, our Board, along with nursing representatives from across the state, has developed a reflective practice model for licensees to evaluate their own practice, develop a learning plan, and provide evidence of steps taken to maintain or enhance their competence. Implementation of this continuing competence model will require statutory changes to authorize the Board of Nursing to collect evidence of competence at the time of licensure renewal. The Board plans to seek this statutory authority in the 2005 General Assembly. As our workforce numbers decrease and fewer nursing personnel will have greater patient care responsibilities, it is imperative that regulatory bodies play a primary role in assuring the public that our licensees maintain competence throughout their careers.

Core Competencies Every Healthcare Professional Should Have

Consistent with the challenge to reframe health professions education as proposed by the IOM Report *Health Professions Education—A Bridge to Quality*, (2003),[3] state Boards of Nursing and other health professions oversight bodies are formulating standards to include five core competences that clinicians across all health professions should possess in order to achieve the vision of a 21st century quality healthcare system. These core competencies are: (1) providing patient-centered care; (2) working within interdisciplinary teams; (3) employing evidence-based practice; (4) applying a quality improvement framework for all care provided; and (5) utilizing informatics to communicate, manage knowledge, mitigate error and support decision making. To prepare all health professions to deliver care in this manner will require a significant shift from our traditional "silo" approach of education for each health profession to integrating educational opportunities across the health professions—from pre-licensure through career-long continuing education.

The NC Board of Nursing is currently in the process of drafting revisions to our education program standards to address these core competencies and other requirements for building a workforce prepared to deliver the level of care envisioned by the *Quality Chasm* report. The Board will carefully review the recommendations from the NC IOM Task Force on the NC Nursing Workforce related to enrollment, attrition, National Council Licensure Examination (NCLEX) pass rates, and national accreditation to assure our future standards will support an adequate supply of nurses who are well-prepared to provide care in this complex world of healthcare. We envision program standards that support innovative learning opportunities for nursing students which incorporate new teaching-learning modalities as well as more creative utilization of settings for clinical learning experiences. With the increasing body of evidence that strongly suggests the need for a better transition from education to entry-level practice, the Board, through its Foundation for Nursing Excellence, has begun to explore mechanisms to address this need. Consistent with the NC IOM recommendation for convening a group to study options to improve school-to-work transitions, we plan to work with a wide spectrum of stakeholders to develop, pilot and recommend a transition-to-practice model for statewide implementation within the next five-to-eight years.

Finding Solutions to Other Nursing Workforce Issues

Since the year 2001, the Board has been asked to approve the development of six new PN education programs and four new RN education programs in a state that already has the second highest number of nursing education programs in the southern region of the US. As we look at the number of new programs that are seeking Board approval in light of the projected faculty shortages that will become most acute by 2010, North Carolina must find a way to share these vital resources across programs if we hope to produce the number of nurses needed for the future. Although the NC IOM report addresses funding needs and mechanisms to assure that current resources are maximized within the existing educational programs, little has been done to address the impending faculty shortage in terms of sharing resources among programs either on a regional or statewide basis. In this new information age, the technology is available to support non-traditional resource sharing and teaching-learning opportunities across programs. If this does not occur, some programs may cease to exist within another 10-to-12 years.

Other Questions that Need to Be Debated (with solutions to be formulated by key stakeholders)

How many nursing education programs can North Carolina support? Should the state institute a more formalized process for the approval of new programs that considers a variety of factors, including type of program, geographic overlap with existing programs, and demographics of the population to be served? Should there be a cap on the number of new programs or should this continue to be a market-driven process?

In addition to NCLEX pass rates, what outcome measures are needed to better assure the competence of entry-level practitioners? As referenced in the NC IOM report, NCLEX pass rates were never intended to be used as a single outcome indicator of the quality of a nursing education program.[4] As we develop further evidence through research studies, how do we articulate and measure the entry-level competencies that one needs in order to practice safely in this complex healthcare environment?

In order to further support the delivery of safe care, should there be limitations set on the number of hours a nurse could work in a 24-hour period and within a seven-day work week? Should there be standards set related to nurse:patient ratios? If so, by whom?

Moving Forward

For more than 100 years, North Carolina has had a rich history of advancing nursing practice to meet the needs of our citizens. We are now at another critical time in our history where changes need to be made in all aspects of our profession—education, practice and regulation—to continue the legacy. Thanks to the coordinating efforts of the NC Institute of Medicine, grant monies from The Duke Endowment, and the commitment of nursing and related healthcare leaders across our state, the Task Force on the *North Carolina Nursing Workforce Report* lays out a plan of action that we must implement if we wish to have a sufficient and well-qualified nursing workforce to meet the needs of our citizens in the 21st Century. The next chapter of our nursing history is in our hands—may we be good stewards of our legacy and committed to meeting the healthcare needs of all North Carolinians. **NCMJ**

> *"We are now at another critical time in our history where changes need to be made in all aspects of our profession—education, practice and regulation—to continue the legacy."*

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COMMENTARY

North Carolina's Community College Commitment to Nursing Education

H. Martin Lancaster

The most important task of North Carolina's community colleges is to prepare the people of our state for good jobs with great futures. Now and for the foreseeable future, healthcare, particularly nursing, offers a tremendous number of those jobs.

Health programs make up one of the largest, fastest growing and most important areas of study in the community colleges of North Carolina. Our community colleges educate most of the nurses and allied health personnel working in our state's hospitals, long-term care facilities, home health agencies, health clinics and doctors' offices.

About 60% of North Carolina's registered nurses (RNs) come from community college programs. The report of the Task Force on the NC Nursing Workforce notes that community college nursing graduates do very well, performing above the national average on their licensure exams; and that approximately 90% of our RN graduates stay in North Carolina to begin their nursing careers.

It just makes sense for the NC Community College System to devote time, talent and money to allied health programs, and it makes sense for our state to increase dramatically its investment in those programs.

Community College Nursing Programs

We are working hard to increase the number of associate degree students prepared to sit for their RN licensure exam. Currently, 51 of our 58 comprehensive community colleges campuses have associate degree programs with an enrollment of approximately 5,300 students.

We collaborate with baccalaureate institutions to increase the education level of the state's nursing graduates as well as to increase the number of graduates prepared to complete their degrees to become registered nurses. A number of our community colleges work with institutions within the University of North Carolina (UNC) System to provide degree-completion programs for nurses (RN-to-BSN) who have earned associate degrees in nursing and wish to obtain a bachelor's degree in nursing (BSN). While the bachelor's degrees come from the universities, many of these programs are physically located on community college campuses and linked to universities by distance learning technology. Locating these programs on our campuses increases student enrollment and greatly strengthens the likelihood that underserved rural areas will have community college and university graduates who remain in that area.

We also offer a pre-major within our college transfer program for students who want to transfer into a nursing program at a university. This program is part of the Comprehensive Articulation Agreement with the University of North Carolina.

Our practical nursing programs have also grown in recent years, with more than 1,100 students enrolled in 34 programs. With the support of the healthcare industry, we have put significant effort into establishing and expanding programs for nursing assistants.

We are also involved in early recruitment of talented young people who should consider health as a career. A number of community colleges participated in the establishment of Allied Health Science Academies which provide courses in the health sciences areas to high school students. More than half of the system's colleges administer placement tests to approximately 8,000 students still enrolled in high school to determine the student's readiness for college level work.

In addition to these external partnerships, our community colleges work together to meet the needs of our students and the healthcare industry. These efforts involve collaborative agreements between our colleges. We have more than fifty health-related collaborative agreements between our colleges. These agreements assist in providing educational resources to as many students as possible by:

1. Providing classroom instruction in remote areas of the state;
2. Pooling available resources to provide cost-efficient education;
3. Providing arrangements for joint utilization of clinical sites; and
4. Eliminating the repetition of course requirements for our students.

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Barriers to Community College Nursing Program Growth

Despite all these programs and all these students, we know that we are not keeping up with demand. The nursing shortage is acute and growing. Community college programs at every level need to grow to meet that demand. However, we face significant obstacles to that growth.

First, the state provides funds neither to establish new community college programs nor to expand existing ones. Colleges must depend upon the generosity of private funders, such as The Kate B. Reynolds Charitable Trust, for start-up money. Neither does the state provide sufficient funds through the "FTE"[1] formulas to cover the actual costs of providing nursing education. Because health programs require low student-teacher ratios, specialized equipment and facilities, expensive supplies and highly qualified faculty, they cost much more than does the average community college program.

Second, many students come to us unprepared for the rigor of nursing programs. Most of our students are adults in their thirties and older. Many must strengthen reading, writing and math skills before they start their nursing courses. Many juggle complex family challenges along with their studies. These students can and do succeed; however, they need strong counseling and student support services along the way. Without that support, too many of them switch to less challenging programs or drop out completely, leaving community college nursing programs with a significant problem of student retention. Unfortunately, North Carolina's community colleges simply do not have enough counselors and other student support personnel to do the job that must be done for retaining these students.

Third, we are on the brink of a crisis in recruiting and keeping qualified faculty members. Part of the problem is money, plain and simple. Last year our system celebrated its fortieth anniversary. The dedicated men and women who were "present at the creation" are retiring in great numbers. Will we be able to pay enough to attract the next generation of great teachers? Not if we continue to stay mired at the bottom—literally—of community college faculty salaries in the southeast and near the bottom nationally. Current salary levels make it easy for business and industry to recruit faculty from our system. Another part of the recruitment problem is a shortage of nurses with advanced degrees. Currently, community college nursing directors must have at least a master's degree in nursing. To acquire a voluntary National League of Nursing (NLN) accreditation for each program, all faculty must hold a master's degree. A number of our colleges have had great difficulty in recent years convincing qualified directors prepared at the master's level to move into their communities for the modest salaries they can offer.

> *"About 60% of North Carolina's registered nurses (RNs) come from community college programs."*

Fourth, community colleges compete for clinical space with hospital and university programs and with each other.

Recommendations that Would Bolster Community College Nursing Programs

I am pleased that the Task Force on the NC Nursing Workforce has put forward thoughtful, significant recommendations addressing these important challenges in nursing education in North Carolina's community colleges.

I consider five of them to be of particular urgency.

1. The NC General Assembly should reclassify community college-based nursing education programs (ADN and PNE) as "high-cost" programs and provide additional funds ($1,543.39) per FTE student to cover actual costs of operating these programs. (Rec. # 3.6)

While this would not solve the problem of funding for start-up and expansion, it would help keep community colleges from losing money on every student enrolled in these essential programs.

2. The General Assembly and/or private philanthropies should invest funds to enable NC community colleges to employ student support counselors specifically for nursing students and to provide emergency funds to reduce the risk of attrition for students in ADN and PNE programs. (Rec. # 3.8)

I find it difficult to imagine a better use of new money than this one. According to the report of the Task Force, "If these ADN nursing education programs could increase their retention/graduation rates by just 10%, given the fact that such a high proportion of these ADN graduates stay to practice in North Carolina, it could increase our annual number of new registered nurses by over 450 per year."

I believe that the best way to accomplish that goal is to provide the strongest possible assistance to motivated students who want to succeed and simply need extra attention to make sure they do. Yes, it is tempting to say that we could achieve similar results if we raised admission standards and enrolled only those students who had already succeeded in school. If we do that, however, we will close the "open door" to opportunity for many, many North Carolinians. The "open door" is more than a logo for North Carolina's community colleges; it represents what we do and why we do it.

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[1] Full-time equivalent student

3. The Comprehensive Articulation Agreement between the Community College System and the UNC System campuses (Associate in Arts degree), and the bilateral articulation agreements for students with an Associate in Applied Science degree (AAS) in Nursing and the UNC System, should be carefully evaluated and improved by the Transfer Advisory Committee (TAC) so that students wishing to advance from one level of nursing education to another will experience these transitions without course duplication. (Rec. # 3.28)

While not every registered nurse educated at a community college wants a baccalaureate degree, those who wish to specialize, teach and take on significant management responsibilities do. Some of our existing programs that help students earn BSNs work well; others, particularly the pre-major, need significant work. Following the mandate of the NC General Assembly in 2003, our System and the UNC System are now working with an independent consultant on a comprehensive review of our transfer programs, including those in nursing.

4. The NC General Assembly should increase funding to the NC Area Health Education Centers (AHEC) to offer off-campus RN-to-BSN and MSN nursing programs using a competitive grant approach which is available to both public and private institutions statewide. (Rec. # 3.20)

Graduate nursing education is not, of course, the business of community colleges. However, we depend upon this education for our instructors and directors and will support its expansion through shared facilities, distance learning technology and innovative collaboration. The Community College System is in strong support of having all of its already NC Board of Nursing-approved programs take an additional step of becoming nationally accredited by the National League of Nursing (NLN) voluntary accreditation process. This voluntary process requires that all nursing faculty hold a master's degree. To achieve this goal requires the availability of nurses with master's degrees and the funds to pay the salaries required.

5. Clinical facilities (hospitals and nursing homes, particularly), through their statewide trade associations, and in collaboration with all nursing education programs in their respective geographic areas/regions, should undertake to foster a more transparent and equitable system for the allocation of clinical training sites among nursing education programs on a sub-state regional basis. (Rec. # 3.4)

Increased collaboration between and among all educational institutions must be done to put into practice the use of all available clinical facilities by all educational agencies, if we are to collectively increase the number of graduates prepared to sit for the licensure exams.

Necessary Resources

How quickly will the NC Community College System and our partners be able to act on these recommendations? As do so many things, a large part of that answer depends on money.

The state of North Carolina has been struggling for the past few years with one of its worst fiscal crises in recent memory. While the NC Community College System has been spared the depth of budget cuts that some other agencies have received, we have had to make many reductions even as we face escalating enrollments. Any more cuts, particularly in health areas, will severely limit colleges' ability to meet student and industry demand.

There is no feasible way, from a budget perspective, that the NC Community College System can maintain its current production and supply additional highly educated and qualified healthcare professionals to the marketplace with the current funding stream. The NC Community College System may soon be faced with enrollment caps, especially in nursing and allied health programs.

We would not be able to provide the quality or number of educational opportunities for our citizens if not for collaborative efforts with our local high schools, universities, local Area Health Education Centers, the NC Board of Nursing and the NC Center for Nursing. Financial support from hospitals and foundations and other state and private agencies is critical for implementing and expanding programs. We must develop a coordinated, comprehensive and systemic resource development framework statewide to capture resources, and include more state funds, which are needed to provide educational opportunities.

With our continued efforts and commitment to meeting the needs of our citizens, we will strive to reduce the shortage of nurses and other healthcare professionals. **NCMJ**

The University of North Carolina System and Nursing in North Carolina

Gretchen M. Bataille, DA, and Alan R. Mabe, PhD

For over a year, North Carolinians committed to ensuring a strong nursing workforce within the state have met to review data, study "best practices" in our own and other states, and make recommendations for how North Carolina institutions that educate and employ nurses can best serve our citizens. The University of North Carolina (UNC) is committed to taking the steps necessary to address both the number of nurses needed and the appropriate educational level for those nurses. Board of Governor's Chair J. Bradley Wilson charged the Committee on Educational Planning, Policies and Programs of the Board of Governors to examine the current nursing shortage in North Carolina and to make recommendations for UNC's role in responding to the shortage. The statewide NC Institute of Medicine Task Force on the NC Nursing Workforce has been critical to UNC's examination of its own role in responding to the nursing shortage issue. Now that the Task Force has completed its work, Chairman Wilson has appointed a special committee of the Board of Governors to review their findings and develop a set of recommendations for UNC's response to the nursing shortage issue.

Nursing Education Programs and Enrollment

UNC has nine campuses providing prelicensure baccalaureate nursing (BSN) degrees. The same nine campuses also offer Registered Nurse (RN)-to-BSN degrees and, in addition, Fayetteville State University (FSU) and UNC at Pembroke (UNCP) have a joint RN-to-BSN degree program. FSU and UNCP are planning to establish prelicensure BSN programs on each campus to provide increased access to students seeking baccalaureate degrees in nursing in their regions. Two campuses, UNC at Chapel Hill (UNC-CH) and Winston-Salem State University (WSSU), have developed accelerated BSN programs for students who already have a bachelor's degree in some other field, but with intensive study for 14-16 months these students can receive a BSN degree that will qualify them to sit for the nursing exam.

UNC responded to the nursing shortage in the late eighties and early nineties by increasing enrollment and the number of graduates at the bachelor's-level, doubling the number of BSN graduates between 1990-91 and 2000-01 (509 to 1,017). Similar to the national picture, the enrollment and number of graduates at the baccalaureate level began a slow decline in the late nineties. For fall 2003 we have seen a dramatic reversal of this enrollment trend with a 16 % increase over 2002 to 2,303 students, the largest enrollment in undergraduate nursing ever for UNC. The number of baccalaureate graduates has continued to decrease, but we expect a reversal of that trend once these enrolled students complete their programs. At the master's level the number of graduates more than doubled between 1990-01 and 2000-01 (100 to 253). Master's enrollment for fall 2003 has climbed to 794, the highest level ever. The number of graduates for fall 2003 was 244, which was an increase over 2001 but slightly below the previous high of 253. UNC now has doctoral programs at UNC-CH and East Carolina (ECU), and the Board of Governors has approved UNC Greensboro (UNCG) to plan a new doctoral program in nursing. Enrollment in doctoral work is growing. Sixty-two students were enrolled fall 2003, and seven students received doctorates in 2002-03. UNC is well aware that the expansion of nursing

> *"Each of the existing undergraduate programs turns away qualified students because of limited faculty, space, or insufficient clinical sites."*

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programs will require additional nursing faculty, and has particularly focused on producing master's-level (MSN) students in nursing education to respond to the needs for faculty in the community colleges in North Carolina. In addition to the site-based programs, two UNC campuses, ECU and UNCG, offer an online MSN in nursing education accessible from anywhere in the state.

Creating More Nurses and Nursing Faculty

The core recommendations from the Task Force for UNC are for more nurses, for higher levels of education for current and future nurses, and for producing more faculty members for nursing programs at the associate and bachelor's levels as well as for our graduate programs. This means that UNC campuses should expand the number of students enrolled in prelicensure BSN programs and accelerated BSN programs to increase the number of RNs in North Carolina. UNC's contribution to raising the educational level of nurses in North Carolina will involve more nurses coming into the profession at the BSN level, an expansion of the number of nurses enrolled in RN-to-BSN programs, and an expansion of nurses enrolled in master's and doctoral programs. The nursing faculty shortage will be addressed by expanding opportunities in master's and doctoral programs. At the master's level it will be particularly important to expand opportunities in MSN programs in Nursing Education because that credential is crucial for the community colleges to be able to expand their programs to meet accreditation requirements. The Task Force on Nursing recognized this as a critical contribution of UNC campuses.

The Office of the President has been supportive of increasing access to baccalaureate and master's programs using online technologies, having allocated over $500,000 to the campuses to expand online access at both levels in the past two years.

Each of the existing undergraduate programs turns away qualified students because of limited faculty, space, or insufficient clinical sites. The requirement for a 10:1 student/faculty ratio in clinical courses is not consistent with existing enrollment patterns on the campuses and, in this difficult budgetary climate, makes it harder to expand. Some of the campuses have received support from local hospitals that provide classroom space, clinical preceptors or funds to hire additional faculty, and such partnerships need to be explored further. The Area Health Education Centers (AHEC) has been very supportive and helpful in seeking additional clinical sites.

Throughout the year, we have explored with the deans of nursing the conditions that preclude the production of more nurses at every level. The issues are many. There is a need for faculty development funds for existing faculty to learn new skills or for master's trained faculty to seek doctoral degrees. For most campuses, faculty salaries are an issue, making recruitment difficult. Doctoral-level (PhD) trained faculty have opportunities for high-paying positions outside the academic environment. Some campuses have no space to grow larger programs or no large classrooms to accommodate larger classes. Additional graduate fellowships are needed to meet the financial needs of students engaged in doctoral study. All of these issues are compounded by the extensive budget cuts our campuses have faced over the past three years even as the university has received new enrollment funding.

Articulation

UNC supports the nursing programs at the community college campuses and recognizes the importance of seamless articulation of students from the community college Associate Degree in Nursing (ADN) programs to four-year programs. Increasingly, such needs are being met through bilateral or system-wide agreements, and we agree that it is time for another review of general and specific articulation issues as they relate to nursing. We also recognize the need to expand enrollment at every level, including licensed practical nurses (LPNs) and nurse aides.

Student Support

Another need is the expansion of the Nurse Scholars scholarship to provide more support for those students in the program. Graduation rates would be improved if students did not have to work while in school. A Nursing Fellows program modeled on the NC Teaching Fellows program could provide resources to campuses to support nursing students. Rather than a four-year program, this could be a two-year upper-division program for universities as well as a two-year program for ADN students.

UNC and the NC Center for Nursing have provided support for the College Foundation of North Carolina to establish an online module directed to students seeking a career in nursing. Information about existing programs and scholarship support is available at that site (www.CFNC.org). This is part of a larger effort that will need to be expanded to make career opportunities in nursing known to a wider group of students as they make career choices. It will be very important for this work and the work of others to promote a more diverse nursing workforce that will include more underrepresented minorities as well as males.

Conclusion

While our focus has been on those recommendations for UNC, other recommendations are of equal importance, particularly those focusing on retention in the workplace. Our nursing deans look forward to working with the committee on advanced practice nursing proposed in the report.

Few of these recommendations come without costs. The University of North Carolina intends to take the recommendations of the Task Force seriously and to craft the biennial budget request to maximize the use of limited state funds to address the shortage that exists and is anticipated in the future. We are fortunate to be in a state that recognizes that the health of its people is critical to its future. **NCMJ**

COMMENTARY

Private Colleges and University Nursing Programs in North Carolina

Mary Champagne, PhD, RN, FAAN

American nursing and healthcare are at a critical juncture. We are in the beginning years of a deepening shortage of registered nurses and nurse faculty, and headed toward two possible futures. In one scenario, we look to old solutions or continue as we are: the nurse shortage increases in severity, patient care suffers, and, as noted in the Robert Wood Johnson report (*Healthcare's Human Crisis: The American Nursing Shortage,* April, 2002) a major public health crisis occurs. In the second scenario, we are innovative and proactive in increasing enrollment in nursing programs, improving the educational level of all nurses, and improving the work environment of nurses; and we leverage public-private partnerships in education, industry, government and philanthropic foundations to enhance our efforts. The result is a recovering nurse supply, nurses well prepared to provide excellent care in our complex and increasingly technologically sophisticated care system, and a sufficient investment in the health of the public that ensures all North Carolinians will receive the nursing care they deserve.

We are presented at this time with the proverbial "window of opportunity," with choices to make in securing a preferred future to ensure the health of the public. The North Carolina Institute of Medicine (NC IOM), with financial support from The Duke Endowment, has developed a blueprint for our state's preferred future. The plan is wise and forward thinking, noting that a multi-modal long-term approach is needed, and that all must fully "do their part" if we are to succeed.

Growth of the number of nurses educated at the BSN-level and growth of graduate programs to prepare nurse faculty are key recommendations of the NC IOM report. The private colleges and universities in North Carolina make substantial contributions in each of these areas, and are committed to doing even more. As the report notes, the "privates" educate about one-third of all baccalaureate and master's prepared nurses in North Carolina. The programs are of high quality-retention, graduation and NCLEX pass rates are high; and remarkably between 75% to 95% of graduates stay in North Carolina to practice. In some instances this reflects a greater than expected benefit, as out-of-state students relocate to North Carolina to practice nursing following graduation.

Expanding Private Colleges and Universities

Increasing the capacity of private colleges and universities is largely tied to the funding mechanisms in place in each to allow for expansion. For the most part our schools are funded through tuition dollars and philanthropic gifts. Starting or expanding programs requires "seed money" for the first few years. Philanthropic dollars are incredibly important in this

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effort. Two recent examples illustrate the impact of private foundation support for growth of private colleges and university nursing programs. Our school, the Duke University School of Nursing (DUSON), was able to re-instate a pre-licensure BSN program which now admits 50 students each year thanks to funding from the Helene Fuld Health Trust. And while 50% of the first graduating class was from "out of state," 81% stayed in North Carolina and are providing care at the bedside. Philanthropic funds were also critical to our collaboration with the Southern Regional Area Health Education Center to deliver a master's degree in nurse education to nurses in rural North Carolina. This program, funded by The Duke Endowment, has, in the last two years, graduated over 30 students, who will teach in community colleges and hospitals in underserved areas of our state.

The Importance of Student Support

A unique challenge faced by private colleges and universities is providing sufficient scholarship support to students. The majority of students in the "privates" are North Carolinians, and need help in financing their education. They are not wealthy. I know from my personal experience as dean, that scholarship support often makes the difference between a student pursing or not pursuing education in nursing. My experience is validated by the comments of other deans and directors in North Carolina's private colleges and universities. Expanding the North Carolina Nurse Scholars program, extending the state tuition support to second degree baccalaureate and master's degree nursing students, and enacting the Faculty Fellows Program would markedly impact the ability of private colleges and universities to increase enrollments. Most important to this effort, is philanthropic scholarship support in the form of endowments from private foundations to the private schools of nursing. Philanthropic support of students has long lasting and far reaching effects. This investment in students reaches all the patients they expertly care for over the years of their nursing career; it is an investment with untold dividends.

"...scholarship support often makes the difference between a student pursing or not pursuing education in nursing."

Hospitals and other healthcare agencies can also play a critical role in supporting students in private colleges and universities. Innovative examples include "loan repayment" programs for students who agree to work in the healthcare agency following graduation, direct scholarships to students, faculty support through actual dollars to the college, joint hospital and school faculty appointments, and provision of clinical staff to supervise students in clinical rotations. Careful analysis will demonstrate that these arrangements, properly structured, result in a winning situation for all parties. Our school, for example, partners with the Duke University Health System (DUHS) in a "loan repayment" program for our baccalaureate students. Using traditional methods, students can borrow total tuition costs for their education, and sign an agreement with DUHS that guarantees employment, and payment of one-third of the loan plus interest for each of three years worked. Financial modeling, which included weighted costs of recruitment and retention of nurses and salary for staff and traveling nurses, demonstrated that DUHS would fully recoup its investment.

The private colleges and universities look forward to working with the many partners involved in the NC IOM Task Force on issues that affect us all in increasing and improving the nurse workforce. We support measures to build an interest in nursing as a career, collaborations to enlarge and more efficiently use clinical training sites, improving the scope of practice of APRNs, and enhancing the work environment of all nurses. We aim to do our best in partnering to ensure a highly educated nurse workforce for today and tomorrow. Working together to secure our preferred future, we cannot fail. The best is surely yet to come. **NCMJ**

Are Hospital-Related Nursing Programs the Answer?

Anita A. Brown, RN, MEd

Hospital-related nursing education has been a part of the fabric of healthcare and healthcare education in North Carolina for well over a 100 years. During the 1950s there were as many as 44 hospital-related nursing schools preparing graduates for registered nurse licensure and employment positions in North Carolina hospitals. In the 1960s more than 80% of the Registered Nurses (RNs) in the United States were educated in hospital-related programs. With the advent of the community college as well as the ever-changing financial challenges of the hospital industry, many hospitals began closing their nursing education programs or merged them into those new community colleges. By the 1990s, 10% of the United States' nurses were educated in hospital-related programs. It is well documented that in the United States and North Carolina, 60-70% or more of working RNs are employed in hospitals.

Historically, hospital-related programs have awarded the "diploma" as the educational credential to those students who graduated. When hospital-related education began, associate and baccalaureate degree programs in nursing did not exist and the "diploma" was the accepted academic credential. Because hospital-related education began as apprentice-type programs, the perception has lingered that these are nothing more than on-the-job training or workforce development programs. As nursing education has evolved, hospital-related programs have changed from the apprentice style educational formats to curriculum plans, which mirror today's associate and baccalaureate degree programs, including college-level general education courses with nursing major courses. Throughout the United States many hospital-related nursing programs have transitioned to associate degree (ADN) or baccalaureate (BSN) programs as part of becoming colleges of health sciences offering allied health programs as well as nursing. In 1998 a report on hospital-related colleges prepared by the Lewin Group, identified 348 hospital-related colleges/programs in the United States.

There are five hospital-related colleges/programs in North Carolina: Mercy School of Nursing at Carolinas Health Care System in Charlotte, Presbyterian Hospital School of Nursing at Presbyterian Hospital/Novant in Charlotte, Watts School of Nursing at Durham Regional Hospital in Durham, Cabarrus College of Health Sciences at NorthEast Medical Center in Concord, and Carolinas College of Health Sciences at Carolinas Health Care System in Charlotte. While Mercy, Presbyterian, and Watts' programs continue to award diplomas as the academic credential, the curricula in these programs are comparable to associate degree programs currently offered in North Carolina's community and private colleges. Cabarrus College of Health Sciences and Carolinas College of Health Sciences have developed associate degree nursing programs as part of their strategic development as colleges of health sciences. It is worth noting that both of these institutions include a variety of allied health programs at the associate degree level and Cabarrus College also has baccalaureate degree programs including BSN completion.

While the number of hospital-related programs is small, the impact of each is large in their respective areas. With their inception dates varying from 1895 to 1947, collectively these five programs have graduated approximately 11,000 nurses. Of

Table 1.
North Carolina Hospital-Rated Nursing Programs

	% Graduates Staying To Practice In NC	Average Retention Rate	Average Graduation Rate
Cabarrus College of HS	98%	65-70%	60-65%
Carolinas College of HS	97%	65-70%	64%
Mercy SON	96%	60-65%	57%
Presbyterian Hospital SON	98%	60-65%	65%
Watts SON	97%	56%	69%

Program survey data - March 2004. (SON = School of Nursing HS = Health Sciences)

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the 2,467 first-time NCLEX-RN takers in North Carolina in 2002, 10.2% (252) were from the five hospital-related programs. Of the six largest registered nurse education programs in the state (in terms of students taking the NCLEX), two are hospital-related programs, Presbyterian and Carolinas. These five programs also produce graduates who, on average, pass the RN licensure exam at a rate of approximately 90% on first writing.

A hospital-related nursing student tends to be older than the average university student with age ranging from 25-29 years. Most students have prior college experience, degrees, and/or careers in other fields. According to a survey of the five hospital-related programs, (March 2004), 97% of their graduates remain in North Carolina to practice. Most graduates stay within the community where they were educated and many of these associate degree and diploma graduates pursue BSN or master's (MSN) degrees.

Advantages of Hospital-related Nursing Education Programs

Several advantages of hospital-related programs are due to the relationship with their sponsoring hospital. The students in hospital-related programs typically have the best of both the education and the healthcare provider worlds as these hospitals provide excellent, often cutting edge, clinical opportunities. While the programs tend to get first choice for clinical experiences at their sponsoring hospital, most negotiate, as do other programs, for selected and limited clinical sites. All hospital-related programs report that 100% of their full-time faculty are master's prepared and all meet or exceed the NC Board of Nursing requirements for clinical experience. Hospital-related programs provide a significant recruitment resource to their affiliate hospitals, as many of the graduates choose to work in the hospitals where they receive their clinical experiences. Frequently, students in hospital-related programs can find meaningful work experience in the hospital as nursing assistants or other related jobs while they are enrolled in the nursing program. This sets the stage for a seamless transition from the role of student to employee when the student accepts employment beyond graduation. This seamless transition is beneficial for financial, human resources, and orientation reasons. Obviously, it can therefore significantly reduce the cost to hospitals for recruiting and orienting these new graduates. Hospitals sponsoring these programs report consistently lower RN vacancy rates than other hospitals in the state.

Although hospital-related programs are somewhat insulated from state and political budget considerations, a disadvantage for these programs is there is no state or federal funding to support their operations. A prevailing myth is that hospital-related programs are adequately funded due to the Medicare pass-through funding available to hospitals that support nursing and allied health education. While hospitals that sponsor nursing programs are eligible to receive the Medicare pass through funding, it is up to the institution as to how the funding is allocated and that funding represents a modest portion of overall program costs.

Hospital-related programs in North Carolina tend to utilize approximately 80% of their approved NC Board of Nursing slots. It is important to note that on average the hospital-related programs also retain 65-75% of their students in contrast to significantly lower rates of 50% or lower reported by the community colleges. Hospital-related programs report average graduation rates of 60-70%. While some 60-70% of their graduates remain at the sponsoring institutions for employment, these graduates tend to be mobile, but do remain in North Carolina in much higher percentages.

Hospital-related programs have the same concerns as other programs regarding "aging of the professorate" and availability of academically and experientially qualified nursing faculty for replacements. Salaries at these programs generally are more competitive due to internal equity issues including clinical salaries and lower faculty turnover rates. These factors contribute to higher faculty satisfaction rates and stable work environments.

The attributes of hospital-related college programs as described in the Lewin report, which make them valuable to student and local healthcare providers are:

- Programs are closely aligned with and responsive to the healthcare marketplace.
- These programs substantially contribute to local workforce development.
- These programs provide important career mobility opportunities.
- Expertise in clinical teaching is a hallmark of hospital-related programs.

While anecdotal comments reflect that there are hospital administrators who believe that working with the community colleges and the universities is preferable to sponsoring a hospital-related nursing education program, it is worth noting that one major hospital in North Carolina reactivated its nursing education program in the 1990s after many years of working with a local community college, citing issues of insufficient quantity and quality of graduates under the existing relationship. Given the vagaries of today's healthcare economies, especially for hospitals, it may not seem prudent to recommend reactivating hospital-related nursing programs. However, for five hospitals in North Carolina, which have weathered the financial and educational trend storms, nursing shortage issues have been removed from or are very low on their list of priority concerns.

Although the NC Institute of Medicine Task Force on the NC Nursing Workforce did position itself in support of strengthening and expanding all types of nursing education programs in North Carolina in order to meet the projected needs, it became apparent that due to the small number of hospital-related programs as compared to the community college and university systems, these programs would receive limited attention in the Task Force deliberations and recommendations.

Therefore, it is imperative that as policy makers and stakeholders determine how best to respond to the recommendations of the Task Force, hospital-related programs and their students must be included as part of the answer. **NCMJ**

How LPNs Can Be Part of the Solution

Patricia A. Beverage, LPN

One of the most common questions I am asked is: What is the difference between a registered nurse (RN) and a licensed practical nurse (LPN)? My standard response has been their level of education and the dependence or independence of their practice. It is surprising how many medical professionals do not know the difference in the levels of nurses working with them. To them, a nurse, is a nurse, is a nurse.

Licensed practical nurses (LPNs) use specialized knowledge and skills to provide care for the sick, injured, convalescent, and disabled under the direction of physicians and registered nurses. LPNs are required to pass a licensing examination (NCLEX-PN) after completing a state-approved practical nursing program. Thirty-two of the 33 North Carolina PN education programs are a part of the NC Community College System. The Department of the Army runs the one other PN educational program.

LPN Origin and Practice

LPNs were created amidst another severe nursing shortage during World War II. The NC Nurse Practice Act was amended to regulate the practice of a Licensed Practical Nurse. These nurses were to be taught the basic knowledge of pathophysiology and would be educated primarily in the delivery of hands-on nursing care. This would enable RNs to care for a larger number of patients with the assistance of educated and licensed personnel.

Depending upon location, LPNs work in operating rooms, nurseries, and labor and delivery units. LPNs work on medical/surgical units, cardiac and intensive care units. LPNs work in emergency rooms, ambulatory care clinics, public health and occupational health clinics. LPNs provide care in assisted living facilities and in nursing homes. In fact, LPNs supervise care provided by nursing assistants in most nursing homes.

LPNs take vital signs, treat wounds, give medications, and perform venipuncture. LPNs insert catheters, nasogatric tubes, assist with hygiene, feed patients, record intake and outputs in addition to caring for their patient and their family's emotional needs. In some facilities, LPNs can give intravenous medications, hang blood, or other higher levels of care. LPNs can also assist in developing care plans. In doctor's offices and clinics LPNs perform tasks such as giving immunizations or clerical duties. LPNs also work in private homes, which may include providing simple meals for patients, doing light housekeeping, and teaching the family members to perform simple nursing tasks.

Practical Nurse education prepares LPNs to "assess" patients—just like RNs—and report these assessments to direct supervisors, as do the RNs. The difference is that LPNs are not permitted to perform an intervention without first reporting their findings.

LPN Employment

Over the past 20 years, NC LPNs have seen major changes in the location of their employment opportunities—from being primarily hospital-based to nursing home-based. More LPNs have found employment in community agencies, such as health departments, mental health facilities, hospice and home care.

The US Bureau of Labor Statistics (BLS) predicts a continued decline in LPN positions in hospitals.[1] The BLS also predicts an increase in the use of LPNs in medical offices and clinics, ambulatory surgical centers and emergency medical centers as the occurrence of sophisticated procedures that were only performed in hospitals move to these facilities. Advancing technology will play a major role in the growth of the use of LPNs in these healthcare arenas. LPN employment in nursing homes is also expected to grow, as the need for long-term care expands along with our growing aging population.

Table 1.
LPN Place of Employment in 1982 and 2001

Place of Employment	1982	2001
Hospital	62%	19.5%
Nursing Home	15%	39.5%
Community Agencies	1%	9.5%
Medical Offices	8.4%	18.9%

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Suggestions from LPN leaders

The elected professionals representing LPNs believe the state of North Carolina could help alleviate part of its nursing shortage by allowing LPNs to play an active role in all aspects of nursing. A noted national leader in nursing, Dr. Margaret McClure, RN, EdD, FAAN, President of the American Academy of Nursing, said it best, "Nursing needs people with different skill sets and talents—whether it's an aptitude for technology or interpersonal communications. Everyone can find a place to thrive and be happy and be useful in this broad and challenging field."[2]

The NC LPN Association Executive Board recommended the following to the NC Institute of Medicine Task Force on the NC Nursing Workforce:

1. Ask employers to help LPNs obtain continuing education. If LPNs do not meet employer needs in facilities, employers should help and/or allow LPNs to obtain those courses or certifications needed to meet these needs.
2. Provide LPNs with career ladders. Offering LPNs an opportunity to advance will inspire them to seek further education or certifications. Recognition, money and benefits are attractive incentives.
3. Involve LPNs and the rest of the staff in developing more flexible and amiable work schedules to help meet their personal needs. This could help decrease the number of "call outs" and the scramble for last minute replacements.
4. Challenge LPNs to improve. LPNs have untapped potential to succeed. Challenge them to do so.
5. Respect LPNs. LPNs would like to feel respected and recognized for the critical role they play in healthcare.

The Task Force Report aptly stated that:

> "For adults, with or without family commitments, wishing to enter the nursing workforce, the PNE program is an efficient way of doing so. It assures access into the nursing profession for nontraditional, high school and adult students who do not have more than 12 months to invest in educational pursuits because they must support a family. LPNs have limited opportunity with regard to career ladders and educational programs that allow them to advance their nursing careers. Considering the need for nurses at the bedside, program length and accessibility, the PN education may be one of the more cost-effective ways to increase direct care nursing workforce numbers."

The Task Force also made recommendations in Chapters 3 and 4 that address some of the NC LPN Association requests. The Task Force recommended that community colleges expand the production of prelicensure PNs (Rec. # 3.1d); hospitals and other nursing employers consider tuition remission programs to encourage their nursing employees to pursue LPN-RN, RN-BSN, MSN or PhD degrees (Rec. # 3.27); and healthcare employers improve the work environment (e.g., by involving nurses in policy making and governance decisions and providing opportunities for advancement) (Rec. 4.1a-j).

We feel this is a first step toward using LPNs as part of the solution to the predicted nursing workforce shortage. Again, as Dr. McClure said, there is a place for everyone in healthcare and nursing. My hope is that this Task Force report helps us to find the means to that end and to make healthcare safe and available for the citizens in North Carolina. **NCMJ**

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COMMENTARY

A Critical Need for a More Diverse Nursing Workforce

Virginia W. Adams, PhD, RN, and Patricia J. Price-Lea, PhD, RN, C

As we face a potential nursing shortage, we should consider who is missing from the current nursing workforce. Racial and ethnic minorities are underrepresented in the North Carolina nursing workforce, as are men. Only about 12% of the RN workforce were racial and ethnic minorities in 2001, compared to 28% of the state's population.[1] This percentage has increased only slightly over the last 20 years when only 8% of the RN workforce was part of a racial or ethnic minority (1982). LPNs more closely reflect the state's diverse population: 26% of the LPN workforce was from a racial or ethnic minority in 2001.

Males are even more under-represented in the nursing workforce: only 6.6% of RNs, and 5.1% of LPNs are men, compared to 49% of the state's population.[2] While it is important to address both of these issues—the recruitment of racial and ethnic minorities and men into nursing—this paper focuses on efforts to increase the supply of racial and ethnic minorities in the nursing profession.

Table 1.
Racial Composition of Licensed RNs and LPNs in the NC Nursing Workforce (2001)

	RNs	LPNs
White	87.8%	73.7%
African American	8.7%	23.2%
American Indian	0.6%	1.2%
Asian or Pacific Islander	1.6%	0.4%
Hispanic	0.5%	0.7%
Other	0.5%	0.6%
Unknown	0.3%	0.3%

Source: Lacey, Linda M. and Shaver, Katherine. North Carolina Trends in Nursing: 1982 - 2001 RN and LPN Workforce Demographics. March, 2003. www.nursenc.org/research/Trends2001/workforce_demos.pdf

Why Diversity in Nursing Is Important

Attracting a more diverse population into the profession serves many purposes. First, studies have shown that racial and ethnic minorities are more likely than their white cohorts to serve underrepresented communities.[3] This helps improve access to healthcare for minority patients and reduce healthcare disparities. When given a choice, patients are more likely to select a healthcare professional of their own racial or ethnic background and are generally more satisfied with the care provided them by these providers. Minority health providers are also more likely to practice in community-based settings that serve low-income populations or in settings less coveted by non-minority nursing professionals. In North Carolina, for example, African-American RNs are more likely to practice in public health clinics, mental health facilities or long-term care settings: they comprise 9% of the total RN workforce, but 13% of the long-term care, 13% of the public health, and 20% of the mental health facility workforce.[4]

Minority providers can also help bridge cultural and language gaps in practice and in education. For example, Latino nurses can help bridge language gaps. Currently, more than 5% of the state's population is Latino, many with limited English proficiency. Increasing the numbers of Spanish-speaking Latino nurses could help ameliorate language and cultural barriers that exist for many of the recent Latino immigrants to our state. Bilingual nurses in practice and education contribute substantially in diminishing these barriers.

A diverse student body and workforce can also improve the cross-cultural training of all students. The interaction of students from diverse backgrounds provides a broader perspective of racial, ethnic, and cultural differences. Reaching out to racial and ethnic minorities could also help broaden the pool of potential nurses. In short, creating a more diverse workforce is beneficial in creating a sense of community, narrowing the health disparity gap, and promoting the health of all people.[5]

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Recruiting, Admitting, and Graduating Racially Diverse Nusing Students

To achieve a more diverse RN workforce in North Carolina, we must do more to recruit, admit and graduate racial and ethnic minorities in nursing programs.

Recruiting minorities into nursing: Ideally, recruitment should begin by reaching out to underrepresented populations while in elementary and high schools to encourage them to explore a career in nursing and to advise appropriate classes that will academically prepare them for nursing programs. The NC Institute of Medicine Task Force Report on the NC Nursing Workforce has partially addressed this problem. It recommended:

> The North Carolina General Assembly should appropriate additional funds to the NC Center for Nursing (NCCN) for the next five years to expand and enhance the outreach and recruitment efforts targeted to racial and ethnic minorities and males. The NCCN should report to the NC General Assembly on an annual basis on the progress in recruiting minorities and men into nursing. Funding should be tied to meeting certain performance thresholds. An image campaign about nursing and nursing work targeted specifically to the African American and Hispanic/Latino communities, as well as males in general, should be strengthened and promoted. Such a public information campaign should make clear the multiple pathways available to any person interested in a nursing career, as well as the opportunity for advanced educational opportunities following entry to the profession through any portal. (Rec. #3.22d).

Further, the Task Force also recommended that high school, community college and university guidance counselors receive additional training to provide better information to students who may be interested in a nursing career (Rec. #3.23).

While these recommendations are helpful, they will not fully address the problem. The NC Center for Nursing can help create an interest in nursing programs among underrepresented populations, but it is not an educational institution, so consequently has no authority to admit these students. In addition to the new appropriations to the NCCN, funds should be appropriated directly to nursing education programs for targeted outreach and recruitment efforts. Not only can educational institutions reach out directly to students, but they can also develop partnerships with community leaders to create trust and a positive image of the institution. The nursing educational programs that receive funding should be held accountable for increased admissions and subsequent graduation of nursing students from the various racial and ethnic populations.

Nursing education programs: To achieve a more diverse nursing workforce, nursing programs first must admit and graduate students from diverse backgrounds. Together, leaders in education and practice must be accountable for the preparation and graduation of a critical mass of registered nurses from racial ethnic backgrounds beginning with African Americans.

Segregation and Nursing Education: Historic Barriers and Progress

Historically, the opportunity to provide a quality education for African American students was limited, as the education of African Americans was restricted to Historically Black Colleges and Universities (HBCUs), first through laws and later through practice. The legal right for African Americans to attend predominantly white institutions was not guaranteed until 1954, when the Supreme Court in *Brown v. Board of Education of Topeka Kansas*, 347 U.S. 483 (1954), nullified *Plessy v. Ferguson*, 163 U.S. 537 (1896), which had supported "separate but equal" education. One year after the *Brown* decision, North Carolina was still fighting against admission of black students to the University of North Carolina. This was resolved in 1955, when UNC was legally required to admit black students in *Frasier v UNC Board of Trustees*, 134 F.Supp. 589 (1955).[6] Despite the Brown decision, educational institutions in this state and around the country made it difficult for black students to enroll.

Historically, when black students were denied admission to all-white programs, both black and white leaders initiated nursing programs for black students. HBCUs boast of graduating most of the African American registered nurses in North Carolina.[7] From 2001-2003, 65% of the African American nursing graduates in the public baccalaureate and higher degree programs were awarded degrees from three of its HBCUs.[8] In 2001, for example, HBCUs in North Carolina educated 3.4% of the active RN workforce, but 26% (~1,750) of the practicing African American RNs.[9]

Although Historically Black Colleges and Universities have produced a disproportionate proportion of the African-American nurses currently practicing in the state, it is the responsibility of all public nursing programs in North Carolina to produce a more diverse workforce. To achieve this goal, institutions and nursing programs must be committed to a more diverse student body. In addition, they can employ other strategies which can help improve their records of training and graduating a diverse student population:

- **More inclusive admissions policies.** Rather than relying primarily on standardized tests, traditionally white educational programs need to consider additional methods for admitting students to nursing programs. Because minority students are more likely to be educated in lower-wealth schools with fewer educational opportunities, they often score lower than whites or Asian-Americans on standardized tests. Admissions committees should consider other qualities linked with professional success in their selection process, including leadership, personal life experiences, commitment to service, and multilingual abilities. In addition, minority faculty should be asked to serve on admissions committees.
- **Hire more minority educators and help prepare white faculty to be more attuned to the needs of a diverse student population.** Nationally, only 9.5 % of full-time nursing faculty represent racial/ethnic minority groups.[10] This statistic

suggests a dire need for more minority educators. However, all educators, not just those from racial and ethnic minority groups, need to be culturally sensitive to the needs of underrepresented student populations. One option to help sensitize white faculty to the needs of minority student populations is to encourage white faculty to have visiting professor immersion experiences on campuses with a more diverse student population.

- **Mentoring and social support.** A critical mass of underrepresented groups should be admitted to ensure their social support rather than admitting one or two students in the typical class. Further, while not unique to a minority student population, nursing schools should provide academic and social supports needed to ensure academic success, including faculty mentoring, academic tutoring and educational counseling services.
- **Removing financial barriers.** Minority students often come from lower-income families and may find the cost of education to be prohibitive. Scholarships, loan forgiveness and stipends are needed to help assist these low-income students (of any racial or ethnic background) to pay for their nursing education.
- **Other strategies.** Other reliable strategies include avoiding labels that create unnecessary hurdles for students or perpetuate old stereotypes of racial/ethnic groups, developing curricula and teaching standards that recognize commonalities and respect for differences, and ensuring the history of underrepresented groups as part of the curriculum.

If North Carolina and its public nursing education system intend to remain strong and be a model for the rest of the country, it has to provide quality education for all of its citizens. Moreover, it needs to acknowledge and embrace the benefits of a diverse registered nurse workforce. Proficiency in relating to cultures different from one's own becomes an essential ingredient in the skill set for the 21st century healthcare professional. Success for students from diverse populations means success for the state and improved healthcare for its citizens. Due to widening racial disparities in healthcare, this phenomenon is significant.

Students who learn together are more likely to work well together. Microbiology teaches us that organisms improve their chances of survival by interacting with one another. Therefore, if individuals tend to work only with their own ethnic group, everyone's existence is threatened. Leveraging diversity expands one's capacity to learn and survive. Patients, communities, and the healthcare system will be the beneficiaries of a more diverse registered nurse workforce. **NCMJ**

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Developing an Adequate and High Quality Nurse Aide Workforce in North Carolina

Susan Harmuth, MS, and Jesse S. Goodman, III

North Carolina is experiencing a shortage of direct care workers. Direct care workers include an array of paraprofessional caregivers such as nurse aides, home health aides, and personal care aides.[1] Nurse aides work under the supervision of a registered nurse and represent a significant portion (54%) of North Carolina's direct care workforce.[2] Nurse aides are employed in a variety of healthcare settings such as hospitals and doctors' offices and are also widely employed in an array of long-term care settings such as home care agencies, adult care homes and skilled nursing facilities.

Nurse aides (and other direct care workers) are recognized as the front-line caregivers in the long-term care arena and are the staff likely to have the most direct contact with residents. Nurse aides help residents with basic daily living tasks such as bathing, dressing and toileting and also perform various healthcare tasks such as taking vital signs, changing dressings, skin care, transferring, positioning and turning, and basic restorative services.

Direct Care Worker Turnover Rates

The North Carolina Department of Health and Human Services, in collaboration with the UNC Institute on Aging, annually compiles turnover data on direct care workers employed in licensed home care agencies, adult care homes and nursing facilities. Data collected through this process helps illustrate that the average annual turnover rate for Nurse Aides in North Carolina's nursing facilities was 95% in 2002. This compared to 115% for direct care workers in North Carolina's assisted living facilities and 37% for direct care workers employed in licensed home care agencies. Table 1 shows average annual turnover rates for 2000 through 2002 for direct care workers in three major categories of long-term care settings.

Table 1.
Average Annual Turnover Rates of Direct Care Workers in NC, 2000-2002

Setting	2000	2001	2002
Skilled Nursing Facilities	100%	103%	95%
Adult Care Homes	119%	113%	115%
Home Care Agencies	50%	50%	37%

Note: All percentages have been rounded to the nearest whole number. Turnover data for these settings is collected and analyzed annually through a collaborative effort between the NC Department of Health and Human Services and the UNC Institute on Aging.

According to the US Bureau of Labor Statistics, nurse aides are among the top 10 occupations nationally with the largest projected growth rate between 2002 and 2012. The number of nurse aides needed nationally will increase by 25% between 2002-2012. In contrast, North Carolina is projected to see a 36% increase in the number of nurse aides needed between 2000 and 2010 (most recent state-specific data available) increasing from 44,850 in 2000 to 61,050 in 2010. This equates to 2,220 new job openings per year over the ten-year period. The projections are inclusive of both new jobs created and existing jobs that are vacated.

North Carolina's Nurse Aide I Registry includes all individuals who have successfully completed a North Carolina approved Nurse Aide I Training and Competency Evaluation Program or a Competency Evaluation Program. Over the last three years North Carolina has seen an increase of over 16,500 individuals eligible to work as Nurse Aide I's. While this increase has helped to relieve the workforce shortage, much of this increase may be attributed to the reduction in employment opportunities in other competing sectors as a result of the soft economy. It is anticipated that improvements in the economy will bring added competition from other employment sectors for these

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individuals. Therefore, the challenge that faces the state is the development of incentives, both financial and career advancement, which will keep these individuals in the healthcare field.

Recruitment and Retention Efforts

The NC Department of Health and Human Services, in collaboration with many partners, has a number of initiatives underway to improve the recruitment and retention of direct care workers as well as improve the quality of direct care jobs. The Kate B. Reynolds Charitable Trust provided grant funding for the design and planning of the recruitment and retention initiative, which included the initial funding for the Win-A-Step-Up program as well as the turnover and labor market data collection efforts outlined earlier in this article.

Major activities underway include the development of two new job categories intended to provide career advancement opportunities for paraprofessionals and respond to staffing needs of long-term care related providers. The two job categories include a medication aide and a geriatric nurse aide.

> *"North Carolina's population and nursing care workforce, like the nation's, is aging and there will not be enough people in the workforce to fill healthcare positions when they are needed the most."*

The Medication Aide Project is a cooperative effort between the NC Department of Health and Human Services and the NC Board of Nursing, and is in the second year of development. The project is now in the final stages of developing standards for prerequisites and training requirements for faculty and students, statewide competency testing and the creation of a statewide registry. Pilot testing is expected to begin in the spring of 2004. Legislation that may be needed to implement this initiative will be developed for introduction in the 2005 session of the North Carolina General Assembly.

The Geriatric Aide Project is a cooperative effort of the NC Department of Health and Human Services and the NC Community College System. A curriculum is currently under development and is focused on more in-depth education for nurse aides in the areas of prevention and care of pressure ulcers, unplanned weight loss/dehydration, infection control, pain management, behavioral management, resident depression, safe mobility, care of the terminally ill and care of the caregiver. This educational program will require Nurse Aide I training as a prerequisite and will be a key component of the state's overall career ladder initiative for direct care workers.

- A program, known as Win-A-Step-Up, is a voluntary program that provides financial and other incentives to nurse aides working in nursing facilities in exchange for completion of certain training components and agreeing to stay with their employer for a specific period of time. Employers must agree to provide either a wage increase or bonus (or both) to participants who complete the training and retention commitment. This program is a collaborative effort between The NC Department of Health and Human Services and the UNC Institute on Aging.
- North Carolina is one of five state-based coalitions funded nationally to implement a *Better Jobs Better Care* demonstration grant. These 42-month demonstration grants, funded by The Robert Wood Johnson Foundation and The Atlantic Philanthropies, are intended to implement policy and practice changes that will improve the ability to attract and retain high-quality direct care workers to meet the needs of long-term care consumers in both home-and-community and facility-based settings.

Specifically, North Carolina's *Better Jobs Better Care* coalition will develop, pilot, and implement a uniform set of expectations and criteria. These will be applied on a voluntary basis in home care, adult care homes and nursing facilities across the state and will result in a special licensure designation for entities that meet the voluntary criteria. Expectations and criteria being developed will address issues such as: effective care teams; peer mentoring, coaching supervision and other supportive workplace criteria; staff development and career advancement opportunities, safe and balanced workloads, etc. This special licensure designation is intended to potentially serve as the basis for awarding a differential reimbursement increase or eligibility for labor enhancement funds.

Nurse Aide Training

Because nurse aides represent such a large component of the direct care workforce, statewide availability of nurse aide training programs is a key factor in the success of any direct care recruitment efforts being implemented. The NC Community College System has taken on the responsibility of serving as the primary resource for nurse aide training across the state. In some parts of the state, access to a community college-sponsored nurse aide training program by persons interested in working as a nurse aide is limited. This is due to a variety of reasons, including insufficient clinical lab space and demand for nurse aide training programs by students interested in enrolling in registered nurse training programs. The Community College System's ability to respond to training needs of both persons seeking further professional nursing education and nurse aide training will be an important building block to developing an adequate and stable

supply of nurse aides available to provide care in long-term care related settings, hospitals and other healthcare-related settings.

Conclusion

The nursing workforce challenges that North Carolina faces are complex, with even more complex solutions. The current workforce shortage is seen as short-term, but the labor shortage that is predicted for the next 30 years is not. North Carolina's population and nursing care workforce, like the nation's, is aging and there will not be enough people in the workforce to fill healthcare positions when they are needed the most. According to the US Bureau of the Census *1999 Statistical Abstract of the United States*, between 2010 and 2030, there will be a 7% increase in the number of people 65 and over as a proportion of the total population and a 6% decrease in the proportion of people ages 18 to 64, relative to the total population. Competition for qualified individuals to enter the healthcare workforce of the future will be keen and the North Carolina Institute of Medicine and the Duke Endowment should be applauded for their foresight in recognizing the need for North Carolina to act now to develop a comprehensive approach to address this complex issue. We believe that the initiatives that are currently underway and supported by the Task force on the NC Nursing Workforce to address the direct care workforce shortage are a good start. **NCMJ**

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1 The US Bureau of Labor Statistics classifies direct care workers into three major categories including: 1) nurse aides, orderlies, and attendants; home health aides; and personal and home care aides and attendants. It should be noted that the term "direct care workers is not to imply theat licensed nurses are not involved in direct patient care.

2 US Bureau of Labor Statistics, 2002 Employment and Wage Data, North Carolina specific data. It should be noted that the term "direct care workers" is not to imply that professional nurses are not involved in direct patient care.

COMMENTARY

The North Carolina Area Health Education Centers' Role in Addressing Nursing Workforce Issues

Thomas J. Bacon, DrPH, Gail O. Mazzocco, RN, EdD, and Karen D. Stallings, RN, MEd

Introduction

The need for nurses at all levels of the healthcare system continues to grow at a pace that outstrips the current supply, both nationally and in North Carolina. The report of the North Carolina Institute of Medicine Task Force clearly documents the multiple strategies that will be required to address this highly complex problem. We must increase the output of nurses from our educational institutions, although that alone will not solve the problem. We must improve the retention of nurses in the profession by strengthening the work environment, empowering nurses as decision makers, recognizing outstanding performance, and fostering career growth opportunities. We must also attract young people and second career professionals into nursing that represent the rich diversity of the North Carolina population.

For over 30 years the North Carolina AHEC Program has worked in close collaboration with academic nursing programs, employers, and practicing nurses to prepare and retain a nursing workforce that can meet the healthcare needs of our state and our communities. We remain committed to developing innovative approaches to improving the recruitment, retention, and quality of the nursing workforce. AHEC nursing faculty work with the NC Center for Nursing, the NC Board of Nursing, the NC Nurses Association, and a wide variety of nursing groups to maximize efforts.

Core AHEC Nursing Initiatives

Promoting Careers in Nursing

To prepare a more diverse healthcare workforce, the AHEC Program conducts programs to recruit underrepresented and disadvantaged middle and high school students into health careers. AHECs work annually with over 25,000 young people in order to inform them of opportunities in the health field, including nursing. These programs offer mentoring, hands-on experiences in clinical settings, and also include academic work to strengthen students' skills in math, science, and communication, so that they can succeed in entering and completing nursing programs.

Nursing Student Training in AHECs

Education of nursing students takes place in a variety of healthcare institutions, agencies, and educational settings throughout AHEC regions, and, whenever possible, in underserved rural and urban areas with vulnerable populations. Essential clinical training for primary care nurse practitioners (NPs) and nurse midwives is provided under the auspices of the Area Health Education Center (AHEC) Offices of Regional Primary Care Education. Last year 2,551 student weeks of community-based experiences for NP students were supported through AHEC.

> *"North Carolina continues to require more nurses prepared at the baccalaureate level and above."*

Continuing Education

Continuing Education (CE) plays a major role in professional career development. The state's nine AHECs offer a variety of nursing CE programs and technical assistance services to address changing technology, clinical guidelines, patient safety, new medications, specialized nursing care, physical assessment, transition from acute care to home, and long-term care.

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Spanish language and cultural competency training programs help nurses work more effectively with our growing Latino population. Last year, AHEC offered 650 nursing continuing education programs, attended by more than 16,750 nurses. The NC Institute of Medicine (NC IOM) Task Force Report on the NC Nursing Workforce points to the fact that nurse retention in workplace settings is increased with progressive management practices, when nurses feel empowered in the decisions that are made, and when education is valued. AHEC continuing education programs teach nurses to become effective managers, a fundamental element in workforce retention.

Special Legislative Initiatives

In 1989, the NC General Assembly allocated funding to the NC AHEC Program for three initiatives: nurse refresher programs, educational mobility programs, and clinical site development.

Nurse Refresher Program

The AHEC Program collaborates with UNC-Chapel Hill to offer a refresher program for registered nurses. The course, which includes self-study modules and preceptored clinical experiences, helps registered nurses who have not been employed return to the workplace. Additionally, nurses who are currently employed but would like to move into new clinical areas may also use the program to update their knowledge and skills. Over the last 13 years, approximately 1,300 nurses have enrolled in this recruitment and retention program and almost two-thirds of them have returned to clinical practice.

Educational Mobility through Off-Campus Degree Programs

North Carolina continues to require more nurses prepared at the baccalaureate level and above. AHEC nurse faculty collaborate with schools of nursing to develop and operate off-campus RN-to-BSN and MSN programs in underserved areas of the state. These programs meet the need for flexible distance education formats, allowing nurses to advance their educations while continuing to work in their home communities and care for their families. AHECs provide on-site assistance such as classrooms, library resources, information services, logistical help, and student support. Given current faculty shortages in schools of nursing, master's degree programs that prepare faculty with both clinical and didactic educational preparation are especially needed. The 120 students who are currently enrolled will soon join the more than 1,000 graduates of AHEC sponsored off-campus programs.

Clinical Site Development

New clinical training sites in rural, long-term care, and critical care settings assist schools of nursing to maximize enrollment and provide significant periods of training in workforce shortage areas. As directed by legislation, the NC AHEC Program provides clinical site development grants to the schools of nursing within the community colleges and the constituent institutions of the University of North Carolina. AHEC nurses work with schools of nursing to identify new clinical sites for development, assist with funding, provide preceptor training, and consult on areas related to student use of clinical sites. More than 250 clinical sites have been developed as part of the grants program and 52 new sites are currently being developed.

New Initiatives

While existing endeavors have been both effective and supportive, AHEC is also working on new strategies that address current employment challenges. Several of these approaches enhance nurses' continuing education opportunities, even while assisting with the development of supportive work environments.

The Nursing Management Institute (NMI), funded through The Duke Endowment, offers training for nurses to develop the administrative skills that are required in today's healthcare environment. This on-line certification program, which includes essential management content, is convenient, inexpensive, and may be completed either as a series or as individual modules. Moreover, an organization may enroll a group of staff members in the program and benefit from the shared knowledge and understanding of an entire employee cohort.

Magnetizing Your Organization is an initiative that has a similar purpose. This statewide program assists healthcare institutions that may not be able to achieve magnet status learn about and institute enhancements that are typical of Magnet organizations. Day-long programs have already been presented in three regions of the state, where over 300 participants have benefited by the program.

Finally, the **Clinical Teaching Associate (CTA) project**, designed by Northwest AHEC has been piloted this year by North Carolina Baptist and Forsyth Hospitals, Winston Salem State University and Forsyth Technical Community College. According to the NC IOM Task Force *Report on the NC Nursing Workforce*, many able students are turned away from nursing programs, in part because of the lack of clinical faculty. The CTA project, funded by an AHEC grant, allows appropriately prepared staff nurses to work at their employing institution as clinical faculty members for part of their regular work time. Clinical teaching associates have the opportunity to explore a new role, introduce current clinical skills to students and increase student enrollment.

Current Challenges and Opportunities for the Future

The three initiatives described above are examples of ways that AHEC has expanded its historical role to create additional training capacity and sharpen its focus through its traditional continuing education efforts. Unfortunately, all three of these initiatives have been funded with grant support, either from foundations or through special AHEC grants. Due to state revenue shortfalls, the AHEC budget has been reduced by approximately 15% over the last four years. As a result, all new initiatives in nursing and other fields have been funded by either reallocating existing funds or utilizing grant dollars.

There are a number of additional training needs that exist across the state that AHEC is prepared to address, assuming funding is forthcoming in future years. As the state grows out of the recession, it is hoped that additional state resources will be appropriated to address these critical nursing issues, as well as those affecting other health professions. Some of the areas where AHEC is prepared to take the lead, either building on existing programs or developing new initiatives, are as follows:

a. **Expanded training capacity.** Building on its current efforts, AHEC is prepared to fund additional clinical site development grants, and fund companion efforts in preceptor and faculty development. These will be essential if the baccalaureate and community college programs are to add the kind of clinical training capacity they need in order to expand enrollments. As it has in the past, AHEC will focus these grants in underserved areas, and in specialty areas where clinical sites have historically been in short supply.

b. **Expansion of educational mobility grants.** A clear recommendation of the IOM Task Force is to expand greatly the career mobility opportunities for nurses at all levels. With additional resources, AHEC is prepared to both expand existing educational mobility grants and to develop new areas of focus. Areas where there continues to be unmet need include:

   - LPN-to-RN Programs
   - Educational Masters Degree Programs in remote site locations, in order to prepare additional faculty to fill vacancies in community colleges and universities
   - PhD Outreach Programs, in order to prepare additional faculty for baccalaureate and masters programs
   - Grants to Private Schools of Nursing, most of whom were excluded in the Legislation of 1989 creating the current grants program

c. **Retention Strategies.** Programs such as the Nurse Management Institute as well as the Magnetizing Hospital Series are designed to strengthen the working environment for nurses and improve retention. With additional resources, AHEC can provide permanent funding for these programs and similar efforts to strengthen the work environment. Programs are also needed to create skills labs for smoothing the transition from education to work, and AHEC is prepared to support the development of these programs as well.

d. **Diversity Initiatives.** Building on its prior work in health careers with young people, the AHEC Program is prepared to expand its work to the undergraduate level as well. AHEC proposes to develop a new grants program, patterned after the clinical site development grants, which would support innovative programs by community colleges and universities to recruit a more diverse student body. AHEC would offer grants to the schools to develop programs that recruit and retain more underrepresented groups, including minorities and men, into the field.

Conclusion

The AHEC Program has a long history of offering programs to improve the recruitment and retention of nurses for all types of healthcare settings in the state. As a partner organization of the NC IOM Task Force, and as part of its strategic vision for the future, the AHEC Program is prepared to build on successes of the past and develop new programs to assure that North Carolina has an abundant supply of high quality nurses to meet its needs well into the next decade. **NCMJ**

Transitioning from School-to-Work:
One Successful Model

Cindy Craven, RN, BSN, CCRN, Tammi Mengel, RN, MSN, CNAA, and Martha Barham, RN, MSN, CNAA

In the mid-1990s, the environment at High Point Regional Health System (HPRHS), like that of other healthcare organizations, was becoming increasingly complex. The healthcare team was challenged to meet the needs of a "sicker" patient, hospitalized for a shorter period of time, without compromising the quality of care delivered. Despite this increasing complexity, the orientation process for new graduate nurses remained unchanged. Orientation for a new graduate at HPRHS consisted of two weeks of general nursing orientation followed by department-specific orientation. The duration of department specific orientation varied from eight to 26 weeks, depending on the clinical specialty. Although each new graduate was assigned to a preceptor, learning opportunities and skill development were limited, as was constructive feedback. Inadequacies of the current program to successfully transition the individual from school environment to practice environment were demonstrated by the frequent need to extend the customary orientation period. This method of orientation did little to foster growth and development, especially critical thinking skills, and frustrated both the preceptor and the graduate nurse.

> *"Producing a competent, successful and happy nurse requires a partnership between nursing schools and healthcare organizations."*

At the same time, another nursing shortage was looming. Enrollment in area schools was declining and fewer student nurses were graduating. This new reality forced organizations to closely examine their recruitment and retention strategies as they positioned themselves to compete for the limited nurse resources. In examining retention effectiveness, HPRHS discovered an alarming trend related to retention of new graduates. In-depth analysis revealed the turnover rate of new graduates at 24 months was 48%. This unacceptable turnover rate was attributed directly to the stress of the transition from recent graduate to competent practitioner. As a result, in the spring of 1997, following painful open and honest dialogue between staff educators and department directors, it became clear that the current orientation process was in need of a major overhaul. The consensus was that new graduates were minimally prepared to care for patients, yet organizationally we expected an almost overnight transformation from student to expert clinician. This indeed was a very unrealistic expectation. A new program was desperately needed to support the recent graduate's transition from student to professional nurse, while reducing the level of stress experienced by the new graduate and preceptor.

Adopting a New Orientation Model

In the spring of 1997, a committee was formed, including staff educators, department directors and the Chief Nursing Officer, to create a new orientation model. To gain further understanding of opportunities for improvement, graduate nurses employed within the previous year were included in the process to provide feedback on the strengths and weaknesses of the current orientation process. Patricia Benner's "Novice-to-Expert" model provided the theoretical framework for development of the Graduate Nurse Orientation-Success in Specialty Program or GNOSIS (a Greek word meaning specialized knowledge).[1] The goals of the program were to implement an orientation process that would assist the new graduate in

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his/her transition from student to novice practioner and to improve the retention of new graduates. Additionally, it was believed that improvements in the orientation process would also positively impact the work environment by reducing the stress levels of precepting nurses and nursing colleagues.

Given the critical role preceptors play in the success or failure of an individual's orientation, adequate preparation of the preceptors was deemed essential to ensure a successful transition to the GNOSIS program. To facilitate the shift in thinking, each preceptor was educated on Benner's model. Emphasis was placed on preparing the preceptors to provide new graduates with experiences designed to develop organizational skills, set priorities, and develop critical thinking and technical skills.

GNOSIS

The ten-week GNOSIS program includes both didactic and clinical experiences. Greater emphasis is placed on clinical "hands on" learning opportunities, as this is the area in which the new graduate has the least experience. Identification of personality type and learning style was felt to be an important factor in promoting optimal learning and growth experiences and, therefore, was a new addition to the orientation process. The structure of each week consists of one classroom day focused on a specific body system or care process with the remainder of the week spent in clinical areas that will enhance the knowledge gained in the classroom. Classroom activities draw from the expertise of a variety of disciplines including staff educators, case managers, respiratory therapists, chaplains and other healthcare providers. The classes cover topics related to all clinical areas including:

- Basic patient care skills (nurse aide skills/tasks)
- Basic nursing care skills (physical assessment techniques, admission and discharge process, equipment, skills such as insertion/removal of feeding tubes, catheters)
- Basic cardiac, neurological, respiratory, renal and gastrointestinal (anatomy and physiology, assessment, commonly seen diseases, medical care, nursing care, routine orders and common medications)
- Drug administration (review of drug classes, medication administration documentation, administration techniques, use of intravenous pump)
- Wound care (wound care protocols)
- Spiritual and ethical issues
- Pain management

Clinical experiences are designed to develop and enhance skills and increase the new graduate's comfort level and confidence in the clinical setting. To ensure that new graduates have the opportunity to maximize their learning experience, they are not counted in the staffing mix. As a result, this allows new graduates an opportunity to observe and participate in experiences frequently not available to them as students such as, cardiac catheterizations, invasive diagnostic procedures and surgical cases. These opportunities assist the new graduate in understanding the dynamics of the total patient care experience and increase their exposure to the organization.

To process the events of the week, new graduates meet with the GNOSIS Program Coordinator at the end of each week and share experiences. This provides an opportunity for the entire group to learn from each other and gives them the opportunity to build relationships. New graduates value time spent in this activity as it facilitates closure to the experiences of the week, enabling them to move forward to the experiences of the coming week.

> *"GNOSIS has given the new graduate the basic skill set necessary to begin this transition and the confidence needed to function in the clinical setting."*

Department-Specific Orientation Follows GNOSIS

Once GNOSIS is completed, new graduates begin department-specific orientation. This orientation time varies based on the clinical specialty. GNOSIS has given the new graduate the basic skill set necessary to begin this transition and the confidence needed to function in the clinical setting. He or she is now able to focus on further development of organizational skills and critical thinking as applied to their clinical specialty. Preceptors acknowledge that the new graduates are better prepared to embrace departmental orientation as a result of the time spent in the GNOSIS program. Graduates of the GNOSIS program have said, "The GNOSIS program not only helped me to develop my skills, it allowed me to see what happens in other areas of the hospital that I won't be working in," and "GNOSIS gave me the time to develop my skills and put what I learned in school together with what I was learning here."

Return on Investment

In terms of financial support, the program is included in the annual operational budget and funded to cover the orientation of 36 new graduates annually. Recognizing the organization's financial commitment for operating this program, new graduates sign a three-year work agreement. Failure to complete the work agreement results in a monetary "fine" to the nurse. The requirement of a work agreement has not proven to be a deterrent to participation in the program as new graduates have recognized the value and uniqueness of this program.

Implementation of the GNOSIS program has resulted in immediate and sustained success. To-date, 22 GNOSIS sessions have been completed. Currently the turnover rate at 24 months is 22% with the majority of turnover being unavoidable, such as relocation or return to school. When asked to evaluate the program, both new graduates and preceptors continue to validate the program's success in preparing the new graduate to practice effectively in the clinical setting.

The program requires an additional human and financial commitment from HPRHS; however, this expense is easily offset by the reduction in turnover, improvements in the work environment, and satisfaction of new graduates and preceptors. One might argue that it is the responsibility of the nursing schools to produce a more qualified, capable clinician. Unfortunately, given the constraints placed on today's educational programs and the complexity of the healthcare environment, it is impossible for one entity to accomplish this lofty goal alone. Producing a competent, successful and happy nurse requires a partnership between nursing schools and healthcare organizations. In this time of nursing shortage, visionary thinking and risk taking will be necessary as strategies are developed to prepare, grow and develop the future nursing workforce. As Florence Nightingale said, "For us who nurse, our nursing is a thing, which, unless in it we are making progress every year, every month, every week, take my word for it, we are going back." Our future nursing colleagues and the public we serve are depending on us to make progress every year, every month, every week. **NCMJ**

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COMMENTARY

Advanced Practice Registered Nurses:
Current Problems and New Solutions

E. Harvey Estes, Jr., MD

The central focus of the Task Force on the NC Nursing Workforce was the chronic shortage of nursing personnel in hospitals, nursing homes and other healthcare facilities, and the steps that can be taken to alleviate and permanently correct this problem within our state. There is not a shortage of advanced practice registered nurses (APRNs), so the problems of this segment of the nursing profession might be considered tangential to or even irrelevant to the work of the Task Force. Nevertheless, practitioners of this segment of the nursing profession presented eloquent testimony to several problems which were perceived as imposing limitations on the full function and effectiveness of their practice. These are addressed in Chapter 5 of the report and in the recommendations within the chapter.

> *"The concept of collaborative practice, in which all practitioners understand and respect the abilities and knowledge of each other has merit and deserves attention..."*

Three major issues were identified: joint regulation by the NC Board of Nursing (NC BON) and the NC Medical Board (NCMB), requirement for physician supervision of practice, and unequal reimbursement for services.

Regulation

Understanding the impact of these issues requires some background review. One might presume that the scope of practice of various professional groups is precisely defined in the licensure laws of these professions. Instead, the scope of practice of the health professions, including medicine and nursing, is defined in very broad and vague terms. While this has been useful in accommodating new functions, as medical and nursing knowledge and experience has grown, it generates conflicts as these professions compete for the same functions. Licensure statutes generally prohibit the practice of that profession by those who are not duly licensed or approved as a practitioner, based on education and examination. The practice of medicine is restricted to those who are licensed as physicians by the NCMB, but there are a number of exceptions, under which physician assistants (PAs), nurse practitioners (NPs), etc., meeting specified education and examination requirements, are permitted to perform medical services under supervision of a licensed physician.

The exceptions, permitting licensed registered nurses (RNs) to perform medical acts, recognize that these practitioners are also licensed and regulated by another professional board, the NC BON. North Carolina statutes provide for a subcommittee of NCMB and NC BON, to establish rules and regulations for the function of these dual-licensed practitioners. The authority of the two subcommittees, relating to NPs and certified nurse midwives (CNMs), differ in composition and authority, in that the latter has members who are not members of either Board, and has the authority to promulgate rules and regulations which do not require approval by either of the parent boards.

This legal and regulatory framework, for all its complexity, has served the professions involved well over the past quarter century. APRNs have rapidly increased in numbers and in public respect, while permitted functions have expanded, and required documentation of physician oversight has been relaxed. Nevertheless, conflicts and friction have been encountered, as evidenced by the concerns expressed by APRNs in testimony before the Task Force. One component group of APRNs, Clinical Nurse Specialist (CNS), is not defined in the statutes, and lacks the protection of its title against use by untrained individuals who do not meet the standards of the group.

As pointed out in Chapter 5 of the Task Force report, some

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states license and regulate the practice of APRNs in a very different manner than in North Carolina. About half do not require physician supervision, and regulate practice through the nursing board alone. Some APRNs would prefer that North Carolina join this group. This action would be opposed by the NCMB, by most physicians, and their professional society, the NC Medical Society. These groups strongly favor some form of oversight by physicians.

A time honored method of resolving such differences between professions is to promote the introduction of a legislative act, changing current statutes to accomplish the new intent. This approach has inherent limitations, the most important one being that the NC General Assembly has only secondhand information about the working environment in which these conflicts arise, and the practicality of the proposed remedies. In their desire to please as many of the interested parties as possible, while still protecting the public interest, they may pass legislation which does not meet the needs of either the proposing or the opposing parties.

Instead, the Task Force recommends that the NC Institute of Medicine form another task force, with appropriate membership representing the major concerned groups, to consider these issues, and recommend action. Hopefully, if new legislation is required, it will be supported by all sides on the issue as it is discussed in the NC General Assembly.

Payment Inequities

The issue of payment inequities is not one which can be solved by this approach, as reimbursement policies are set by many parties. Medicare policies are established at a federal level, and insurance company policies are set by the individual companies. Nevertheless, the new task force may want to include this issue with the others as it discusses actions for the future.

Physician Supervision

Potential legislation to resolve the issues cited in Chapter 5 may not be the most important function of the new task force. The second issue, required physician supervision, brings with it an implied hierarchy of expertise, physician over APRN, which may or may not be accurate. One can easily envision a practice setting in which a NP may have the highest level of expertise in diabetes management, in which case it might be more appropriate that the NP "supervise" the physician. The concept of collaborative practice, in which all practitioners understand and respect the abilities and knowledge of each other has merit and deserves attention by the task force. A joint statement by the American College of Obstetricians and Gynecologists and the American College of Nurse-Midwives[1] embraces this approach, and has been helpful in resolving similar problems between these two groups. The process of discussion, seeking mutual understanding and thinking together about new directions may be the single most useful function of the new task force.

Both physicians and nurses choose to enter their respective professions in order to serve their patients. Traditionally, they have worked together to accomplish this joint purpose. I hope that the suggested new NC Institute of Medicine Task Force, if it comes about, will promote and enhance this tradition, and lead to an outcome as useful and productive as that of the most recent Task Force on the NC Nursing Workforce, whose work and recommendations are summarized in this issue of the *Journal*. **NCMJ**

REFERENCES

1 Joint Statement of Practice Relations between Obstetrician-Gynecologists and Certified Nurse Midwives/Certified Midwives. Approved by the American College of Nurse-Midwives, American College of Obstetricians and Gynecologists, October 1, 2002.

> *The American College of Obstetricians and Gynecologists (ACOG) and the American College of Nurse-Midwives (ACNM) recognize that in those circumstances in which obstetrician-gynecologists and certified nurse-midwives/certified midwives collaborate in the care of women, the quality of those practices is enhanced by a working relationship characterized by mutual respect and trust as well as professional responsibility and accountability. When obstetrician-gynecologists and certified nurse-midwives/certified midwives collaborate, they should concur on a clear mechanism for consultation, collaboration and referral based on the individual needs of each patient.*
>
> *Recognizing the high level of responsibility that obstetrician-gynecologists and certified nurse-midwives/certified midwives assume when providing care to women, ACOG and ACNM affirm their commitment to promote appropriate standards for education and certification of their respective members, to support appropriate practice guidelines, and to facilitate communication and collegial relationships between obstetrician-gynecologists and certified nurse-midwives/certified midwives.*
>
> ** Certified nurse-midwives are registered nurses who have graduated from a midwifery education program accredited by the ACNM Division of Accreditation and have passed a national certification examination administered by the ACNM Certification Council, Inc.*
>
> *Certified midwives are graduates of an ACNM Division of Accreditation accredited, university affiliated midwifery education program, have successfully completed the same science requirements and ACNM Certification Council, Inc. national certification examination as certified nurse-midwives and adhere to the same professional standards as certified nurse-midwives.*
>
> *Approved October 1, 2002*
> *American College of Nurse-Midwives*
> *American College of Obstetricians and Gynecologists*

COMMENTARY

North Carolina Center for Nursing and the Nursing Workforce

Brenda L. Cleary, RN, PhD, FAAN

The NC General Assembly created the NC Center for Nursing in 1991 "…to address issues of supply and demand for nursing, including issues of recruitment, retention, and utilization of nurse resources. The mission of the Center for Nursing is to assure that the State of North Carolina has the nursing resources necessary to meet the healthcare needs of its citizens." Legislatively mandated goals include:

1. To develop a strategic statewide nursing workforce plan for North Carolina, addressing issues of supply and demand.
2. To convene various groups that include representatives from nursing, other healthcare professions, the business community, consumers, legislators, and educators to review the policy implications of the Center's work.
3. To enhance and promote recognition, reward and renewal activities for nurses in North Carolina, through a comprehensive statewide recruitment and retention program.

Since its inception, the NC Center for Nursing (NCCN) has become a model for the nation, as more states take a long-range strategic view of nursing workforce issues. We have amassed a comprehensive database on state-level nursing supply and demand. We developed winning recruitment and retention materials and initiatives that are being adapted throughout the country. In addition to a primarily politically appointed Board of Directors, we have an Advisory Council of over 50 stakeholders in nursing and healthcare who inform the work of the Center. In recent years, we received a grant from The Robert Wood Johnson Foundation to partner with the NC Area Health Education Center Program on workforce planning activities and a related grant from the Helene Fuld Trust to support articulation among North Carolina's nursing education programs and enhance educational mobility for North Carolina nurses.

While the NC Center for Nursing has the most comprehensive state-level database on nursing supply and demand, this information becomes more powerful when it is used not only to guide workforce planning efforts, but also to directly influence policy. Having served as a member of the NC Institute of Medicine (NC IOM) since 1996, I have come to admire and appreciate the effective process of the Institute in studying relevant issues and making thoughtful health policy recommendations. I was very enthused when early planning efforts developed to pursue a partnership with the NC IOM and other key stakeholders to address nursing workforce issues. Other NCCN staff and members of our Board of Directors quickly became engaged in this important evolution of our work.

Immediately preceding the early discussions of convening a statewide Task Force on the nursing workforce, NCCN convened forums in conjunction with the NC Nurses Association (NCNA) and the NC Board of Nursing (NC BON) in every Area Health Education Center (AHEC) region of the state. The purpose of these nine forums was to allow local stakeholders to weigh in on strategies to strengthen the state's future nursing workforce.

I will use the major themes emanating from the regional forums as a framework to tie in emerging priorities with the recommendations of the Task Force on the NC Nursing Workforce in order to note the progress we are making, as well as to identify some challenges that lie ahead.

> *"The Task Force on the NC Nursing Workforce took painstaking efforts to examine nursing education issues in terms of both quality and quantity, as reflected in several Task Force recommendations."*

Brenda L. Cleary, RN, PhD, FAAN, is Executive Director for the NC Center for Nursing and a member of the Task Force on the NC Nursing Workforce. She can be reached at bcleary@ga.unc.edu or 222 N. Person Street, Raleigh, NC 27601. Telephone: 919-467-5132.

Greater Collaboration between Nursing Education and Practice

Nursing is an applied science and discipline. However, at times it seems that there are separate "silos" of nursing education systems and nursing care delivery systems. Through a collaborative effort of NCCN and AHEC funded by the Robert Wood Johnson Foundation, regional and state planning alliances of leaders in all types of nursing education programs and major nursing practice settings were formed. In discussions of how to disseminate and implement Task Force recommendations, Task Force members recognized the need for these relationships to be sustained. Leaders in nursing service should be more integrally involved in curriculum development and nursing educators should be grounded in the practice arena through joint appointments and other arrangements. Clinical preceptor models will become increasingly important, owing to faculty shortages.

Better Preparation of New Nursing Graduates in Critical Thinking, Time Management, Accountability, Interpersonal Skills, and Leadership Abilities as well as Hands-on Clinical Skills

Strengthening meaningful collaboration between nursing education and service also relates to this priority. The Task Force on the NC Nursing Workforce took painstaking efforts to examine nursing education issues in terms of both quality and quantity, as reflected in several Task Force recommendations. The NC BON is facilitating significant work in this area with their recent focus on the congruence between education and practice.

The Need for a Formal Transition from School to Work

The Task Force addressed this looming issue in a free-standing recommendation, acknowledging that it was a challenge that belonged to both nursing education and the nursing service sector. In my Robert Wood Johnson Executive Nurse Fellowship project, I am focusing on ways to increase the number of master's prepared nurses in direct patient care who can provide clinical leadership to nurses with varying levels of preparation in order to improve patient outcomes and cost-effectiveness; who can help patients and families navigate the complexities of today's healthcare system; and who can mentor new graduates, thereby reducing healthcare errors and decreasing nurse turnover. Key staff from NCCN are collaborating with key staff at the NC BON and the NC BON Foundation to develop a proposal for a more standardized internship/residency for every North Carolina nursing graduate. We will seek external funding to pilot proposed models.

Support for Better Articulation and Access in Nursing Education

There are four Task Force recommendations related to enhancing educational mobility options that are so important in a profession that offers multiple pathways to initial licensure as a Registered Nurse (RN). Associate degree curricula that include transferable courses, articulation agreements, a common core of course requirements at the baccalaureate level, as well as a statewide RN-to-BSN Consortium are all recommendations that are derived from the work of the Statewide Steering Committee on Articulation in Nursing Education, convened by the Center for Nursing. These actions will not only reduce barriers and duplication for nurses pursuing additional education, but also offer promise in terms of sharing faculty and other resources across nursing education programs. Resource sharing will become more critical than ever in ensuing years, with tight budgets and faculty shortages. We will also need to continue to look at better career pathways for qualified Licensed Practical Nurses (LPNs) and Nurse Aides (NAs) as the demand for RNs skyrockets. Finally, as reflected in the Task Force report, we need to reach more men as well as racial and ethnic minorities, with the aim of doubling their numbers entering the RN workforce by 2010.

Address Capacity of Nursing Education, with Emphasis on Faculty Resources

The Task Force recommendations regarding nursing education address funding of nursing programs, financial aid for nursing students, and other means of strengthening the quantitative and qualitative dimensions of the capacity of our nursing education programs. Pass rates on licensure exams among NC nursing graduates are higher than national averages. However, of special concern to NCCN, in light of our mission, is the number of students we lose prior to graduation through attrition, a factor limiting our educational capacity that was illuminated in the NC Center for Nursing's survey of nursing education programs in North Carolina. The California Community College System has developed a research-based model for predicting success of applicants to nursing education programs. This work may be relevant for our own community colleges as they study the relationship between admission policies and graduation/attrition rates as recommended by the Task Force. The recommendation on enhancing support services is also very important as success in nursing school nearly always involves an interaction of multiple variables and not simply academic attributes. Funding for the Faculty Fellows Program will be a significant step in addressing an evolving faculty shortage. But we must also look further at non-traditional methodologies for delivering nursing education, as represented in the recommendation for expansion of distance learning and on-line formats, as well as in prior discussion in this commentary regarding sharing resources.

Healthier Workplaces: Magnet Principles and Other Healthy Workplace Models

The Task Force on the NC Nursing Workforce built on the previous work of the Professional Practice Coalition convened by the NC Nurses Association as well as joint efforts of NCNA and the NC Hospital Association in empowering nurses and creating healthier workplaces. As an appraiser for the American Nurses Credentialing Center Magnet Recognition Program, I have witnessed the synergy that occurs with strong nursing leadership and governance, nurse satisfaction and retention, and the ability to enhance patient outcomes and satisfaction.

Innovative, Cost-effective Strategies to Reduce Nurse Workload and Paperwork

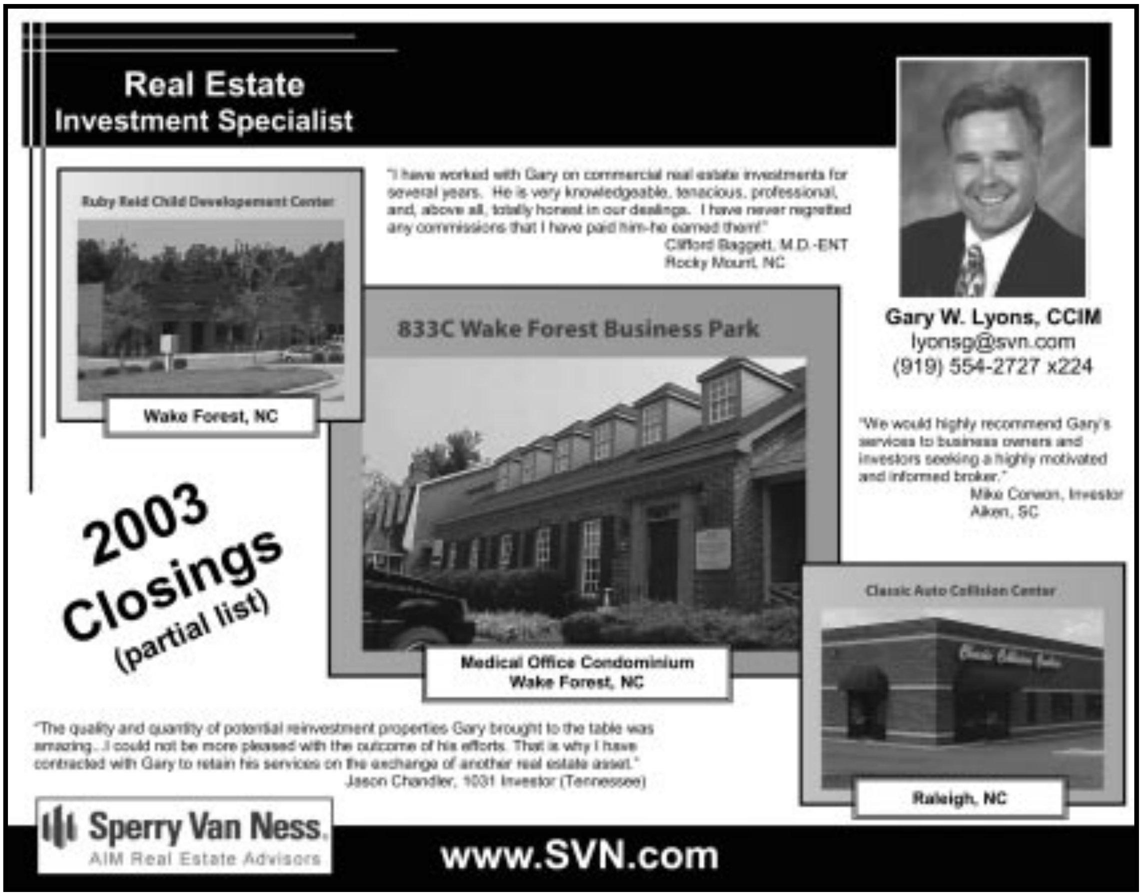
A survey of staff nurses conducted by NCCN in 2001 revealed an increasing paperwork burden. This paper work burden was perceived by nurses to be up an average of six percent from the previous year. Just as we need to enhance the use of technology in education, we need to streamline patient care with point of care data entry systems and other innovations that improve safety and accuracy while saving time and energy. The NCNA House of Delegates has resolved to look at these issues further.

Better Understanding and Management of the Effects of Staffing, both in Terms of Numbers and Credentials, on Patient Outcomes

Dr. Sean Clarke of the University of Pennsylvania described the work of a team of researchers led by Dr. Linda Aiken to the Task Force. The research he described, which needs further replication, used large sets of patient data to look at the impact of staff mix (RNs, LPNs, NAs) as well as the educational preparation of the RNs in the staff mix on surgical mortality and failure to rescue. Findings reveal that having a higher ratio of the RNs in the staff mix and more RNs with baccalaureate and higher degrees lowers mortality and failure to rescue rates. These kinds of findings and the increasing complexities of healthcare support movement toward a more educated workforce.

Nursing workforce issues are complicated issues and many challenges lie ahead. Fortunately, this great state brings multiple strengths to the table. Our more than 100-year professional nursing history, since the very first nursing license in the country was issued here in 1903, is a story of courage, fortitude, and innovation. We have not suffered from the recent much more dramatic shortages that have plagued other states. This reflects a track record of the willingness of multiple stakeholders to work strategically together and to take the long view toward a healthier future for all North Carolinians. **NCMJ**

The North Carolina Center for Nursing provides seed grants to assist hospitals, health departments, schools of nursing and other healthcare related agencies in creating innovative programs to recruit and/or retain people in the nursing profession. To learn more about the Center's Recruitment and Retention Grant Program, visit www.nursenc.org.



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Mental Health Reform

To The Editor:

Thank you for dedicating a recent issue to a discussion of mental health reform in North Carolina. While waving the flags of lower costs and better services, politicians and administrators in state government are radically changing the mental health delivery system. The Department of Health and Human Services is reducing the number of hospital beds for severely mentally ill; thereby, forcing these patients to seek treatment, if they so choose, from private or community resources. At the same time, the administration is pushing local communities to reduce direct service and hire private providers to meet the needs of the mentally ill, developmentally disabled, and substance abuse patients. Doctors Marvin Swartz, Joseph Morrissey, and Nicholas Stratas have written extensively of the numerous problems with proposed reforms. It strikes me that these problems encompass three primary areas with financial concerns at the heart of each.

First, there are limited numbers of well-trained private clinicians who can offer wide-ranging multidisciplinary services to the targeted population. I suspect only a small fraction of this population of clinicians will be willing to provide services for reimbursement typically offered by the government. And which of these clinicians will cooperate with quality assurance requirements (assuming the state will demand and measure quality service)?

Second, community resources either don't exist, are grossly inadequate, or severely under-funded. Alternative treatment services are simply unavailable in many areas. And don't underestimate the confusion and diffusion of responsibility that will occur when two areas or counties argue over which is responsible for treating a particular patient. In addition some patient care providers working in community as well as state facilities have sought employment elsewhere because they are fearful of losing their jobs as a result of the state's plans to "reform" the mental health system.

Third, under the state's plans, patients and family members will face one more hurdle in seeking treatment since the facilities where they have been treated will not provide direct services. They will be directed elsewhere. One can only guess how much support and guidance these persons will receive as they navigate the "reformed" system. And one can only guess about the financial concerns and questions these persons will have when they are sent to private providers. Indeed, this assumes that the patient makes a rational decision to continue to pursue treatment at another time, in another place, from another provider, and while facing uncertain financial responsibilities.

Many letters and articles highly critical of the state's mental health "reform" have been printed. It is unfortunate how timely and prescient those admonitions have been. A few weeks ago a store in Raleigh was robbed and police were called. A man scuffled with them and bystanders and reached for a policeman's pistol. The man was subdued but then dropped dead. Police officers and rescue personnel made heroic efforts, but the lives of all involved were forever altered. We later learned the man was mentally ill, not taking medications or receiving treatment, abusing cocaine, and a danger to himself and others. To complicate matters even further, there had been some sort of dispute between two counties centering on whether and how to have this individual committed.

In the past this man may well have been readily committed to a state psychiatric hospital; his illness stabilized, and he and the public protected from harm. Today there are fewer hospital beds and limited community resources available to treat the mentally ill, and patient care providers are leaving the system. Those that remain in the system face the impossible task of providing quality care with fewer resources. Sick, vulnerable people are being denied appropriate care. If the state has its way, the future may hold for us more senseless crime, violence, homelessness and death. And we'll be reading and hearing more tragic stories involving the mentally ill and developmentally disabled.

Charles L. Johnson Jr., PhD
Clinical and Clinical Neuropsychology
Cary, NC

"Today there are fewer hospital beds and limited community resources available to treat the mentally ill, and patient care providers are leaving the system."

Running the Numbers

A Periodic Feature to Inform North Carolina Healthcare Professionals
About Current Topics in Health Statistics

From the State Center for Health Statistics, North Carolina Department of Health and Human Services
www.schs.state.nc.us/SCHS

2002 North Carolina Live Births Attended by Certified Nurse Midwives

Deliveries attended by a Certified Nurse Midwife (CNM) are increasing rapidly in the United States and in North Carolina. In 2002, there were 307,527 CNM-attended live births in the United States, accounting for 7.6% of all live births.[1] Since 1983 when the North Carolina legislature passed the "Midwifery Practice Act" making CNMs legal birth attendants, the percentage of resident live births attended by CNMs has risen dramatically. In 1983, CNMs attended less than 2% of all live births; by 2002 CNM-attended births had risen to 9.2%, or more than 10,800 births in the year (Figure 1).

Table 1 shows demographic characteristics, risk factors, and birth characteristics for CNM-attended deliveries compared to all North Carolina resident live births.

Demographic Characteristics

Mothers with CNM attendants were more likely to be unmarried, have less than a high school education, and to have received WIC (a program which provides nutritional assistance to low-income mothers) while pregnant. Under Title XIX of the Social Security Act, state Medicaid programs are required to cover CNM services. In 2002, 43% of CNM-attended births in the state were covered by Medicaid, compared to 42% of all live births. Women whose delivery was attended by a CNM were slightly less likely to be of a racial minority and a little more likely to be a resident of a rural region. This may be related to the fact that CNM-attended deliveries were more prevalent in the Western portion of the state where the minority population is smaller and the rural population is larger.

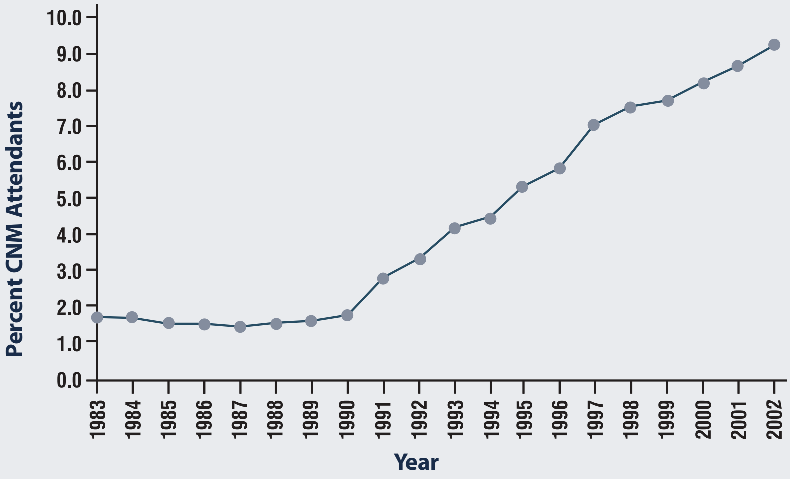
Risk Factors

Mothers with CNM birth attendants were more likely to report smoking during pregnancy and receiving late (after first trimester) or no prenatal care, compared to all live births. In addition, women attended by CNMs were more likely to give birth outside a hospital setting (2.5% vs. 0.5% for all live births). CNM-attended deliveries were less likely to have medical risk factors recorded on the birth certificate (27%) compared with all live births (30%). In addition, CNM-attended deliveries were much less likely to involve twins, triplets, or other multiple births.

Birth Characteristics

Nearly all CNM-attended births (99%) were vaginal deliveries compared to 73% of all North Carolina live births. CNMs used obstetrical procedures such as ultrasound, electronic fetal monitoring, or stimulation of labor to aid delivery at about the same rate as other attendants (97-98%). Approximately 28% of CNM-attended deliveries had one or more labor or delivery complications reported on the birth certificate compared to 36% of all live births. Infants delivered by CNMs were less likely to be of low birth weight (less than 2500 grams). In 2002, 4.3% of

Figure 1.
1983-2002 North Carolina Resident Births: Percent with Certified Nurse Midwife Attendants



CNM-delivered babies were low birth weight, compared to 9.0% of all live births. This is likely to be related to their lower medical-risk clientele.

It should be noted that the quality of the attendant data on the North Carolina birth certificate has not been assessed. CNMs have expressed uncertainty regarding the validity of the coding of the delivery attendant on the birth certificate. A survey conducted in 1993 by the American College of Nurse Midwives found that 6% of the deliveries CNMs attended were not attributed to them.[2] Also, continuity of care cannot be assessed from the birth certificate attendant data. For example, a woman may have received all of her prenatal care with a CNM, but if a labor complication led to a cesarean section, the delivery would be attributed to a physician. Thus, some poor birth outcomes associated with delivery complications may be recorded as physician-attended deliveries, even though a CNM provided the prenatal care.

Table 1.

2002 North Carolina CNM-Attended and Total Resident Live Births by Demographic Characteristics, Risk Factors, and Birth Characteristics.

	CNM Attendant		Total Live Births	
	Number	**Percent**	**Number**	**Percent**
Total Births	**10,840**	**9.2%**	**117,307**	**100.0%**
Demographic Characteristics:				
Minority race	2,775	25.6%	32,190	27.4%
Hispanic	1,410	13.0%	15,063	12.8%
Maternal age less than 18	527	4.9%	4,890	4.2%
Less than a high school education	2,728	25.2%	26,652	22.7%
Medicaid	4,704	43.4%	48,833	41.6%
Received WIC during pregnancy	4,899	45.2%	45,820	39.1%
Resident of rural region	6,141	56.7%	64,235	54.8%
Unmarried	4,035	37.2%	40,646	34.6%
Risk Factors:				
Maternal medical risk factors[a]	2,954	27.3%	35,179	30.0%
Mother smoked	1,603	14.8%	15,440	13.2%
Late/no prenatal care	1,915	17.7%	18,236	15.5%
Delivered outside a hospital	267	2.5%	540	0.5%
Multiple birth	55	0.5%	3,880	3.3%
Birth characteristics:				
Vaginal delivery	10,749	99.2%	85,811	73.2%
Obstetrical procedures[b]	10,623	98.0%	113,632	96.9%
Delivery complications[c]	3,080	28.4%	42,446	36.2%
Low birth weight (< 2500 grams)	464	4.3%	10,550	9.0%

[a] Includes pre-existing maternal medical problems such as anemia, diabetes, & hypertension as reported on the birth certificate.
[b] Includes procedures such as ultrasound, electronic fetal monitoring, & stimulation of labor as reported on the birth certificate.
[c] Includes delivery problems such as breech , fetal distress, and long labor as reported on the birth certificate.

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2. Walsh, LV, Boggess JH. Findings of the American College of Nurse-Midwives Annual Membership Surveys, 1993 and 1994. *J Nurse Midwifery* 1996: 41: 230-5.

Contributed by Kathleen Jones-Vessey, MS
State Center for Health Statistics, North Carolina Division of Public Health

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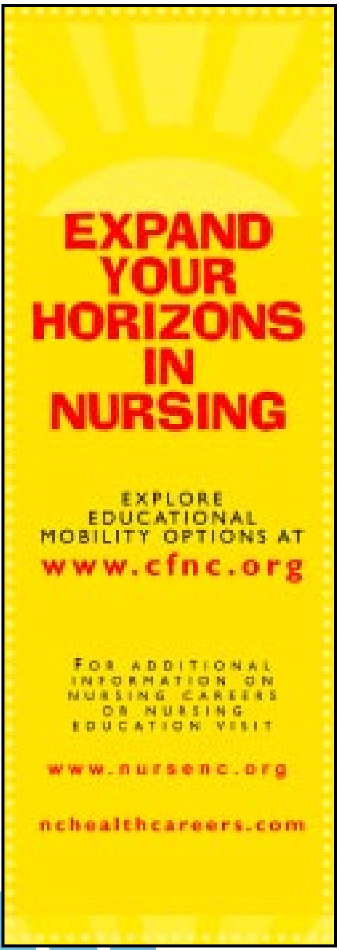

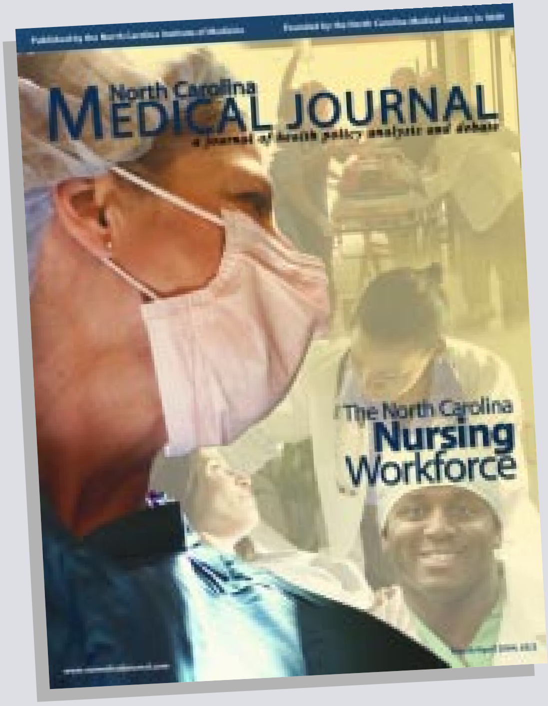

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Members of the NC Institute of Medicine are appointed for five-year terms by the Governor, and each task force convened by the Institute typically includes at least one-third of its membership from among the appointed members. Topics to be addressed through task force efforts are chosen following requests from the Governor, the General Assembly or agencies of state government. In some cases, topics are selected on the basis of requests from a number of stakeholder organizations across the state where this type of analytical process is considered to have potential value.

The NC Institute of Medicine assumed the role of publisher of the *North Carolina Medical Journal* in January 2002 when the North Carolina Medical Society reached the decision to cease support for its publication. The Institute views the *North Carolina Medical Journal* as an extension of its mission. The *Journal* provides a forum for stakeholders, healthcare professionals, and policy makers and shapers to study and discuss the most salient health policy issues facing our state. Like many states, North Carolina is grappling with issues such as an increasing number of uninsured, the unmet health needs of the growing Latino population, a critical shortage of nursing personnel, the health risks of tobacco and obesity, rising prescription drugs costs, mental health system reform, the increasing societal burden of chronic illness care, the threat of bioterrorism and the necessity of assuring adequate public health preparedness—all in the midst of an economic downturn. Each of these issues presents unique challenges to healthcare providers and state policy makers. Yet, a fully implemented task force to consider each of these sets of issues is not feasible. The *Journal* makes it possible to present an organized and balanced overview of some of these issues, six times per year, and allows interested persons the opportunity to engage in the ongoing discussion of these issues throughout the year. The Institute hopes that our readers of the *Journal* will, in this way, become involved in the continuing debate about the most promising avenues for assuring the highest standards of health and healthcare for all North Carolinians.

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While medical researchers in North Carolina have many journals to which they can submit their manuscripts, we want them to consider keeping their work here at home. To be more specific, we invite the authors of our state to submit their papers to the *North Carolina Medical Journal*.

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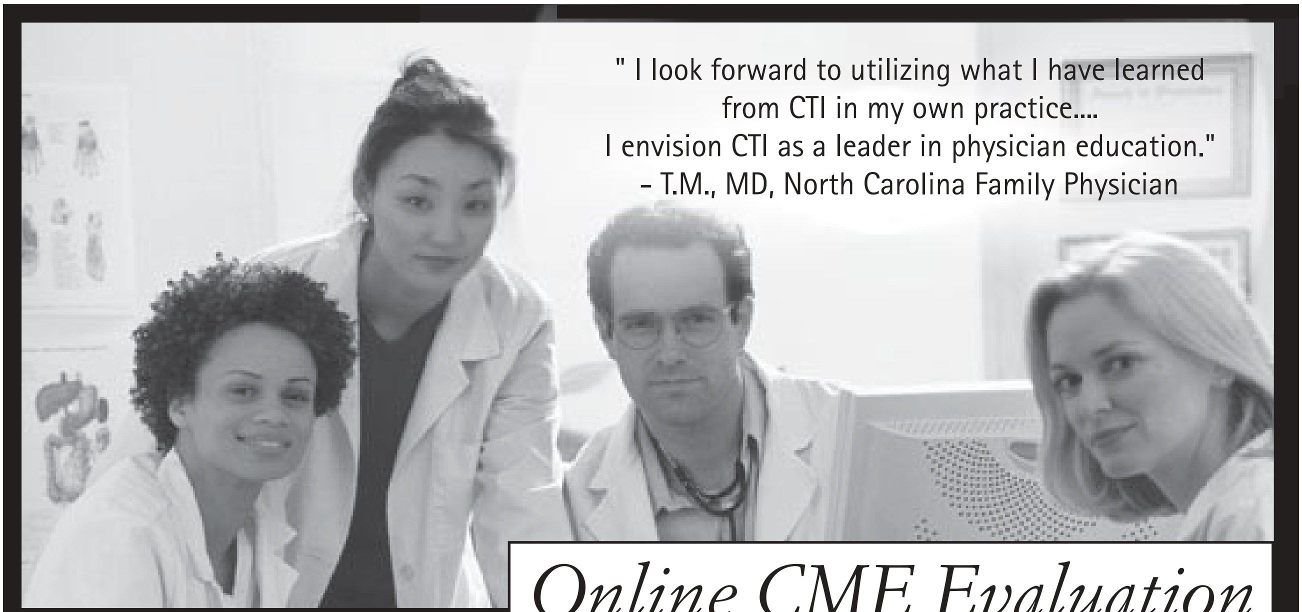

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FOR THE LITTLEST PEOPLE.

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It will be like no other facility in the area, offering you services you won't get anywhere else.

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The plans are big. For our littlest patients.

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Fifty years ago, Americans joined together to help the March of Dimes fund polio research. Your generosity led to the vaccines that have saved generations of children. Today a new epidemic threatens our babies—premature birth. Each year more than 460,000 are born premature. It's the leading cause of newborn death and many disabilities. Please go online to help us raise research funds. Together we can find the answers that will save premature babies.

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North Carolina MEDICAL JOURNAL

a journal of health policy analysis and debate

Infant Mortality in North Carolina

A New Perspective on a Persistent Problem

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March/April 2004, 65:3

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A partnership that's working for eastern North Carolina

Kinder, gentler heart surgery

A sophisticated robotic device has helped cardiothoracic surgeons take the heartache out of mitral valve repair. Surgeons associated with the Brody School of Medicine at East Carolina University and the Cardiovascular Center at University Health Systems of Eastern Carolina have developed and perfected a minimally invasive procedure that uses the da Vinci™ Surgical System to repair mitral valve defects. This technique reduces trauma and pain and allows patients to recover faster.

The first multi-center clinical trial, which led to FDA approval of the procedure, was supervised by Dr. W. Randolph Chitwood, Jr., director of the Cardiovascular Center in Greenville. The Center now trains physicians from around the world to perform mitral valve repair using the da Vinci system. The Brody School of Medicine and University Health Systems are making things happen — in the region, in the state and in the world.

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fittogether

Fit Together Launched for a Healthier NC

As medical professionals you see the evidence every day – the Centers for Disease Control and Prevention report that 27 percent of North Carolina high school students are overweight or at risk of being overweight and more than half of North Carolina adults are overweight or obese.

In April, Blue Cross and Blue Shield of North Carolina and the N.C. Health & Wellness Trust Fund Commission announced a $4.5 million comprehensive statewide campaign to battle obesity and promote healthy lifestyles.

A study in the Journal of the American Medical Association reports that obesity can cut 20 years off the expected life span of young people. Some public health experts believe that the coming generation of adults may have a shorter life expectancy than the current generation if current trends do not change.

The Fit Together partnership is designed to help create a climate of change. The good news is that simple steps, such as regular, moderate physical activity, can improve health. That can mean something as easy as yard work, family walks or playing outdoors.

There are many innovative initiatives already underway in communities across our state. Fit Together will serve as a clearinghouse for information about obesity and "best practices" in obesity programs across North Carolina. And Fit Together will include a three-year public education campaign. We all know that obesity is becoming a health crisis; now we have to help North Carolinians create healthier habits.

As the state's largest health insurer, BCBSNC has made tackling obesity a top corporate priority. In the coming months, we will be announcing new services for our members designed to prevent and treat obesity and tools for medical professionals so you can help your patients improve their physical activity and nutritional habits.

We will be announcing more details about Fit Together soon, including a television ad campaign, an awards program and a Web site. We invite you to share information about programs in your area that could help us overcome obesity and to start the conversation with your patients today.

For more information about Fit Together or to share information about successful programs in your community, e-mail us at **feedback@fittogether.org**.

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ARTICLE

POLICY FORUM: *Infant Mortality in North Carolina: A New Perspective on a Persistent Problem*

COMMENTARIES

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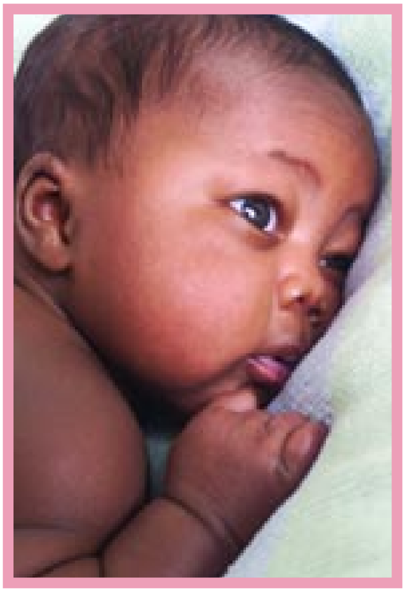

"Blessed with superb medical facilities and a reputation for advanced healthcare planning, our state has perennially ranked among the worst in rates of infant death among all 50 states."

Demand for Continuing Medical Education Programs on Cancer Care Among Primary Care Physicians in North Carolina

Roger T. Anderson, PhD, Kathleen Dziak, BA, Jeffery McBride, MA, MBA, Fabian Camacho, MS, Anita C. Hege, MPH, and Frank M. Torti, MD

Abstract

Background: *Primary care physicians have a central role in cancer prevention and control services, yet relatively little attention has been given to their needs for continuing medical education (CME) that clarify or update screening guidelines, enhance recognition of signs or symptoms of cancer, and address ongoing health issues in patients treated for cancer (e.g., pain control, lymphedema, tertiary prevention).*

Methods: *A random sample of 600 primary care physicians practicing in urban and rural locations in North Carolina was selected to assess past cancer-related CME sessions, and demand for current cancer education topics.*

Results: *Of 539 eligible, 231 surveys were returned (43%). Approximately 37% of respondents had attended no cancer-related CME in the last two years. Highest interest for cancer CME topics was found for screening for breast and skin cancers, general update diagnostic skills, pain management and patient/family support, side effects from treatment, lymphedema management and lymphedema diagnosis, genetic susceptibility, diet and smoking cessation. Interest levels by CME topic did not vary by urban/rural practice settings.*

Conclusion: *There is low access but high demand for cancer-related CME topics among primary care physicians. Strategies are needed to fill this need and to assess impact.*

Keywords: *cancer screening, CME, primary care.*

Introduction

Cancer is an increasingly common diagnosis and cause of death nationally among adults. In North Carolina, one in every two men and one in every three women will be diagnosed with cancer during his or her lifetime. The economic costs of cancer care and impact to families in North Carolina are estimated at $2.9 billion annually.[1] Primary care physicians occupy an important position in delivering effective and high quality care for cancer prevention and control, through screenings, referrals, patient education, and, for those treated for cancer, coordinating longer-term disease management. For cancer prevention, guidelines for early detection through routine screening have been established for breast, cervix, colon, and prostate cancers conditioned on considerations of patient age and known risk status.[2-8] However, evidence exists that life-saving prevention, early detection, and control may not be carried out even when beneficial support is overwhelming.[9] Reasons for this gap are complex, but potential confusion over cancer screening detection policy from a lack of uniformity in type and interval screening specifications among the various medical professional organizations guiding primary care has been cited as important.[7] At the same time, technology for cancer screening is advancing as genetic markers and new immunologic assays replace traditional tests, potentially adding to the complexity of obtaining and interpreting the screen for the patient. For patients with a history of cancer, the primary care physician may play a pivotal role by leading the patient's general health maintenance (in the context of a cancer history) and promoting the prevention of recurrence. Physician education in comprehensive, state-of-the-art cancer prevention and detection and health maintenance is therefore central to delivering effective cancer screening and prevention services.

Keeping abreast of new developments in cancer prevention

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Kathleen Dziak, BA, and **Jeffery McBride, MA, MBA**, served as research assistants in the Department of Public Health Sciences, Wake Forest University School of Medicine.

and control can be a challenge for primary care physicians (PCPs).[10] Many physicians rely on formal continuing medical education (CME) courses to provide information. There are a number of formats by which physicians receive CME credit (e.g., didactic, large or small discussion groups, workshops, internet access, etc.). Each format has strengths and/or weaknesses.[11-14] There is a growing body of literature regarding which type of CME format primary care physician's prefer[15-17] and which patient care topics physicians seek most.[18] However, in the area of cancer control, no studies have been published on PCP interest or need for CME programs for primary care providers despite the fact that cancer is a leading chronic disease with formal best practice recommendations for screening[19] and vigilance. Given competing community resources for educational programs to fulfill category 1 credit requirements and the availability of funds to attend such sessions, the most effective cancer CME programs are likely to be those meeting the demand and interest of the intended physician audience.

In North Carolina, an Advisory Committee on Cancer Coordination and Control (NCACCC) has been established to develop and coordinate a comprehensive cancer control plan for the state.[20] A centerpiece of the committee's strategy is collaboration with primary care systems and medical associations to identify resources needed to promote cancer prevention and control. To meet this objective, this study was conducted to assess demand for cancer care and treatment CME in both urban and rural areas of the state. This report: **1**) describes interest levels in the four distinct aspects of cancer-related healthcare services: screening, diagnosis, treatment, and follow-up care by physician characteristic and patient groups served; and **2**) examines the preferred method of accessing a cancer-related CME program.

Methods

A sampling frame was assembled of all primary care physicians listed on the North Carolina Physician Roster, and grouped according to urban and non-urban area using the North Carolina Data Center designations of metropolitan place names.

The survey was designed to collect data on screening, diagnosis, treatment, follow-up care, and preferred method for receiving CME on cancer related topics. A 66-item needs assessment survey was developed by study collaborators at the Wake Forest University School of Medicine (WFUSM). The prototype instrument was pre-tested at WFUSM among physicians in the gynecology and primary care clinics and reviewed for content. New items were generated from content review and physician feedback. Modifications to the survey were finalized and approved by the NCACCC office. The final format included content areas in the following cancer care and prevention topics: cancer prevention and risk factor reduction, screening and interpreting test results, diagnostic techniques, treatment options and prognosis, and follow-up care to surgery. A survey sample of 300 physicians was selected per urban and non-urban grouping (N=600). The sample was mailed a questionnaire with a postage-paid return mailer. Returned and completed surveys from the initial mailing were tracked and a replacement survey was sent after a two-week non-response period. After the second mailing, telephone calls were placed to the physician's office when the phone numbers were available in the listing. Arrangements were made with office staff to deliver a faxed copy of the survey.

Data analysis was performed to describe means and proportions of the survey category responses. Tests of significance were performed using two sample t-tests with pooled variance estimates, and judged to be significant at $p < .05$ without correction for multiple comparisons. To describe CME topics of most interest, ratios of 'very interested' (VI) to 'not at all interested' (NI), were calculated as VI/NI. This ratio served as a means of ranking CME topics in terms of strong preference (or demand) among items in the case where there may be considerable variability in interest for the topics considered. For example, a topic where 30% of respondents are 'very interested,' 40% are 'interested' and 30% are 'not interested' (30/30 = 1) has much less widespread appeal than a topic with interest ratings of 30%, 60%, and 10%, respectively (30/10=3). In the former case the number of respondents who desire the CME topic is balanced by the number who have no interest at all, whereas in the latter, the CME topic is appealing to most. Thus, a ratio larger than 1 indicates more interest than disinterest for the topic; a ratio below 1 suggests that high level interest may be specific to subgroups, such as practice type. Tests of significance were performed on the logarithms of the demand ratios, using asymptotic statistics described in Agresti.[21] The null hypothesis in this case was that the logarithm of the demand ratio is equal to 0 (so that the demand ratio is equal to 1).

Results

Survey Return Completion Rate

Removal of invalid addresses (N=21) and non-practicing physicians (N=40) resulted in a final sample size of 539 physician names. Of these, 97 (18%) initial mailings were returned, with a replacement survey being sent after a two-week non-response period yielding 54 additional responses (10%). After the second mailing, telephone calls were placed to the physician's office when the phone numbers were available in the listing. Arrangements were made with office staff to deliver a faxed copy of the survey resulting in another 80 (15%) completed surveys for a cumulative total of 231 (43%) surveys completed and returned.

Physician Profile

The physician mean number of years in practice was 16.6 years (±12) and the provider mean age was 48.2 years (±11). As shown in Table 1, approximately 48% of physician respondents classified themselves as family medicine, 27% internal medicine, 20% gynecological, and 4.5% as other. Most respondents were male (89%), with a majority serving rural group practice settings (55%). Survey respondents estimated that more than one-third of their patients were smokers (34%) and nearly one-third (32%) had an estimated income below $20,000 per year.

Table 1.
Respondent Physician Profile: Gender, Type of Practice, Type of Specialty, Patient Population Served, and Estimated Population Low Income/Underserved

Category	Sub-Category	N (%)
Gender	Female	(11.1)
	Male	(88.9)
Practice	Private	(21.3)
	Group	(71.0)
	Other	(07.7)
Specialty	Family Medicine	(48.4)
	Internal Medicine	(26.9)
	Gynocology	(20.2)
	Other	(04.5)
Patient Population/Service area	Urban practice	(44.6)
	Rural	(55.4)
Estimate of low-income/Underserved	Patients with income < $20,000	(31.7)
	Patients with high school diploma	(24.3)
	Current smokers	(34.1)

A substantial proportion of physicians, nearly 37%, had not attended any cancer-related CME sessions in the past two years, and only 22% indicated attending one session (see Table 2).

Table 2.
Continuing Medical Education: Number of Sessions Physician Attended in Past Two Years

Number of Sessions	Percentage
0	36.9%
1	21.7%
2	15.2%
3	12.0%
4+	14.7%

CME Interest

Table 3 summarizes physicians' interest in participating in cancer-related CME topics. The highest interest in the *Screening* category was in general screening, with 58% being 'very interested.' For the *Diagnosis* and *Treatment* categories, 47% of primary care physicians surveyed were 'very interested' in a general update of diagnostic skills and 35% were 'very interested' in side effects from treatment for follow-up care. For cancer *Prevention* topics, 53% of physicians were 'very interested' in methods to identify and address high risk.

Demand ratios

In Table 4, the item response, or 'demand,' ratios show that within the *Screening* CME topic category, general screening (23.12), breast (7.63), and skin (3.67) drew highest levels of interest (demand), while colonoscopy (0.47) exhibited lowest interest. In the *Diagnosis* and *Treatment* topic categories, general update diagnostic skills (8.12), pain management (4.49) and patient/family support (3.28) were reported to be of high interest, while research protocols (0.53) had the lowest interest. The highest interests in *Follow-up care* were side effects from cancer (3.35), side effects from treatment (2.72), long-term follow-up (1.88), lymphedema management (1.20) and lymphedema diagnosis (1.05), while lowest demand was therapist availability (0.92). For *Risk factor prevention* and *Risk reduction* topics, genetic susceptibility (4.04), diet (2.97), and smoking cessation (2.45) showed highest interest, while sun exposure (1.08) exhibited comparably lower interest.

There were no statistically significant differences in CME interest and demand proportions by urban/non-urban practice location (data not shown). For medical specialty type (Table 4), family medicine practitioners had a statistically higher ($p < .05$) level of interest in pain management, general prevention, and long-term follow-up of patients treated for cancer. Obstetrics/gynecology practitioners had significantly higher interest in CME topics addressing breast, cervical and ovarian cancer screening, and genetic susceptibility than either internists or family practice physicians.

As shown in Table 5, the preferred method of accessing a cancer-related CME course/program was by in-person lecture (63%), rather than a video-conference or lecture format (6%), which was not favored. In terms of sponsorship, the Area Health Education Centers (AHECs) were viewed as the most favorable mode of sponsorship (37%). Finally, 23% of physicians reported a 'very favorable' attitude toward accessing a CME session over the Internet.

Discussion

This study found a high interest for CMEs focused on selected cancer topics for primary care providers. Further, self-reported attendance at formal CME sessions targeting cancer care was not high, with more than one-third (37%) attending no sessions in the past two years.

Most interest was reported for CME information relating to screening for breast, ovarian, skin and prostate cancers, all of which are highly relevant to primary care and have guidelines for screening that are evolving through evidence-based medicine. Also of interest were sessions on identifying high risk for cancer and strategies for risk factor reduction (e.g., smoking cessation), pain management and side effects of treatment, lymphedema and long-term follow-up care. Relatively low interest was found for specific procedures such as biopsy, sigmoidoscopy, and tumor staging, which primary care providers usually do not perform.

While on-site lectures are the most preferred means of attending a CME session, nearly one-quarter of the respondents viewed Internet CME access as a favorable means of attending CME programs. Unlike CMEs targeted to hospital staff or

Table 3.
CME Topic Interest and Demand Ratio: Screening, Diagnosis and Treatment, Follow-up Care, and Prevention Categories

Category	Item	% Very Interested (VI)	% Not Interested (NI)	Ratio (VI/NI)
Screening	Breast	48.1%	6.3%	7.63
	Ovarian	42.2%	7.8%	5.41
	Skin	37.1%	10.1%	3.67
	Cervical	42.1%	11.9%	3.54
	Clinical breast exam	39.6%	16.4%	2.41
	Disc results with patients	36.1%	15.6%	2.31
	Prostate	37.6%	16.6%	2.26
	Flex sigmoidscopy	31.6%	32.3%	0.97
	Excise skin lesions	29.3%	31.8%	0.92
	Punch biopsy	24.8%	32.5%	0.76
	Endometrial biopsy	28.5%	40.5%	0.70
	Colposcopy	18.4%	39.6%	0.47
	General screening	57.8%	2.5%	23.12
Diagnosis and Treatment	Pain Management	46.2%	10.3%	4.49
	Patient/family support	35.8%	10.9%	3.28
	Treatment options	35.0%	12.1%	2.89
	Patient care and management	33.8%	12.3%	2.74
	Relative care	30.2%	19.1%	1.58
	Hospice care	32.1%	20.5%	1.56
	Antibiotic fever	28.5%	23.4%	1.22
	Emetics	26.8%	22.3%	1.20
	Leukopenic fever	26.7%	25.3%	1.05
	Multidisciplinary teams	18.9%	22.6%	0.83
	Research protocols	19.2%	36.4%	0.53
	General update diagnostic skills	47.1%	5.8%	8.12
	Staging	20.8%	23.9%	0.87
Follow-up Care	Side Effects from cancer	32.2%	9.6%	3.35
	Side effects from treatment	34.5%	12.7%	2.72
	Long-term follow-up	32.1%	17.1%	1.88
	Lymphedema management	28.1%	24.0%	1.20
	Lymphedema diagnosis	27.7%	28.4%	1.05
	Therapist availability	23.1%	25.2%	0.92
Risk Factor Prevention/ Reduction	Identify high risk	52.6%	9.9%	5.30
	Genetic susceptibility	42.0%	10.4%	4.04
	Diet	33.0%	11.1%	2.97
	Smoking	35.7%	14.6%	2.45
	Exercise	30.7%	15.6%	1.97
	Genetic counseling	29.2%	23.1%	1.26
	Sun exposure	23.2%	21.4%	1.08

healthcare providers within academic clinical departments capable of attracting large numbers, primary care physicians in the community may find it more difficult to attend off-site CMEs, making video conferencing an attractive media format to adopt for category 1 credit.

While needs assessments, such as this one, are the cornerstone of sound education, studies are needed on the effectiveness and impact of various continuing education formats in terms of number reached and, ultimately, in changing cancer prevention and control practices or outcomes. The effectiveness of CME programs as

Table 4.
Topic Demand Ratio† by Specialty: Screening, Diagnosis and Treatment, Follow-up Care, and Prevention.

Category	Item	Family Medicine	Internal Medicine	OB/ GYN
Screening	General screening	24.0***	59.5***	47.0***
	Skin	4.1***	11.0*	2.4
	Breast	6.6***	8.0**	70.6***
	Cervical	4.1***	1.4	63.6***
	Ovarian	14.0***	1.7	69.7***
	Prostate	5.1***	2.0	0.6
	Flex sigmoidscopy	1.4	0.6	0.8
	Punch biopsy	1.0	0.4*	1.4
	Excise bio/skin	1.5	0.3**	2.0
	Endometrial biopsy	0.9	0.1***	3.6*
	Coloscopy	0.4**	0.1***	4.5**
	Clinical breast exam	2.3*	1.2	9.5**
	Discussing results with patients	2.4*	1.4	3.3*
Diagnosis and Treatment	Update diagnostic skill	14.7***	19.0**	3.0
	Staging	0.9	0.9	0.7
	Multidisciplinary teams	1.1	0.5	0.9
	Treatment options	3.3***	1.7	4.3*
	Find protocols	0.7	0.2**	0.8
	Pain management	8.2***	2.7	2.0
	Leukopenic fever	2.0*	0.8	0.4
	Antibiotic fever	1.6	1.0	0.8
	Emetics	2.3*	0.7	0.9
	Palliative care	2.4*	1.5	0.7
	Patient care/management	3.5***	3.0	1.4
	Hospice care	2.5	1.1	0.8
	Patient/family support	4.5	2.2	4.0
Follow up care	Side effects from cancer	1.0	0.5	0.9
	Side effects from treatment	3.3***	1.7	4.3
	Lymphedema diagnosis	0.7	0.2**	0.8
	Lymphedema management	8.2***	2.8	2.0
	Therapist availability	2.0*	0.8	0.4
	Long-term follow up	1.6*	1.0	0.8
Risk Factor Prevention/ Reduction	General Cancer prevention	19.0***	8.5**	8.5**
	Diet	8.0***	0.8	4.7*
	Exercise	6.2***	0.5	3.0*
	Smoking	3.2***	1.5	2.8*
	Sun exposure	2.8**	0.4*	1.1
	Identify high risk	8.4***	5.2***	2.9*
	Genetic susceptibility	5.3***	1.8	37.5***
	Genetic counseling	1.9*	0.8	1.0

Note: * P-val <.05, ** pval < .01, *** pval <.001. Test of significance on log (ratio) performed, † ratio of 'very interested' to 'not interested'

effective instruments of change has been challenged.[22-24] Davis and colleagues[25] reviewed the general research literature covering 24 separate CME-based interventions and found that benefit, in terms of provider practice or healthcare outcomes, was dependent upon method of delivery, nature of the interaction, and enabling resources provided. Didactic CME-based interventions failed to change physician behavior, despite effects on knowledge and attitude. Studies using interactive techniques, such as case discussion or demonstrations, were more effective, as were sequenced interventions allowing practice and feedback loops, and enabling materials (brochures, patient reminder cards, etc.) designed to facilitate implementing the recommended changes.

As cancer screening methods and technologies evolve to encompass genetic screens and refinement of risk estimation, the need among primary care providers for continued cancer control and prevention education is likely to grow. Studies are needed to develop effective CME-based interventions for cancer care.

Conclusion

Results of this survey indicate that strong interest exists for cancer CME topics among primary care providers, with more than one-third (37%) of respondents reporting no previous attendance of CME-provided cancer care educational sessions.

Acknowledgement: The authors are grateful for assistance in survey development provided by Dr. Robert L. Michlelutte, Department of Family and Community Medicine, WFUSM. **NCMJ**

Table 5.
Preferences for Continuing Medical Education Format

Format	% Very Appealing
Lecture, in person	62.5%
Lecture, teleconference	6.1%
Small group workshop	20.8%
Independent study	24.1%
Hospital sponsored	24.5%
Area Health Education Center sponsored	36.8%
Panel discussion	12.1%
Internet access	23.1%

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POLICY FORUM

Infant Mortality in North Carolina: A New Perspective on a Persistent Problem

Introduction
Gordon H. DeFriese, PhD, and Kristie K. Weisner, MA

Issue Brief:
North Carolina's Infant Mortality Problems Persist: Time for a Paradigm Shift
Julia L. DeClerque, DrPH, MPH, Janice A. Freedman, MPH, Sarah Verbiest, MSW, MPH, and Stuart Bondurant, MD

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Robert G. Dillard, MD

Infant Mortality 1963 to Present: Medical Developments and Legislative Changes
William R. Purcell, MD

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Folic Acid and Birth Defects Prevention: A Public Health Success Story
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Addressing Perinatal Health Disparities: Another Place for a Paradigm Shift
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Cathy L. Melvin, PhD, MPH, and Sally Herndon Malek, MPH

Preterm Birth in North Carolina
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Joe L. Holliday, MD, MPH

SPECIAL ARTICLE

There Is Life (and Death) Beyond the Infant Year: North Carolina's Recent Experience in Reducing Child Deaths
Tom Vitaglione, MPH

> *"...the largest proportion of infant deaths are associated with general health conditions and health factors present (and in many cases preventable) among women of childbearing ages during the period prior to pregnancy."*

INTRODUCTION

Policy Forum:
Infant Mortality in North Carolina: A New Perspective on a Persistent Problem

For decades, North Carolina health professionals and public health activists have confronted stark statistics, which indicate an inability to adequately prevent infant deaths in our state, especially among racial and ethnic minorities. While comparisons of our infant death rates with those in other states no longer put us at the absolute bottom of the national distribution, we are clearly among the few states at the lower levels of accomplishment with regard to this important indicator of health and healthcare disparity.

For health professionals who have worked so hard to address these issues, the persistence of these problems has been an especially frustrating and challenging part of their careers. Yet, it is important to recognize that measurable and positive changes have occurred, slowly but surely, over the past decade or so. Important changes have been brought about through: assurance of better access to primary healthcare services for pregnant women and children, a campaign to promote consumption of folic acid during women's childbearing years and pregnancy, state and federal nutritional and dietary supplement programs, the availability of excellent neonatal care services across the state, and the Back To Sleep Campaign and other child care initiatives. For a problem as pervasive and complex as this, there is no single intervention that can stem the tide and result in dramatic results overnight.

The Editors of the *North Carolina Medical Journal* are pleased to have an opportunity to focus on these perennial public health issues. The Policy Forum in this issue is made possible through a grant from the March of Dimes of North Carolina, with whom we are pleased to have undertaken a close collaborative relationship in addressing the many issues discussed in these pages. While the March of Dimes did provide funding for the printing and distribution of this issue, the opinions expressed are those of the authors and not the March of Dimes.

We think our readers will find the initial paper in the Forum by Dr. Julia DeClerque and colleagues of great interest. Dr. DeClerque et al. argue for a change in the way we have conceptualized and approached infant mortality in North Carolina and the nation. Drawing on the work of the World Health Organization and a number of agencies and programs here in the United States, these authors call our attention to the fact that the largest proportion of infant deaths are associated with general health conditions and health factors present (and in many cases preventable) among women of childbearing ages prior to pregnancy. Hence, it is suggested and statistically demonstrated that the greatest potential impact on infant mortality rates may be realized by addressing the more general health of women in these age groups, whether or not they are pregnant.

This "paradigm shift" will not be easily explained, or accepted by policy makers who often prefer to invest in healthcare services and programs targeted to specific health conditions, with the expectation that clearly associated results will be demonstrated in the near-term. The proposal for focusing infant mortality reduction efforts with an approach that addresses the general health of women in childbearing ages (whether or not pregnancy has been established) will require a very different perspective and a very different set of programmatic investments. We hope the commentaries that follow this Issue Brief will help clarify the importance of this paradigm shift, as well as provide an update on what is arguably one of North Carolina's most persistent public health dilemmas.

Gordon H. DeFriese, PhD
Editor-in-Chief and Publisher

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Managing Editor

North Carolina's Infant Mortality Problems Persist:

Time for a Paradigm Shift

Julia L. DeClerque, DrPH, MPH, Janice A. Freedman, MPH, Sarah Verbiest, MSW, MPH, and Stuart Bondurant, MD

Improvements over the past two decades in the medical care of women during pregnancy and of newborn infants have contributed to North Carolina's success in reducing its high infant mortality rate to an historic low. These efforts are to be applauded and they must be sustained. One of the largest remaining gaps, however, is the absence of significant initiatives that focus on improving a woman's health before she becomes pregnant. Future improvements in reducing rates of infant death or improving birth outcomes will depend upon a renewed sense of urgency to provide the best healthcare to pregnant women and their babies and a willingness to expand the current focus on improving pregnancies to improving the health and psychosocial well-being of *all* women of reproductive years.

Background

Infant mortality is the leading cause of child death, affecting close to 1,000 North Carolina babies and their families every year. While the state's rate is at an historical low (8.2 deaths/1,000 live births in 2002), North Carolina continues to post one of the highest rates in the nation (Table 1). Racial and ethnic disparities in infant death rates persist: African American babies have a two to three times greater rate of death than white babies (14.2/1,000 and 5.9/1,000, respectively, in 2002). Interestingly, Latino women in North Carolina, many of whom are newly arrived immigrants, have among the best birth outcomes at present. However, experience from other states suggests that the longer immigrants live in this country the more likely they are to experience infant loss. North Carolina currently has a window of opportunity to learn about and sustain the factors that lead to these healthy births. With the rapid growth of a young, Latino population, taking action now may serve to prevent a worsening of the state's infant mortality rate among this group in the future.

While death rates have declined over time, the major causes of infant death have remained fairly constant. North Carolina's babies, like those in other states, are most likely to die as a result of conditions related to prematurity and low-birth weight, congenital anomalies and Sudden Infant Death Syndrome (SIDS). Preterm birth, the leading correlate of newborn death, is increasing for *all groups* in North Carolina. Preterm birth affects more than 15,000 North Carolina babies annually, including one out of every eight white babies, and one out of six for African American babies (Table 1). Young African American women have worse health status (obesity, diet, exercise, exposure to disease) than young white women. Efforts to further reduce infant mortality should emphasize reduction in the glaring health disparities experienced by African Americans in North Carolina—especially children, teenagers, and women of child-bearing years. More than 10,000 babies are born with low-birth weight (less than 5.5 pounds), and more than 3,000 infants are born with birth defects each year in North Carolina causing death, illness, emotional trauma and great economic burden for families and the state.

Studies show that poor birth outcomes can be caused by a myriad of problems. Women with unintended pregnancies or closely spaced pregnancies, those who are under age 18 or older than 35, smokers, and those with high stress and limited resources all have a higher risk of having premature or low-birth weight babies.[1 2 3]

North Carolina's Programs to Reduce Infant Mortality

North Carolina has a long-history of services and programs aimed at reducing the state's high infant mortality rates. Over the years, the state has expanded access to prenatal care and the

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Table 1.
Leading Causes of Infant Deaths (NC, US, Selected Years)

	Total		Non-Latino White		Non-Latino African-American		Non-Latino Native American		Latino	
	NC	US	NC	US	NC	US	NC	US	NC	US
Preterm births* (% live births)	13.2	11.8	11.4	10.6	18.3	17.6	14.1	12.8	11.6	11.4
Low-birth weight births* (% live births)	8.9	7.6	7.4	6.7	13.7	13.1	10.4	7.1	6.2	6.4
Infant Mortality** (deaths per 1,000 live births)	9.0	7.0	6.7	5.8	15.7	13.9	11.8	8.9	6.2	5.7
Deaths due to birth defects** (deaths per 1,000 live births)	.1591	.1413								
Deaths due to SIDS** (deaths per 1,000 live births)	.0844	.0677								
Deaths due to prematurity/low-birth weight** (deaths per 1,000 live births)	.1787	.1112								

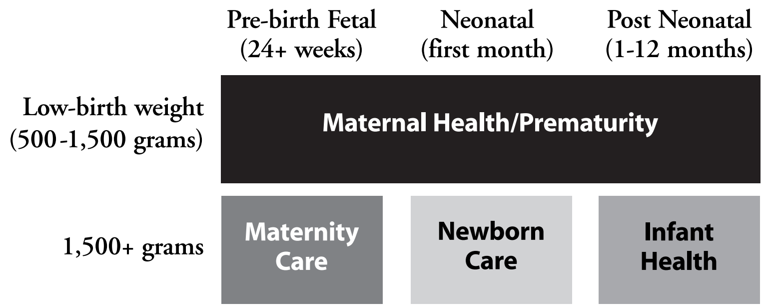
* Data for 1999-2001. Numbers reflect percentage of live births.
** Data for 1998-2000. Numbers reflect deaths per 1,000 live births.
Source: March of Dimes Prematurity Website. Available at: http://peristats.modimes.org/statestep1.cfm?state_id=37 (accessed June 4, 2004).

array of pre- and post-natal services available to pregnant women and infants, increased the state's outreach and education efforts, and expanded family planning services to reduce unwanted pregnancies (see pages 170 and 172). In addition, the state and local communities have helped launch targeted infant mortality campaigns aimed at high-risk groups or communities; and have created special programs aimed at reducing some of the causes of infant deaths. These efforts have helped contribute to a 35% reduction in the state's infant mortality rate since 1988 when provisional data from the Centers for Disease Control and Prevention listed North Carolina as having the worst infant mortality rate in the country. While these efforts have been critically important in reducing the state's infant mortality rate, there is a need to analyze existing data with new eyes to better pinpoint the underlying cause and specific patterns of risk that should be addressed, and therefore the appropriate timing of interventions that will have the most impact.

A New Way of Analyzing the Problem: Perinatal Periods of Risk (PPOR) Analysis

For more than a decade, the World Health Organization has used an analytic approach, the "Perinatal Periods of Risk Analysis" (PPOR) to analyze the cause of feto-infant mortality, and to develop appropriate interventions.[4] In 1997, the Centers for Disease Control and Prevention (CDC), City MatCH at the University of Nebraska Medical Center, the National March of Dimes Foundation, and the Health Resources and Services Administration/Maternal and Child Health Bureau created a partnership to test this model in the United States. PPOR helps to "map" fetal and infant deaths into four distinct periods based on when the deaths occur and the birth weight of the baby or fetus at the time of death. The three categories for the age of death are broken into fetal deaths (24 weeks or greater of gestation), neonatal deaths (within the first month after birth), and postneonatal (1-12 months of life). Birth weight is divided into two categories: low-birth weight (500-1,499 grams) or higher birth weight (1,500 + grams). Because of large reporting differences in vital records across geographic locations, fetal deaths are limited to those occurring after 24 weeks of gestation, and to those fetuses or infants weighing at least 500 grams at the time of death. This analysis creates four groups: maternal health/prematurity, maternity care, newborn care, and infant health (See Figure 1). The maternal health/prematurity category covers all low-birth weight feto-infant deaths, regardless of whether the death occurs in the fetal, neonatal, or post-neonatal time period.

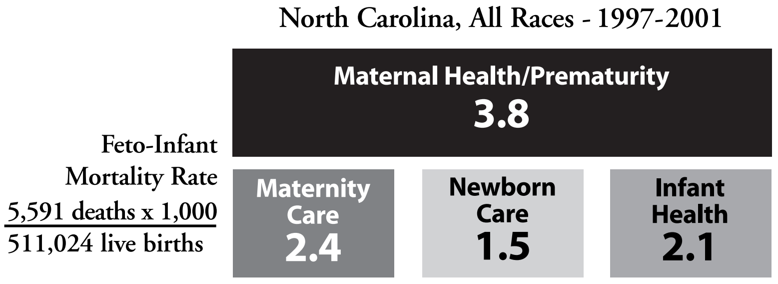
Figure 1.
Perinatal Periods of Risk Analysis



	Pre-birth Fetal (24+ weeks)	Neonatal (first month)	Post Neonatal (1-12 months)
Low-birth weight (500-1,500 grams)	Maternal Health/Prematurity		
1,500+ grams	Maternity Care	Newborn Care	Infant Health

Deaths linked to maternal health/prematurity result from risk factors that are present before a woman becomes pregnant, such as a history of substance abuse, tobacco use, unstable

Figure 2.
Focus on Overall Infant Mortality by Periods in which Deaths Occur



housing/family structure, effects of poverty and stress, or a recent previous delivery. These problems can be addressed by focusing on preconceptional health, unintended pregnancy, smoking, drug abuse, and specialized perinatal care.

Deaths in the maternity care period link to factors that are most prominent during pregnancy, like poor weight gain, infection and lack of prenatal care. Some of these deaths can be prevented by ensuring women have early and continuous prenatal care, referral of high-risk pregnancies and good medical management of women with diabetes, seizures, postmaturity or other medical problems. Deaths in the newborn care period are attributed to risks that occur during delivery and through the first month postpartum. Prevention of newborn deaths focuses on advanced neonatal care and treatment of congenital abnormalities. The final period, infant health, includes deaths that occur due to factors occurring after the first month of life through the end of the first year—factors such as injuries, SIDS, congenital anomalies and infections. These deaths can be addressed through SIDS risk-reduction activities, breast-feeding promotion, access to medical homes, and injury prevention. PPOR is more of an heuristic exercise to help clarify the relative risk of these different periods of time and each periods' contribution to the likelihood of perinatal death, and is a tool for examining whether programs are focused appropriately in timing and emphasis of their efforts.

With this in mind, feto-infant deaths can be "mapped" for a geographic area to identify which of the four periods are associated with the greatest mortality risk. Each cell includes the number of fetal or infant deaths that meet the age and weight criteria. For example, a death to an infant in the 26th week of gestation that was under 1,500 grams would be counted in the maternal health/prematurity cell.

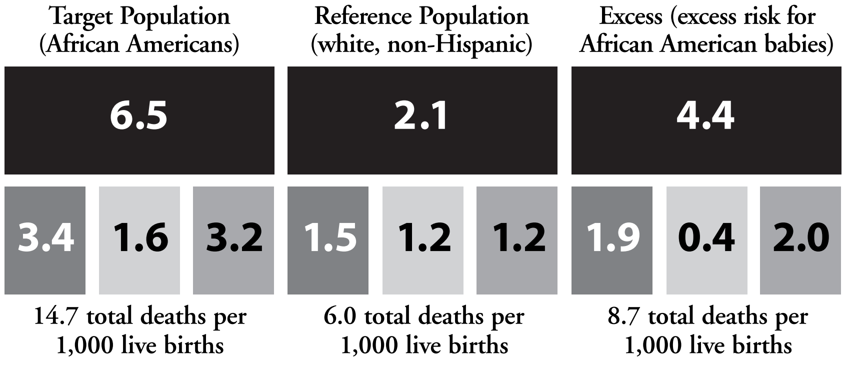
So, what does this analysis look like for North Carolina? There were 5,591 feto-infant deaths in North Carolina between 1997-2001 that met the age and weight thresholds. This yields a feto-infant mortality rate of 9.8 deaths for every 1,000 live births. More than a third of the feto-infant deaths fall into the maternal health/prematurity cell with risks attributable primarily to maternal factors (see Figure 2).

This same analysis can be used to compare rates across different subpopulations. For example, PPOR can be used to compare a high-risk group with a reference group of women expected to have better birth outcomes. Because we know that we have a high infant mortality rate among African-Americans in North Carolina, we can use the PPOR analysis to compare feto-infant birth outcomes of African Americans with a reference group of white, non-Hispanic women, over the age of 20, with greater than a high school education.[5] The difference between the reference and target population risks is the excess risk that exists. This excess risk must be addressed if all members of the local community are to have equal access and opportunity to optimize their health and if there is to be further progress in reducing overall infant mortality rates.

The feto-infant mortality for African American births is extremely high; at 14.7 deaths per 1,000 live births it is more than double that of whites (6.0 per 1,000). It also shows that, for the target population, almost half of the deaths are related to maternal health/prematurity (6.5 of the 14.7 deaths per 1,000 live births). Interestingly, the feto-infant deaths attributed to maternity care and those related to infant health are not as high as those associated the maternal health/prematurity, but at 3.4 and 3.2 per 1,000, respectively, these risks must still be addressed. One surprise that the data show is the extremely *low* rates of excess death attributable to the newborn period (0.4 per 1000). This tells us that African American babies in North Carolina have mortality rates associated with newborn care that are comparable to those among whites. This is cause for celebration, but also a signal that our efforts to address the problem of infant-mortality in North Carolina need a new and targeted approach.

To summarize, this PPOR review tells us that the most prominent period of excess risk for mothers and babies in North Carolina, especially African Americans, is the stage where the majority of the excess risk occurs (4.4 of the 8.7 or

Figure 3.
Excess Feto-Infant Mortality for African Americans in North Carolina 1997-2001



51%) and calls attention to the importance of factors related to the general health of women in childbearing ages. Efforts to improve this situation would direct our attention to the preconceptional period, or the health of women of childbearing ages before they become pregnant or between pregnancies.

This analysis also highlights North Carolina's current strengths and recent accomplishments in newborn care as it relates to infant mortality prevention. Intensive care nurseries and hospitals are doing an excellent job caring for sick neonates and transferring at-risk infants to appropriate facilities. The state's medical technology, expertise, and infrastructure are strong and have had demonstrable success. It is important that this system be maintained, particularly through regionalization, to ensure that tiny and sick babies are born in facilities with the personnel and resources to manage their complex care. Moderate numbers for the maternity care and infant health periods likely also reflect the impact of the many public health and community-based programs already in place that serve pregnant and parenting women.

Women's Health Status in North Carolina

So how does the health of North Carolina's women measure up? The NC Program for Women's Health Research, a collaborative program of the UNC School of Medicine, the UNC School of Public Health and the Cecil G. Sheps Center for Health Services Research, produces an annual North Carolina Women's Health Report Card.[6] The purpose of the report card is to allow the state to chart progress and problems on a large number of women's health indicators. Grades are given based on the percentage change from previous years and/or how satisfactory the current measure of each health indicator is.

As in previous years, the 2003 Women's Health Report Card documented that the state of women's health in North Carolina has much room for improvement. Data show that 45% of all live births were the outcome of unintended pregnancies (66% for African Americans) and that almost 16% of all women received late (after the first trimester) or no prenatal care. There were three cases of HIV/AIDS per 100,000 white women and 54 cases per 100,000 African American women; 248 sexually transmitted disease cases (syphilis, gonorrhea, chlamydia) per 100,000 white women and 2,522 per 100,000 for African American women.

Women's health in North Carolina received an "F" for its high rate of binge drinking among women (4.5%), high percentage of women with diabetes (6.7%), high percentage of women who are obese (23%), and high percentage of women with high blood pressure (28.9%). Indicators for African American women are even higher than those listed here. Additionally, 23% of women in North Carolina smoke (almost 14% during pregnancy), and there were 3,883 hospitalizations per 100,000 women for substance abuse or mental health diagnoses.

Research has shown that women who begin their pregnancies either underweight or overweight, with high blood pressure or diabetes, women who drink, smoke, have mental health problems, or sexually transmitted diseases are at greater risk for poor birth outcomes. The NC Women's Health Report Card clearly documents that North Carolina's women, especially its African American women, have not achieved the health status they need (as reflected by their scores) for achieving healthy birth outcomes. This report card underscores the conclusions reached by the PPOR model. Prenatal care, neonate care and infant health are important, but ultimately the ability to achieve and sustain improved birth outcomes will coincide with improved health status and increased access to care for women before they become pregnant or between pregnancies.

Time for a Paradigm Shift

In light of consistently falling short of the standards set by most other states in the nation, as well as the racial disparity and increasing rates of premature birth seen in North Carolina, there is a clear need to expand our perspective by adding a strong and effective intervention to improve the health of all women of childbearing age, especially young women. Research to find more effective evidence-based prevention strategies should be supported while the sound knowledge we now have provides a basis for the design of reasonable and promising health programs to reduce the burdens of unhealthy lifestyles.

Prenatal care has improved pregnancy outcomes in many ways. However, it has not been shown to be effective in reducing the incidence of premature births.[7] One possible reason for such a failure is that the causes of prematurity are predominately related to a woman's general health, social, environmental, and emotional circumstances.[7-11] In order to reduce the incidence of prematurity, it is reasonable to assume that it will be necessary to address those circumstances before, as well as during, pregnancy. Thus, it is time to reshape the focus of infant mortality reduction efforts. In addition to images of pregnant women and mothers holding newborns, the faces of all women of reproductive age should be part of the picture. A *life course* approach—that acknowledges the cumulative effects of risks and stressors over decades and even generations—should be considered in this new perspective.

To shift to this paradigm a number of things must happen. First and foremost our schools, the healthcare system and community agencies need to help all women, and especially the young, to gain understanding and motivation for healthier lifestyles. There needs to be increased access to and coverage for women's wellness services in many venues. These services need to be comprehensive, widely available, personally tailored, user-friendly and rewarding, and employ a bio-psychosocial approach. Reproductive health measures need to include other health indicators such as oral health, diabetes, blood pressure, smoking status and exposure to secondhand smoke, drug use, nutritional status, domestic violence, levels of stress and coping strategies, and mental health status.

Women must be educated about the need for these services and a demand created. Services should be designed to provide such rewards for participation that recruitment occurs naturally and continuation of participation is sought. Further, providers will require training on topics related to preconceptional or interconceptional health and the need for wellness visits. A screening tool adapted for women's life cycles could be used to help a woman and her provider track her health over her life course. More research will be required and must be conducted outside of the clinical setting and no longer limited to prenatal patients in a medical context. Studies must be designed to incorporate psychosocial, environmental and biological contexts of women's situations to understand multi-level effects. They must also be designed to take place within communities and families.

North Carolina's current initiatives focusing on smoking cessation, folic acid supplementation and family planning should be expanded and instituted statewide. Improving our delivery of these messages to targeted audiences and expanding our reach on these three factors alone will have an impact on the health of future children. In addition, the NC Department of Health and Human Services' focus on reducing health disparities is one that should be embraced widely. Within the mosaic of issues that are part of infant health, it is time that attention be paid to the pieces which represent maternal health and maternal well-being.

Women who are healthy are a vital component of North Carolina's future, whether they are pregnant or not. It's time to make the investment, to assure the health of women, and to have a long-term, positive impact on the health of newborns. **NCMJ**

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Programs and Policies to Address the Problem of Infant Mortality: A Long History

Reducing infant mortality has been on North Carolina's agenda for several decades, albeit with varying levels of intensity and funding. Concerted efforts to prevent infant death began in 1972 when Governor Robert Scott created the Maternal and Infant Health Task Force to determine why North Carolina had such high infant mortality rates. Subsequent groups, including a statewide Perinatal Council (late 1970s to late 1980s) and Governor James Martin's Governor's Commission on the Reduction of Infant Mortality (1989-1995), addressed the same issue and championed legislation and policies, mobilized local coalitions and funded community-based organizations to address this problem. The NC General Assembly also played a leadership role in the fight to reduce North Carolina's infant mortality rate. Between 1990-1994, Senator Russell Walker and Representative David Diamont introduced a four-year infant mortality reduction campaign that helped create or expand many of the existing programs aimed at reducing infant mortality. Subsequently, the NC General Assembly has continued to support legislation and/or funding to address this issue.

Private foundations and organizations such as: the March of Dimes, the Kate B. Reynolds Charitable Trust, The Duke Endowment, and the North Carolina Healthy Start Foundation have also played pivotal roles in helping raise awareness about infant mortality and in supporting programs and research. At the local level, partnerships have developed between the business community, the faith community, local organizations, and coalitions to address the specific needs in the community, to strengthen networks and referrals that serve a common public and to fill gaps in services.

Over the years, efforts to reduce North Carolina's high infant mortality rate have focused on family planning and adolescent pregnancy prevention; improving the quality, comprehensiveness and accessibility of prenatal care; interventions that target particular populations or areas of the state; and interventions targeting specific risk factors or causes of infant deaths. These statewide and local efforts have lead to a 35% reduction in the state's infant mortality rates since 1988 when the state trailed the rest of the nation. However, recent budget cuts could jeopardize the progress that has been made.

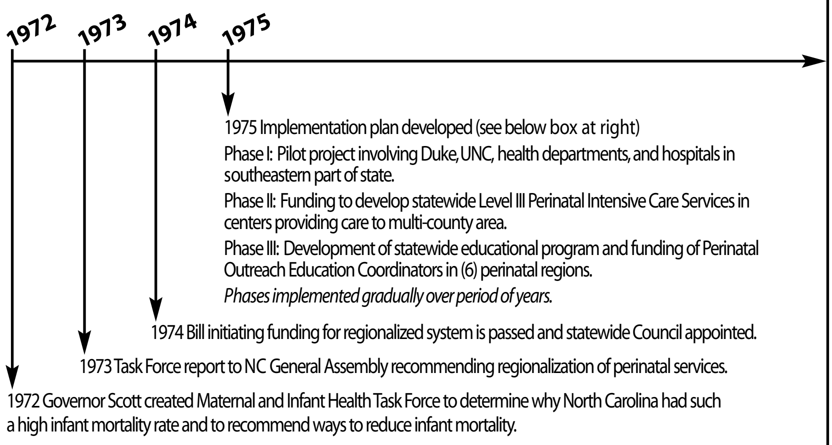
Family Planning and Adolescent Pregnancy Prevention Programs

Pregnancies that are planned by women who are physically, emotionally, socially, and financially ready are more likely to produce healthy babies. Unfortunately, almost half of all pregnancies in North Carolina and in the nation are unintended—often with serious consequences for the babies, women, families, communities, and the state. Family planning services are offered across the state through local health departments and physicians in private practice.

In 1999, the NC General Assembly mandated that insurers provide contraceptive coverage in their private health insurance plans. Women who are on Medicaid also have access to family planning services, and others can access services through local public health departments or community agencies. Nonetheless, there are many women who still lack access to family planning services. The NC General Assembly authorized the NC Department of Health and Human Services to seek a Medicaid waiver to extend family planning services to women and men (ages 19-55) with incomes below 185% of the federal poverty guidelines (See Holliday article, pages 170-172).[1] If implemented, this initiative will provide North Carolina's families with improved access to the services they need to lengthen the intervals between pregnancies (birth spacing), to reduce the likelihood of unintended pregnancies and subsequent abortions, and ultimately to improve the outcomes of subsequent pregnancies once they occur.

In addition, state funding over the years has supported specific programs to reduce adolescent pregnancies, including

A Very Brief Historical Sketch of Perinatal Care in North Carolina



1975 Implementation plan developed (see below box at right)

Phase I: Pilot project involving Duke, UNC, health departments, and hospitals in southeastern part of state.

Phase II: Funding to develop statewide Level III Perinatal Intensive Care Services in centers providing care to multi-county area.

Phase III: Development of statewide educational program and funding of Perinatal Outreach Education Coordinators in (6) perinatal regions.

Phases implemented gradually over period of years.

1974 Bill initiating funding for regionalized system is passed and statewide Council appointed.

1973 Task Force report to NC General Assembly recommending regionalization of perinatal services.

1972 Governor Scott created Maternal and Infant Health Task Force to determine why North Carolina had such a high infant mortality rate and to recommend ways to reduce infant mortality.

PERINATAL PLAN DEVELOPMENT

Mission: To reduce infant mortality and morbidity in NC by developing a statewide voluntary, cooperative, multilevel regionalized system for inpatient and outpatient perinatal healthcare, emphasizing medical, psychosocial, and financial aspects of patients needs. The goals are listed below.

1) Develop (6) Perinatal regions, each will have an active regional committee composed of multi-disciplines.
2) Describe and designate hospitals into one of three types.
3) Recruit the participation of health departments to provide routine screening of pregnant women and infants. Some will establish high-risk clinics.
4) Appoint a Perinatal Statewide Education Committee.
5) Manual "Regionalized Perinatal Health Care Program" published.

STATEWIDE PERINATAL COUNCIL

Discuss and address issues related to perinatal care. Special interest group and committees formed to:

- Study preterm labor - "White Paper" on preterm labor developed.
- Develop "Guidelines for Perinatal Care"
- Develop a Statewide Perinatal Professional Educational Plan
- Appoint a Perinatal Statewide Education Committee

the competitive Adolescent Pregnancy Prevention Program, Targeted Adolescent Pregnancy Prevention Program, the Adolescent Parenting Program and the Adolescent Pregnancy Prevention Coalition of North Carolina. (The state's adolescent pregnancy prevention programs are now under one combined program using TANF funds for teen pregnancy prevention.) Through these concerted efforts, teen pregnancy rates have declined in North Carolina to their lowest since the mid-1980s, thereby reducing the number of high-risk pregnancies, impacting overall infant mortality, and giving more teens a better chance to succeed in life. Funding for these projects, with demonstrated results, has come under attack in recent years due to the state's financial situation.

Improving the Quality, Comprehensiveness, and Accessibility of Prenatal Care

North Carolina ranks sixth in the nation for its excellent track record in ensuring that pregnant women get early and continuous prenatal care.[2] Statewide programs include the Baby Love Program (Medicaid for Pregnant Women), which provides prenatal care and care coordination to pregnant women who are at or below 185% of the Federal Poverty Level (FPL); high-risk maternity clinics, a regionalized Perinatal Referral System; the Perinatal Outreach Education and Training program; prevention and treatment programs for sexually transmitted diseases and HIV/AIDS; residential Perinatal Substance Abuse Treatment Programs; Special Supplemental Nutrition Program for Women, Infants, and Children (WIC); the NC Family Health Resource Line (1-800-FOR-BABY / 1-800-367-2229)—a statewide, toll-free, bilingual information and referral line; and the bilingual First Step Campaign coordinated by the North Carolina Healthy Start Foundation, which distributes free educational materials statewide. These services provide information to pregnant women and help link them with available resources, provide prenatal care in an appropriate setting, address known risk factors, and offer educational opportunities and resources to healthcare providers. Recent budget cuts have threatened some of these critical mainstays of prenatal care and infant mortality prevention (for example, the 2004 NC General Assembly considered proposals to cut the number of pregnant women eligible for Medicaid by reducing the income eligibility criteria). These cuts threaten the state's previous progress in improving the health of pregnant women and babies.

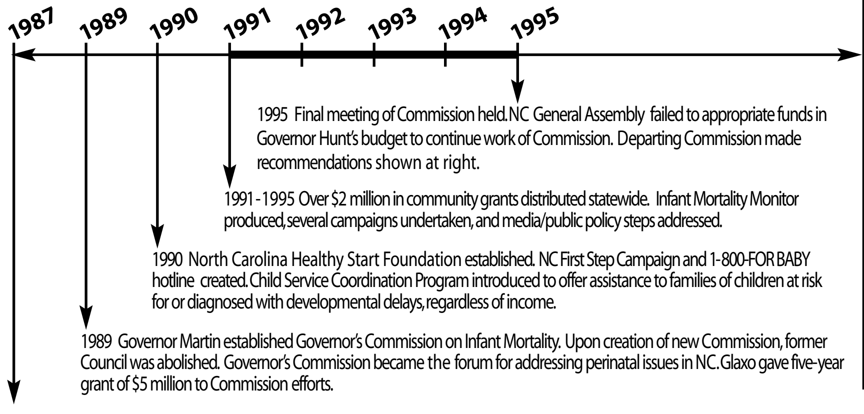
Targeted Interventions Based on Population and Geography

Infant mortality rates vary in North Carolina based on geography, race, and income. A number of unique initiatives in the state address special populations at high risk. The state-funded Healthy Beginnings Program (formerly the Minority Infant Mortality Reduction Program) provides 15 multi-year grants to local organizations that address unique issues in their communities, and the Targeted Infant Mortality Reduction Projects provide funding to eight local health departments to address factors in their community related to reducing infant death. In addition, the federal Maternal and Child Health Branch, US Department of Health and Human Services funds the NC Healthy Start *Baby Love Plus* and the UNC Pembroke *Healthy Start Corps* projects, which are used to coordinate four regional consortia in 17 counties (Triad, Eastern, Southeastern and Northeastern regions). These consortia provide outreach and other services to pregnant and postpartum women such as peer support, transportation, and enhanced case management.

Other programs initiated in the past addressed inequities between prenatal services available in rural and urban regions of the state. Both the Nurse-Midwifery Project and the Rural Obstetrical Care Incentive Program increased rural women's access to quality prenatal care by bringing medical providers to underserved areas; however, these programs were eliminated in prior years' budget cuts.

Targeted Interventions Based on Risk Factors and Causes of Infant Death

North Carolina strategically addresses certain causes of infant death, including SIDS, prevention of birth defects, and risks associated with low-birth weight. For example, the North Carolina Back To Sleep Campaign is a public-private partnership aimed at reducing Sudden Infant Death Syndrome (SIDS),



1995 Final meeting of Commission held. NC General Assembly failed to appropriate funds in Governor Hunt's budget to continue work of Commission. Departing Commission made recommendations shown at right.

1991 - 1995 Over $2 million in community grants distributed statewide. Infant Mortality Monitor produced, several campaigns undertaken, and media/public policy steps addressed.

1990 North Carolina Healthy Start Foundation established. NC First Step Campaign and 1-800-FOR BABY hotline created. Child Service Coordination Program introduced to offer assistance to families of children at risk for or diagnosed with developmental delays, regardless of income.

1989 Governor Martin established Governor's Commission on Infant Mortality. Upon creation of new Commission, former Council was abolished. Governor's Commission became the forum for addressing perinatal issues in NC. Glaxo gave five-year grant of $5 million to Commission efforts.

1987 Baby Love Program implemented. Baby Love designed to improve access to healthcare and service delivery system for low-income pregnant women and children.

Members of Governor's Commission on the Reduction of Infant Mortality final meeting recommendations:

- Maintain widespread attention on importance of healthy babies to North Carolina.
- Continue to publish Infant Mortality Monitor.
- Provide support to local health departments and other local organizations to promote the involvement of community groups, business, health providers and government.
- Continue initiatives to work with NC Business and Industry and their role in infant mortality prevention.
- Research into causes of prematurity, birth defects, and other causes of infant mortality and morbidity should continue and be expanded.
- Modern medical treatment should be in wide use and available to all women in need.
- Improve education for persons planning a family (for pregnant women and young mothers).

the third leading cause of infant death. This statewide, public education campaign, coordinated by the North Carolina Healthy Start Foundation and the state's SIDS Program, helps to promote behaviors before, during, and after pregnancy that reduce the risk of SIDS. As a result, SIDS deaths have decreased 36% in North Carolina since 1995. A new state law, effective December 1, 2003, should help further reduce SIDS deaths in childcare facilities. The law mandates that: babies under the age of 12 months who are cared for in licensed childcare facilities be placed to sleep on their backs, facilities have written safe sleep policies, and all childcare providers receive state approved training.

The prevention of birth defects, the second leading cause of infant death, is addressed in several ways. Pregnant women receive Maternal Serum Alpha-Fetaprotein screening to detect birth defects in utero and genetic counseling services are offered to families before and during pregnancy to assess their genetic risks and/or to receive counseling about a detected condition. The NC Birth Defects Monitoring Program records detailed information about all infants born with birth defects. Not only does this provide critical information for health monitoring and research, the program has a mechanism to refer affected children to Child Service Coordinators as needed. Utilizing a primary prevention strategy, the interagency NC Folic Acid Council works to decrease North Carolina's high rate of neural tube defects through: a statewide public education campaign to encourage women to take a daily multivitamin with folic acid, professional education, a statewide college campus outreach project, and focused initiatives in the western and eastern parts of the state. The Fetal Alcohol Syndrome Coalition addresses prenatal alcohol consumption, the leading cause of mental retardation. Perinatal Substance Abuse Treatment Programs provide gender-specific, in-patient treatment for pregnant women or women with young children. Since the mid-1990s the NC Family Health Resource Line has served as a bed locator service for healthcare providers who need referrals for their pregnant patients or patients with young children.

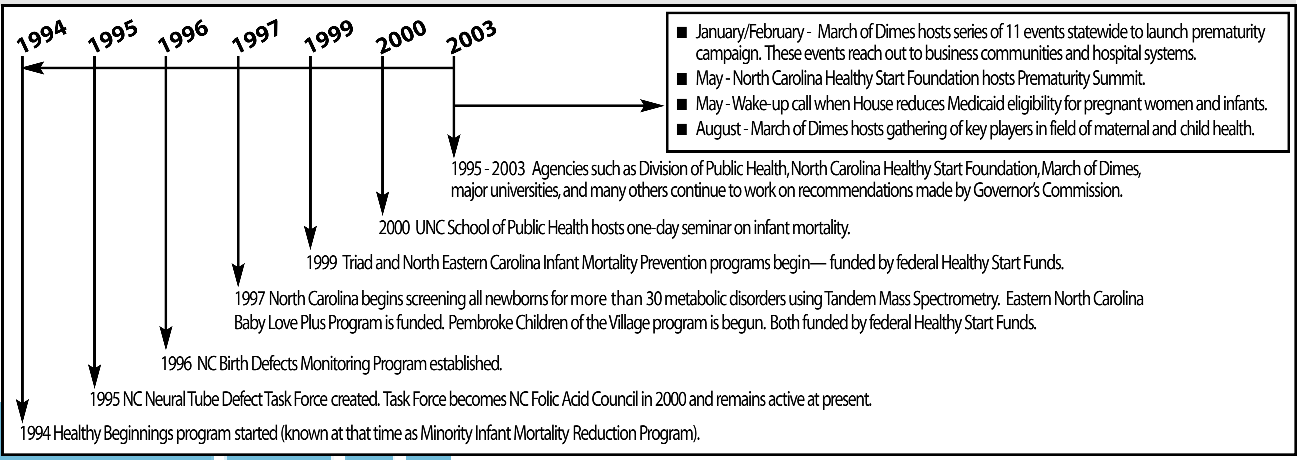
Smoking during pregnancy is the single most preventable cause of low-birth weight, yet North Carolina women smoke at a rate that is greater than the national average (13.2% versus 12.0% in 2001). The statewide Women and Tobacco Coalition for Health has evolved over the years and now plays an important role in promoting smoking cessation for women of reproductive years. North Carolina's "Guide for Counseling Women Who Smoke" has been a national model for healthcare providers since 1996. Trainings have been institutionalized and are now available for public and private providers through *QuitNow NC* and the state's Perinatal Outreach and Education Trainers.

The state also has 12 Level-Three Neonatal Intensive Care Nurseries, which are equipped to care for North Carolina's sickest babies. The Neonatal Transport Program, annual cross-hospital provider conferences, and Neonatal Outreach Educators and Trainers are some of the ways the state addresses prematurity and other birth related problems once they have happened.

In addition, North Carolina leads the nation in newborn screening services that are offered to all babies born in the state. It was the first state to use tandem mass spectrometry—an innovation in newborn screening. North Carolina screens for every disorder including hearing (with the exception of biotinidase[3]) allowing for early detection and treatment of a variety of lethal and potentially debilitating conditions.

Even within the programs described above, and using current proven best practice strategies, there is room for improvement. More pregnant women need to get early prenatal care and to be screened and treated for infections. All pregnant women should be taught the signs and symptoms of preterm labor. More healthcare providers need to be trained, reimbursed and willing to talk with their pregnant patients about alcohol, tobacco and other drugs, and to provide counseling and follow-up services. All new parents should be advised to place their children to sleep on their backs. Additional mental health services are needed and public awareness must be raised about North Carolina's "Safe Surrender" law, which allows a new mother, unable or unwilling to care for her baby, to surrender a young infant (up to seven days old) to a responsible adult and not face criminal charges.

There is no doubt that focusing on pregnancy and neonatal care has improved North Carolina's birth outcomes. Current services and programs are vital to maintaining the hard-earned progress that has been made on behalf of the women and infants of this state.



- January/February - March of Dimes hosts series of 11 events statewide to launch prematurity campaign. These events reach out to business communities and hospital systems.
- May - North Carolina Healthy Start Foundation hosts Prematurity Summit.
- May - Wake-up call when House reduces Medicaid eligibility for pregnant women and infants.
- August - March of Dimes hosts gathering of key players in field of maternal and child health.

1995 - 2003 Agencies such as Division of Public Health, North Carolina Healthy Start Foundation, March of Dimes, major universities, and many others continue to work on recommendations made by Governor's Commission.

2000 UNC School of Public Health hosts one-day seminar on infant mortality.

1999 Triad and North Eastern Carolina Infant Mortality Prevention programs begin— funded by federal Healthy Start Funds.

1997 North Carolina begins screening all newborns for more than 30 metabolic disorders using Tandem Mass Spectrometry. Eastern North Carolina Baby Love Plus Program is funded. Pembroke Children of the Village program is begun. Both funded by federal Healthy Start Funds.

1996 NC Birth Defects Monitoring Program established.

1995 NC Neural Tube Defect Task Force created. Task Force becomes NC Folic Acid Council in 2000 and remains active at present.

1994 Healthy Beginnings program started (known at that time as Minority Infant Mortality Reduction Program).

North Carolina is Moving in the Right Direction

North Carolina continues to post improving infant mortality rates. The rates have fallen to 8.2 per 1,000 live births in 2002. While we continue to rank near the bottom in national comparison, we are slowly moving in the right direction.

The number of babies lost to SIDS continues to decline and the number of babies born with birth defects, particularly those of the brain and spine, continues to decline.

Adolescent pregnancy is at an all time low for North Carolina. Many more women are receiving early and adequate prenatal care.

In Our Favor

1. Major medical centers, universities, and pharmaceutical companies are doing cutting edge research on the topic of prematurity and maternal and infant health. These not only benefit the larger population, but they have the potential to make the latest medical treatment options available to North Carolina's women and infants. They also hold a wealth of information about their study populations.
2. There is strong leadership in the arena of smoking cessation—particularly for youth and pregnant women. This includes having Smoke Free Families leadership in North Carolina, the QuitNow NC campaign supported by NC Prevention Partners and many others, the Women and Tobacco Cessation for Health (WATCH) committee, and award-winning products such as the *Guide for Counseling Women Who Smoke*—a self-help guide for healthcare providers who want handbooks to help pregnant women quit and to reduce second hand smoke exposure. The state has access to national quit lines with one available specifically for pregnant women—and plans to start such a line just for women in North Carolina. The National American College of Obstetricians and Gynocologists (ACOG) organization has supported a strong partnership with North Carolina and is bringing important resources and connections to the table. A number of groups have supported innovative smoking cessation grants across the state. The NC DHHS Division of Public Health has a position dedicated to this issue and the perinatal outreach educators and trainers consider smoking cessation a cornerstone issue.
3. Non-profits such as the March of Dimes and North Carolina Healthy Start Foundation are strong and collaborative players in North Carolina. Through grassroots outreach and excellent education products, these and other agencies build on their strengths to make an impact.
4. The state has a very strong Folic Acid Campaign and a very strong Back To Sleep Campaign.
5. The Division of Public Health's Women's and Children's Health Section is well respected and organized—it manages a host of excellent programs and services.
6. The state receives significant funding from the Federal Healthy Start Intiative (Health Resources and Services Administration/Maternal and Child Health Bureau).
7. The State Center for Health Statistics has a number of key data collection tools, including the NC Birth Defects Monitoring Program (recently funded by the Centers for Disease Control and Prevention as a Center of Excellence), Pregnancy Risk Assessment Monitoring System (PRAMS), and Behavioral Risk Factor Surveillence System (BRFSS). The Cecil G. Sheps Center for Health Services Research at the University of North Carolina at Chapel Hill is an active partner in data organization and evaluation.
8. Healthcare professions in neonatology and maternal/fetal medicine have begun to meet jointly on issues of relevance to both groups.

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3 Biotinidase Deficiency is caused by the lack of an enzyme called biotinidase. This disorder can lead to seizures, developmental delay, eczema, and hearing loss.

COMMENTARY

Improving Pre-pregnancy Health Is Key to Reducing Infant Mortality

Robert G. Dillard, MD

We could have asked our grandmothers. They would have told us what has otherwise taken at least 30 years, countless studies, and millions of dollars to discover. In order to have a healthy baby, a woman must be healthy, not only during pregnancy, but perhaps more importantly, before she conceives.

Efforts to Reduce Infant Mortality Since 1970

North Carolina's high rate of infant mortality compared with other state and national rates has been a source of puzzlement and embarrassment for years. Blessed with superb medical facilities and a reputation for advanced healthcare planning, our state has perennially ranked among the worst in rates of infant death among all 50 states. In hopes of improving the state's position, state leaders in the mid-1970s began developing a system to provide universal access to high-risk prenatal care and neonatal intensive care. It seemed logical that exposing women with pregnancy complications to the best care available would result in improved pregnancy outcomes.

Fifteen years later, few states had a more remarkably successful regional perinatal system than North Carolina's. During those 15 years, North Carolina's infant mortality rate dropped by a dramatic 36%.[1,2] The other 49 states had similar rates of improvement. Most did so without strong regional programs like North Carolina's. Virtually all of the nation's improvement in infant mortality, including North Carolina's, had come as a result of improvements in birth-weight-specific deaths among premature infants. In 1988, only Georgia had a higher rate of infant mortality than North Carolina's.[3]

In 1988, a task force appointed by the NC Secretary of Health and Human Resources reported that the state's excessive rate of infant mortality resulted from an excessive number of premature births. It made a number of recommendations to address the problem, including recommendations to improve prenatal services, but recognized that prematurity and infant mortality reduction required "social and economic interventions" as well as healthcare approaches.[4]

> *"As attractive and relatively inexpensive as prenatal care is, a medical model directed at a six-to-eight month interval in a woman's life can not erase the influence of years of social, economic, and emotional distress and hardship."*

In the first half of the 1990s, the NC Governor's Commission on the Reduction of Infant Mortality was charged with the task of implementing programs to address the problem of premature birth. It disbursed funds from a variety of sources to enhance prenatal services and to focus on social and emotional issues among poor pregnant women during their pregnancy. Acknowledging the dramatic disparity between white and minority populations, the Commission targeted initiatives to minority women.

Prenatal Care Is Not Enough

By the mid-1990s, prenatal care had not been shown to reduce rates of premature birth, especially among poor and minority women.[5] As attractive and relatively inexpensive as prenatal care is, a medical model directed at a six-to-eight month interval in a woman's life can not erase the influence of years of social, economic, and emotional distress and hardship.

Premature birth is strongly associated with poverty, stress, racism, substance abuse, short inter-birth intervals, previous premature delivery, certain types of work activities, and inadequate nutrition. Lower genital tract infections are strongly associated with premature delivery. However, treatment of such infections does not reduce preterm births.[6] It seems increasingly likely that

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such infections are a manifestation of stress in pregnancy.[7]

It is time to disabuse ourselves of the notion that prenatal care is the key to reducing infant mortality by reducing premature deliveries. It is time now to focus on the health of women of childbearing age before they become pregnant. Such a task will be far more difficult than establishing a regional perinatal network or ensuring access to prenatal care. It will entail enhancing education for minority populations to break the vicious cycle of poverty and the stress that comes from it. Communities must own up to the pervasive and devastating effects of racism and then begin to eliminate racism in our culture. We must address the serious consequences of smoking and illegal substance abuse. Women, especially poor women, must have the right to become pregnant when they want to be pregnant and not to become pregnant when they don't want to be. In a time of job shortages in North Carolina, it will be difficult to ensure that pregnant women can avoid jobs that make it less likely that they will deliver a premature baby. However, the short- and long-term economic and social consequences of not doing so overwhelm the modest expenses of temporary reassignment. The overwhelming nutritional problems that lead to poor pregnancy outcomes have their roots in childhood. We must do a better job teaching our children to eat well, and more importantly, we must provide them with better food choices.

> *"It is time now to focus on the health of women of childbearing age before they become pregnant."*

New Approach to Providing Health Services to Women of Childbearing Age.

In addition to community-based initiatives, we need to develop a new approach to providing health services to women of childbearing age.[8] Such an approach would begin in early adolescence and continue until menopause. The system would combine elements of standard medical care, public health, and social services. It would start with a comprehensive, age-linked, annual assessment. The assessment tool would address traditional medical topics, but also focus on social, economic, and environmental issues. Analysis of such a broad individual assessment would facilitate appropriate referral to clinical, public health, and other community resources.

Each community would identify its available resources and link them to applicable sections of the assessment. Such a linked catalog of services would facilitate timely and appropriate referrals. Community care workers, familiar with available resources, would be assigned to women whose assessments indicated the presence of high-risk factors in order to ensure that such women had ready access to the best available resources.

Implementing such a system, including identification of funding sources, development of culturally-sensitive and specific tools, creation of the best methods for gaining access to women who would benefit from the system, and evaluation of the impact of the system will require considerable effort on the part of community leaders. However, if the system were successful in addressing and correcting the serious health, economic, social, and environmental factors that lead to premature birth and other poor pregnancy outcomes, infant mortality rates would drop. North Carolina could then deserve the reputation it has as a forward-looking southern state. **NCMJ**

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COMMENTARY

Infant Mortality:
1963 to Present Medical Developments and Legislative Changes

William R. Purcell, MD

On August 8, 1963 a premature infant boy, Patrick Bouvier Kennedy, was transferred from Otis Airforce Base near Hyannis Port to Boston Children's Hospital. He died the next day at age 39 hours from respiratory distress syndrome.

There was little we could do in 1963 to care for premature and low-birth weight babies. In many hospitals small prematures were kept warm, given oxygen and subcutaneous fluids and sometimes placed on "rocking" beds. Some even suggested that if kept cool they would better tolerate low-blood oxygen levels. As expected, many of the low-birth weight infants who survived were more likely to be "small for gestational age" than "premature."

High Infant Mortality Rates Led to Legislative Changes

In 1963, 31.1 out of every 1,000 babies born alive in North Carolina died before they reached their first birthday. The infant mortality rate for white infants was 22 and 50.6. There were premature nurseries but no real neonatal intensive care units. There were no ventilators designed for premature infants and there was no simple way to measure newborn blood gases. Vascular access through the umbilical cord was used mainly for exchange transfusions. The role of continuous positive airway pressure and surfactant were not generally understood. This was five years before Dr. J. F. Lucey published his article in *Pediatrics* regarding the use of "blue lights" for the treatment of neonatal hyperbilirubinemia.[1] Neonatal hypoglycemia was rarely considered.

Historically, North Carolina has always had one of the highest infant mortality rates in the country. In the early 1970s, the NC General Assembly and the Governors' Office tried to address this problem by establishing a regional perinatal care system and providing funds for maternity clinics, family planning and delivery services. Later, in the mid-1980s, the General Assembly expanded Medicaid to increase coverage for pregnant women and infants. Reimbursement rates for delivery services and prenatal care were increased as well.

In the fall of 1989, the Centers for Disease Control and Prevention (CDC) reported that North Carolina had the worst infant mortality rate of any state in the nation (1988 provisional data). Governor Martin created the Governor's Commission on Infant Mortality and changed Medicaid policies to cover all pregnant teens, regardless of parental income, in an effort to encourage them to seek prenatal care. In 1990, the NC General Assembly implemented a four-year plan to reduce infant mortality by expanding access to prenatal care, primarily through the reduction of financial barriers to that care. This involved expanding Medicaid to cover women and infants with incomes up to 185% of the federal poverty guidelines and again increasing reimbursement for prenatal care and delivery. The Rural Obstetric Care Incentive program was expanded to help offset malpractice insurance premiums for providers who were willing to provide maternity care in medically underserved areas. Funding was provided for teams of nurse midwives to provide obstetrical services in these areas and a nurse midwifery program was created at East Carolina University.

Infant malnutrition became a rarity after the onset in 1974 of the federal Supplemental Nutrition Program for Women Infants, and Children (WIC) Program. The WIC Program provides vouchers to low-income pregnant and post-partum women to purchase food for themselves, their infants and their children up to age five. The Legislature also created a birth defects registry and helped the March of Dimes fund a folic acid awareness program.

Although most infant deaths occur in the perinatal period, measures were taken to reduce the death rate and injury to older infants. Legislation was adopted requiring infant car seats for all infants and back to sleep programs

> *"Historically, North Carolina has always had one of the highest infant mortality rates in the country."*

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for infants in childcare centers. Severe penalties were adopted for operating unlicensed childcare centers or for giving medications to children in childcare centers without parental permission. During this time North Carolina developed one of the best childhood immunization programs in America.

Medical Developments in Obstetrics and Neonatology

Since 1963 there has been a revolution in obstetrics and neonatology with technology leading the way. The use of ultrasound and fetal monitors are now routine procedures and amniocentesis has become a common tool in pregnancy management. The use of Rh (D) immune globulin has made exchange transfusions a rarity. The devastating effects of alcohol usage, smoking, and inadequate folic acid are generally understood.

A real revolution has occurred in the care of premature and sick newborns. A fantastic transport system now brings the medical centers' neonatal intensive care nursery into the local hospital. Pediatricians across the state are trained in the resuscitation and stabilization of sick newborns while awaiting transport teams. Blood gases can be measured percutaneously or with only a few drops of blood. The impact of assisted ventilation, continuous positive airway pressure, surfactant, hand washing, sepsis, hypoglycemia, and phototherapy on the survival of sick newborns is well recognized. Touch and loving care have been shown to increase the chances for survival so now we even encourage parents to touch and hold their ill newborns. This is a far cry from the days when parents weren't even allowed in the nurseries! The recognition of the importance of breast milk in nutrition and resistance to infections have also had a major impact on infant survival and well being.

We Have Reduced Infant Mortality Rates, but Challenges Remain

In 1963 there were 107,322 live births in North Carolina and there were 3,342 infant deaths (31.1 deaths per 1,000 live births). In 2002 there were 117,307 live births with 957 infant deaths for an infant mortality rate of 8.2, the lowest ever recorded in North Carolina. Clearly, the advances in medical knowledge and expertise, coupled with policy changes that made it easier to access prenatal care have helped to improve the state's infant mortality rate. However, we cannot rest on these accomplishments. North Carolina still has a higher than average infant mortality rate. Nationally, there were seven infant deaths per 1,000 live births in 2002. Further, while North Carolina's infant mortality rate has improved for all races, the infant mortality rate is still more than two times higher for minorities (14.2 per 1,000 live births) than whites (7.0 per 1,000 live births).

Patrick Kennedy brought the difficulties faced by premature infants to the world's attention and made all of us in healthcare aware of the inadequacy of our knowledge, our technology, and our ability to provide the help that was needed. Surely some of the credit for the revolutionary advances in obstetrics and neonatology must be given to that tiny baby boy born to Jacqueline Kennedy at Otis Airforce Base in 1963.

Despite the advances in care and treatment, many questions remain only partially answered. What causes prematurity? What causes birth defects? What causes SIDS? What causes racial disparity? We do know that healthy lifestyles help prevent prematurity. We know that adequate folic acid prevents neural tube defects. We do know that placing infants on their backs to sleep reduces the incidence of sudden infant death syndrome. We know that lifetimes of poverty, stress, and subclinical infections may contribute to racial disparity in birth outcomes.

All of these partially answered questions and many more must remain on the front burner of our state and national government and on the front burner of all involved in providing healthcare to pregnant women and their infants. We must continue to find ways to improve North Carolina's unacceptable levels of infant mortality, and especially, racial disparities.

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North Carolina Makes Strides to Reduce SIDS, but Challenges Lie Ahead

Christine O'Meara, MA, MPH

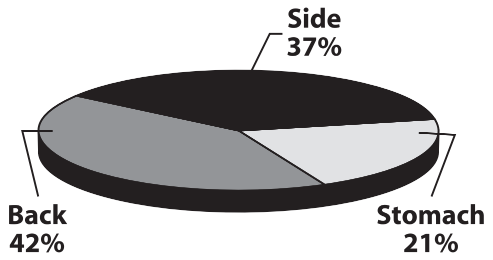
Sudden Infant Death Syndrome (SIDS) is the third leading cause of infant mortality in North Carolina. Five-year trends show that approximately 100 babies under the age of one year continue to die suddenly and unexpectedly in North Carolina each year.

The SIDS landscape is one in which North Carolina's rate has consistently exceeded the national rate. In 1988 the NC SIDS rate was 1.87 per 1,000 live births compared to the US rate of 1.4 per 1,000 live births. In the intervening thirteen years, SIDS rates have dramatically decreased. The state's lowest SIDS rate ever, 0.7 per 1,000 live births, was reported for 2002. From 1995 to 2002 the NC SIDS rate has fallen 36%.[1]

While this decline in SIDS is certainly good news, it tells only half of the story and should be viewed with cautious optimism. As with infant mortality, the SIDS rates reflect an unacceptable disparity among populations. African American infants are dying from SIDS at twice the rate of white infants. From 1998-2002 NC African Americans accounted for 41% of SIDS deaths, a rate of 1.35 per 1,000 live births, compared to the white rate of .66 per 1,000 births or 58% of SIDS cases. American Indians accounted for 1% of SIDS deaths, a rate of .83 per 1,000 live births, during this same timeframe.

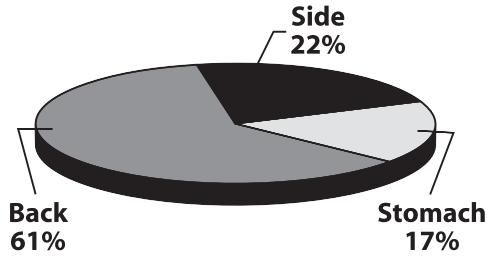
Public education and awareness campaigns have contributed to reductions in SIDS rates. The reversal in the infant sleep positioning message from the prone to the supine or to the side by the American Academy of Pediatrics (AAP) in 1992 and the 1994 National Back To Sleep Campaign's reinforcement of this message resulted in a greater proportion of infants positioned on their back or side for sleeping and a corresponding 50% drop in SIDS deaths nationally.[2] The AAP revised its infant sleep position recommendation for healthy infants from stomach to back only in 2000. Closer to home, the statewide NC Back To Sleep Campaign, also launched in 1994, is credited with contributing to the more than 30% reduction in SIDS we have today.

Figure 1.
1998 Infant Sleep Position – NC PRAMS Data



Source: NC State Center for Health Statistics 2004

Figure 2.
2001 Infant Sleep Position – NC PRAMS Data



Source: NC State Center for Health Statistics 2004

NC Pregnancy Risk Assessment Monitoring System (PRAMS) data collected by the State Center for Health Statistics documents a significant shift in infant sleep position by North Carolina parents and primary caregivers since 1998.[3]

Both Figures 1 and 2 demonstrate that the back sleep position is the most commonly used position for sleeping infants, followed by the side. A comparison of sleep position changes from 1998 to 2001 shows a marked increase of 19% for infants placed on their backs to sleep with corresponding decreases in the side (15%) and, to a lesser degree, the stomach (4%) sleep positions. The NC Back To Sleep Campaign goal, in keeping with the national goal, is to reduce the prone sleep position for infants to not more than 10%.

According to PRAMS data, two-thirds of whites and Latinos place their infants on their backs for sleeping, a practice that is much less common among African Americans (43%). African Americans are much more likely to favor the stomach sleep position for infants (24%) compared to whites (14%) or Latinos (8%). The side sleeping position for infants is also preferred more often among African Americans (32%) and

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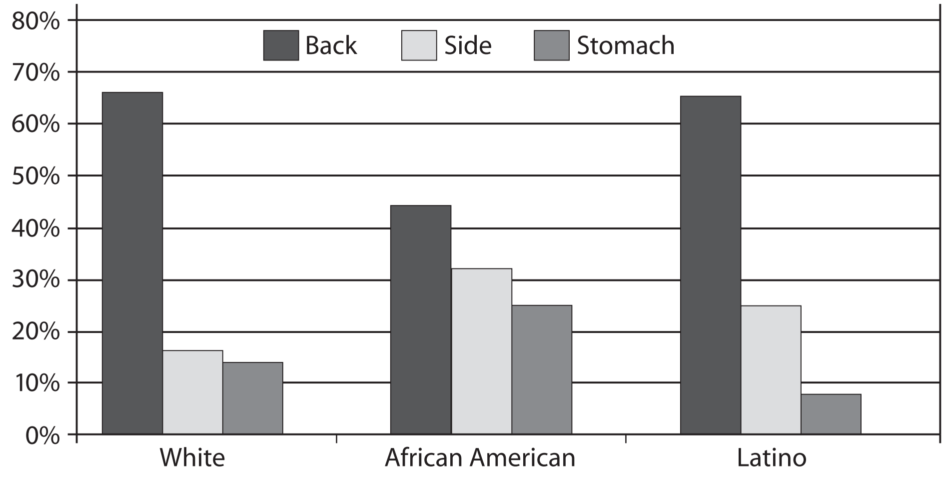
Figure 3.
2001 Infant Sleep Position by Ethnic Group – 2001 PRAMS Data



Source: NC State Center for Health Statistics 2004

Latinos (25%) and occurs less frequently among whites (18%). Cultural practices, the influence of a grandmother in the household, medical conditions, parent's preference, modeling and parent education by medical professionals such as newborn nursery staff, and experience with a previous infant contribute to infant sleep position practices. Concerns about choking, plagiocephaly (flat heads), or a bald spot are oftentimes barriers to placing babies supine for sleeping.

Epidemiological and PRAMS data are critical elements for the NC Back To Sleep Campaign's social marketing strategies and are used to identify audience and sleep position messaging. Statewide data depicting the distribution of SIDS deaths are used to target media markets at the county level. These data point to a continued need to inform North Carolinians about SIDS risk reduction and to particularly engage the African American community in infant safe sleep strategies. State efforts are challenged to keep up with the demand for culturally competent Spanish language SIDS education and outreach for Latinos.

SIDS is a Leading Cause of Deaths in NC Childcare

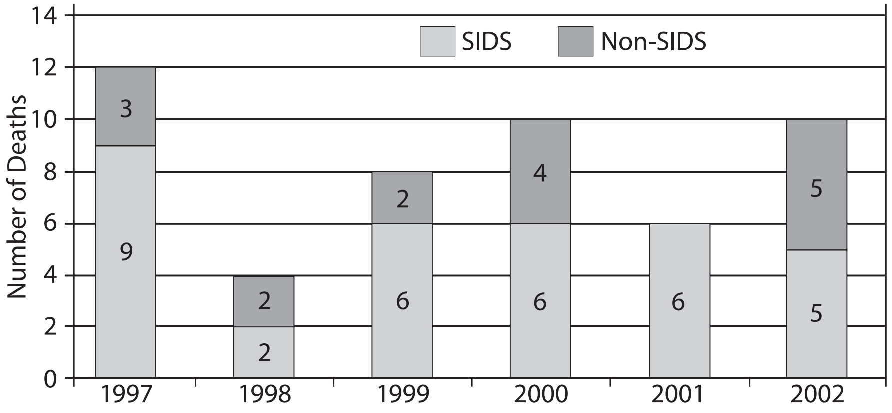
National research suggesting that a disproportionately high number (20%) of SIDS deaths occurred in childcare sounded an alarm that prompted the targeting of childcare providers for SIDS risk reduction education and training. Researchers found that, while more infants were positioned for sleep on their backs in childcare, those succumbing to SIDS in childcare were more likely to have been placed on their stomachs for sleeping. Of the smaller subset of babies (N=99) for whom information about the length of time in childcare was available, one-third had died during their first week in childcare and one-half of these occurred on the first day.[4] Unaccustomed prone sleepers may be at a higher risk when positioned prone. Approximately 7% of North Carolina's SIDS deaths occur in childcare settings, a figure one might expect to observe given Census data and the amount of time infants spend there.

The state has almost 16,000 infants in licensed childcare, according to the NC Division of Child Development (DCD). Figure 4 illustrates that two-thirds of all deaths from 1997 to 2002 in NC childcare were attributed to SIDS. During this six-year period, there were 34 SIDS deaths and 16 deaths due to other causes.

SIDS Risks Present in NC Childcare

Observational and survey data collected in 2002 prior to the implementation of the Infant/Toddler Safe Sleep and SIDS Risk Reduction in Child Care (ITS-SIDS) initial training, and prior to SIDS risk-reduction legislation in 2003, showed that SIDS risk factors were present in a sample of 217 regulated childcare centers and homes in North Carolina. Sleep position varied and included side, stomach, back, and sitting. Babies

Figure 4.
Proportion of SIDS to Non-SIDS Deaths in North Carolina Childcare from 1997 to 2002



Source: NC Division of Child Development slept in a variety of places such as cribs, bassinets, playpens, bouncy-seats, car seats, and, in the case of one childcare home, on a sofa. The immediate sleep environment contained toys, stuffed animals, and excess bedding. Although rare, there was evidence of cigarette smoke in one family childcare home. Very few facilities had a written safe sleep policy in place. Though some caregivers had attended SIDS workshops, childcare providers identified SIDS training and policy development as needed and most expressed a desire to have educational print materials for parents.

Media is a Catalyst to Combat SIDS

A cascade of recent events has impacted how North Carolina's babies are sleeping at home and in childcare. SIDS has been in the media spotlight frequently in the past year, not only as a news feature but also in the halls of the NC General Assembly. Consequently, we are witnessing a ripple-effect of safe sleep policies being implemented in a variety of childcare settings and adopted in private homes.

Beginning February 16, 2003, the Raleigh *New & Observer* published a three-day investigative series entitled *Case Closed: Deaths in Day Care*[5] that focused attention on SIDS, the unauthorized administration of medication in childcare and the operation of unlicensed, illegal childcare in the state. A strongly worded editorial on February 19, described the shortcomings in North Carolina's regulation of day care center's as not only unacceptable, but despicable! This editorial demanded that the Governor and legislative leaders toughen childcare oversight and regulation and outlined several strategies to address health and safety concerns in the state's more than 9,000 licensed childcare facilities. To tackle SIDS, the *News & Observer* called for a state law requiring that infants in day care not be put to sleep on their stomachs. Representative Martha Alexander, a stalwart child advocate, was quick to act, and by late February House Bill 152, the precursor to the NC SIDS Law, had been filed.

The NC SIDS Law

December 1, 2003 is an historic moment in the state's battle against SIDS. North Carolina joined the ranks of a handful of states legally mandating that licensed childcare providers position babies 12 months of a age or younger on their backs for sleeping, having written policies in this regard, and obtaining training for childcare workers. House Bill 152 expanded General Statue 110-91 pertaining to mandatory childcare standards and was ratified as GS 110-91-15. The NC Prevent SIDS law includes a waiver provision based on medical need, for infants six months of age or younger. The law also allows a parent or legal guardian to waive the back to sleep requirement for infants older than six months. This allowance represents a political compromise and is not a best practice in accordance with recommendations of the AAP and the National Resource Center for Health and Safety in Child Care. Nonetheless, other elements of the law do reinforce standards designed to lower SIDS risks in childcare, including the mandate to develop a written safe sleep policy and to discuss it with parents prior to the child's enrollment. The type of required SIDS-related training was unspecified in the law.

NC Childcare Licensing Rules

The next step was to codify the more broadly written law into specific licensing rules for childcare providers. Developing guidelines for everyday practice is the responsibility of the NC Child Care Commission (CCC). The Commission is comprised of legislative appointees and includes childcare providers, community leaders, a pediatrician and Division of Child Development (DCD) staff. The Commission's rules committee, faced with the task of weaving legal requirements into childcare licensing rules, included a subset of Commission members, child advocates, legal counsel, DCD staff members and this author. Rule changes affecting behaviors and environmental factors associated with SIDS risks were proposed, reviewed by the Commission, tweaked, and then posted for public comment for two months from December 2003 to February 13, 2004. Revisions to the proposed rules incorporated feedback from the public review process and were then subjected to legal review by the Rules Review Commission in March and entered into the Code by the Office of Administrative Hearing in April. The resulting licensing rules went into effect May 1, 2004.

Of significance, the rules pertaining to safety and sanitation include prohibitions on tobacco use around children in family childcare homes and vehicles when transporting children, where none had existed heretofore. Secondhand smoke more than doubles the chances of SIDS, exacerbates asthma, is an allergen, and triggers respiratory infections. Tobacco products are a leading cause of childhood poisoning.

The revised licensing rules addressing infant/toddler sleep safety and SIDS apply to childcare providers licensed to care for infants 12 months of age or younger and are summarized as follows:

1. An infant 12 months of age or younger is to be positioned on the back for sleeping unless a waiver states otherwise. A physician waiver exempting back to sleep for infants six months of age or younger is required. Childcare providers may choose to implement a parent waiver for infants older than six months.

   Note: *The Alternative Sleep Position Waiver—Physician Recommendation* form, developed by the DCD, must be completed by the child's primary care physician in the event a medical condition necessitates it. The waiver states the medical reason for a sleep position other than the back and the recommended alternative sleep position must be identified.
2. A notice indicating that a waiver is in effect and stating the recommended sleep position must be posted near the child's crib. The signed waiver is to be kept in the child's file.
3. A written safe sleep policy or poster must be prominently posted and this information communicated to parents before a child is enrolled. The policy must be discussed with

parents of currently enrolled infants within 30 days of the rules' effective date.

4. The crib, bassinet or playpen will have a firm padded surface.
5. Baby's head or face shall not be covered.
6. Tobacco products can not be used at any time children are in care; and smoking or use of tobacco products is not allowed indoors when children are in care, or in a vehicle when children are transported.
7. The room temperature where babies sleep cannot exceed 75°F.
8. Sleeping babies must be visually checked and the frequency of checking and observations documented. This record must be kept on file for one month following the reported month.
9. Awake infants shall have a daily opportunity to play while on their stomachs.
10. The Infant/Toddler Safe Sleep and SIDS Risk Reduction in Child Care (ITS-SIDS) training is the designated training.
11. Owners/operators/directors, lead infant teachers, substitutes and volunteers counted in the child-to-staff ratio must obtain ITS-SIDS training. Providers must renew their ITS-SIDS certification every three years. New hires shall receive ITS-SIDS training within four months of hire or within four months of the rules becoming effective, whichever comes later.

ITS-SIDS Training Project

The Infant/Toddler Safe Sleep and SIDS Risk Reduction in Child Care (ITS-SIDS) Project is a train-the-trainer initiative developed as part of the NC Back To Sleep Campaign, a program of the North Carolina Healthy Start Foundation. It adheres to the AAP recommendations, national child health and safety gold standards and best practices aimed at reducing SIDS. ITS-SIDS was initially funded for two years by the NC Division of Child Development on July 1, 2002—almost one and a half years before the NC SIDS law went into effect. Given the sequence of events and training needs, the Division expanded funding for Phase Three from December 1, 2003 through June 30, 2005.

Project goals are to: (l) introduce a safe sleep standard in NC childcare, (2) develop a cadre of certified ITS-SIDS trainers and (3) provide contact hour credits for childcare providers. The objective is to train 180 certified ITS-SIDS trainers who would, in turn, train 14,500 childcare providers over the course of the three years. ITS-SIDS trainers are made up of Child Care Resource and Referral staff, Smart Start Partnership staff, Child Care Health Consultants, Cooperative Extension Service Agents, Migrant Head Start staff, childcare directors and private trainers.

With changes in the legal and licensing requirements the demand for ITS-SIDS training across the state has skyrocketed. A total of 208 ITS-SIDS trainers have been certified. As of May 28, 2004, over 17,950 childcare providers have received ITS-SIDS training and 982 trainings have been scheduled or completed. While not all North Carolina counties have a resident ITS-SIDS trainer, all 100 counties do have training coverage. A fourth train-the-trainer series is planned for fall 2004 to address trainer attrition and to provide updated information.

How Will the NC Licensing Laws Affect Healthcare Providers?

There are several areas where physicians, perinatal healthcare providers and parent educators are impacted by the sleep safety and SIDS risk-reduction childcare requirements. First, physicians may be approached by parents to complete the *Alternative Sleep Position Waiver—Physician Recommendation* form. This waiver exempts a child 12 months of age or younger from being placed on his or her back to sleep based on a medical condition and specifies the recommended sleep position for that child. The baby's doctor is also asked to indicate the time frame for which the waiver applies. The onus of responsibility for the baby's sleep safety in childcare is shared by both the caregiver and the baby's primary care physician.

Parent-physicians desiring to waive the back sleep position for their child and attempting to sign the medical waiver themselves, muddy the legal waters and place the caregiver in an awkward situation. This scenario has already occurred in North Carolina and in other states. In Illinois, for example, providers are instructed to tell the parent-physician that they must choose. Either they assume the role of parent or that of doctor, but not both.

Particularly striking is the juxtaposition between what parents observe in the hospital or are taught by newborn nursery staff and what is played out in the childcare arena. Tension around the issues of infant sleep position, swaddling, use of sleep positioning devices such as blanket rolls or wedges and co-sleeping twins is a dynamic situation already occurring downstream from the hospital setting and now surfacing in childcare settings.

Not all of North Carolina's hospital nurseries practice the back to sleep standard of care for healthy babies. Some, but not all, of the state's Neonatal Intensive Care Units (NICU) have guidelines for transitioning infants from their stomach or side sleep position to their back; this should be as routine as the testing done for car seat safety among preemies. Similarly, educating about infant sleep safety and transitioning to the back sleep position should be incorporated into routine hospital practices as part of preparing all infants for discharge.

Parents are being taught in the hospital to swaddle infants for comfort and for security, but are they being informed about the signs of overheating, a SIDS risk factor? Are they instructed about when to discontinue swaddling? When parents insist that their four-week, six-week, or three-month old infant be swaddled in childcare, providers are in a quandary. Is swaddling helpful or harmful at these ages? The likelihood of overheating increases for a swaddled child. Furthermore, is the childcare provider using correct swaddling techniques that will prevent the blanket from covering the baby's head?

Bed sharing or co-sleeping with a parent or with a sibling poses dangers to infants by increasing the likelihood of SIDS, overlay (parent or sibling rolling onto infant), suffocation, overheating, entrapment, and injury due to falls from a bed without railings.

The pros and cons of co-sleeping are extremely controversial.[6] Breast feeding advocates promote bed sharing while professionals involved in SIDS risk-reduction education and sleep safety discourage it.

Data suggest that twins are at a greater risk for SIDS due to several factors: being born with a lower birth weight, a shorter gestation, and more complications during pregnancy. The co-bedding of twins in hospitals, at home, and in childcare settings remains a complex issue. Hospital practices for twin sleeping arrangements influences the infant sleep practices that parents adopt at home.[7] In North Carolina childcare, crib sharing among infants—even twins—is a violation of childcare licensing rules, yet parents have sought and have obtained a physician's waiver to allow this practice. In one case the physician stated there was no medical reason for co-sleeping the twins, but that the parent had requested it. Again, the safety of the infants, the reasoning of this decision, and the legality of this action are called into question.

SIDS Risk Reduction in Childcare Reaches Parents

One favorable consequence of the safe sleep standards now required in NC childcare is that caregivers are informing parents about the steps they are taking to reduce SIDS risks. This has a spillover effect and extends the arm of SIDS awareness from the childcare setting into the infant's own home. Indeed, many of the ITS-SIDS trainers are being asked by childcare providers to present at parent orientations or to conduct workshops with parents. Providers can share free educational materials with parents that are developed and distributed by the North Carolina Healthy Start Foundation.

Childcare providers are also taking the safe sleep and SIDS risk reduction message home. Many professional childcare workers are themselves parents or grandparents. Evaluations from their ITS-SIDS training show they plan to adopt the recommendations in their personal lives and to share the information with others.

Growing National Efforts to Address SIDS

The American Academy of Pediatrics has recently reconvened their task force on Infant Sleep Position and SIDS to reassess SIDS-related research and to address issues such as hospital nursery guidelines, waivers in childcare, swaddling and co-sleeping. A position statement updating their 2000 recommendations[8] is expected in autumn 2004. Hospital nurseries and Neonatal Intensive Care Units (NICUs) nationwide are re-examining their sleep position guidelines in light of the earlier standards set forth by the AAP. And, the AAP together with the National Resource Center for Health and Safety in Child Care and other national SIDS organizations has initiated a nationwide "Back To Sleep Campaign" for childcare facilities and has incorporated elements of North Carolina's ITS-SIDS training curricula. The AAP is partnering with the National Conference of State Legislators to promote safe sleep/back to sleep and SIDS risk reduction legislation in states across the county.

North Carolina is Leading the Way in SIDS Risk Reduction

North Carolina is an active leader in SIDS risk reduction in childcare. The state has adequate SIDS-related legislation, carefully revised licensing rules, a robust ITS-SIDS training program and an active Back To Sleep public education and awareness media campaign in motion. Networking occurs on a national level and statewide provider and parent education is fostered through the solid cadre of ITS-SIDS trainers. However, challenges and gaps remain, particularly in the areas of developing and sustaining more in-depth and interactive parent and grandparent SIDS risk-reduction interventions. There is a pressing need to competently address targeted SIDS risks for African Americans and among our growing Latino population and to make culturally and linguistically appropriate outreach available to Latino childcare providers and families. And there remains a need for hospital nurseries and NICUs across the state to convey and model a clear and consistent safe sleep/back to sleep message to parents.

Limitations on workplace tobacco use in childcare settings and growing awareness among childcare providers and parents via the ITS-SIDS training that smoking triples the SIDS risk (babies' secondhand smoke exposure doubles it) may stimulate an increased demand for smoking cessation services. Healthcare providers can play a significant role in reinforcing information about the link between SIDS and smoking. Counseling women not to smoke or to avoid secondhand smoke during pregnancy is an essential first step to combating SIDS. The relationship between pre-term/low-birth weight births and SIDS needs to be more clearly understood. This information should then be conveyed to women and families.

While we have a steady compass and a roadmap to help plot our fight against SIDS, only time will tell the extent to which recent policy changes will impact the tragedy of SIDS in childcare and possibly in family homes. It is clear that too many North Carolinians have experienced heartbreak because of SIDS and that we must adequately support community-based efforts to promote infant/toddler sleep safety and SIDS risk reduction in culturally and linguistically appropriate ways for families, other caregivers, and for healthcare professionals. More can and should be done to inform parents and caregivers that lowering SIDS risks begins before the baby is born as well as afterward. **NCMJ**

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Baby's Safe Sleep

Keep room temperature 68° - 72° F. Not over 75° F

Use a firm mattress with a tight-fitting sheet

Remove toys, stuffed animals and pillows when baby sleeps

Check on sleeping baby

Keep cigarette smoke away

Keep baby's face and head uncovered

Do not use wedges and bumper pads

Keep baby from overheating, dress baby in layers that can be easily removed

Place baby at the foot of the crib
If you use a blanket:
- Use a light blanket
- Tuck it along the sides and foot of crib
- Cover baby from chest down

ALWAYS PUT HEALTHY BABIES ON THEIR BACKS TO SLEEP

Take these steps to lower the risk of Sudden Infant Death Syndrome (SIDS)

STOMACH TO PLAY BACK TO SLEEP

FOR MORE INFORMATION

www.NCHealthyStart.org or call 1 800 367 2229

N.C law and child care licensing rules require that babies 12 months of age or younger be placed on their backs to sleep in child care. A waiver may apply under certain conditions.

COMMENTARY

Folic Acid and Birth Defects Prevention:
A Public Health Success Story

Robert E. Meyer, PhD, MPH, and Anna Bess Brown, MPH

Not very many years ago, prevention of birth defects was rarely given serious consideration as an important public health strategy for reducing infant mortality and improving birth outcomes. Some common misconceptions about birth defects—that they are rare events which account for relatively few infant deaths, and that they are essentially unpreventable—probably contributed to the fact that birth defects were largely overlooked as a focus of most infant mortality reduction efforts. Yet, contrary to the perception of many people, birth defects (or congenital malformations, as they are sometimes described) are not that rare. Approximately 3% of all infants are born with serious birth defects. In North Carolina, that translates to about 3,000-3,500 babies affected each year—a number that is 50% greater than the number of babies who are born with very low-birth weight. Birth defects are listed as the underlying cause of death in about one in every five infant deaths in North Carolina, and approximately 30% of all infants who die in the first year of life have one or more birth defects diagnosed. Moreover, many types of birth defects are largely or entirely preventable. Some examples include fetal alcohol syndrome, retinoic acid embryopathy, congenital rubella syndrome, and folic acid preventable birth defects such as anencephaly and spina bifida. While it is true that the etiology of the majority of birth defects is currently unknown, the same is also true for most preterm births, yet the latter still has been a chief focus of infant mortality reduction efforts for decades.

"Birth defects are listed as the underlying cause of death in about one in every five infant deaths in North Carolina..."

Beginning in the early 1990s, a series of landmark events began to set the stage for a significant change in the perception of birth defects as an issue deserving of public health attention. The first of these was the completion of the randomized controlled trial conducted by the Medical Research Council in the United Kingdom which, building upon previous observational studies, demonstrated that preconceptional intake of the B-vitamin folic acid could prevent up to 70% of spina bifida and anencephaly, the two most common types of neural tube defects (NTDs).[1] In September 1992, the US Public Health Service published the recommendation that "All women of childbearing age in the United States who are capable of becoming pregnant should consume 0.4 mg of folic acid per day for the purpose of reducing their risk of having a pregnancy affected with spina bifida or other neural tube defects."[2] In 1996 the Food and Drug Administration promulgated a rule requiring all enriched grain products to be fortified with folic acid, effective January, 1998. Subsequently, the national Institute of Medicine reaffirmed the US Public Health Service recommendation and added that women of childbearing years should take 0.4 mg of *synthetic* folic acid daily.

In North Carolina during this time, a concerted effort took root to reduce the prevalence of neural tube defects by promoting awareness and consumption of folic acid among women of childbearing age. In 1994, the NC Neural Tube Defect Task Force, later renamed the NC Folic Acid Council, was created. North Carolina was among the first states in the United States to establish such a council, and the group has achieved national recognition for the leadership role it has taken to promote the benefits and consumption of folic acid. Recognizing the need for better surveillance data to help design, target, and evaluate folic acid interventions, the Council worked with the NC General Assembly to establish the NC Birth Defects

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Monitoring Program (BDMP) in 1995. The purpose of the BDMP is to collect, analyze, and disseminate critical information needed for the prevention and treatment of birth defects in North Carolina.

Data from the BDMP indicated that the neural tube defect rate in North Carolina was approximately twice the national rate, and that the rate in the western part of the state was nearly three times that of the United States. Thus, the initial focus of the state's folic acid awareness efforts concentrated in the western region, in partnership with the Fullerton Genetics Center and other key healthcare providers in the region. The results of these efforts were impressive. Between 1995 and 2002, the prevalence of NTDs in the western region has decreased by about 75%—or approximately twice the decline seen compared to the state as a whole which, concurrently, had also reaped significant benefits from an array of local, state, and national folic acid initiatives. These initiatives include the fortification program and numerous public awareness campaigns both within and outside the state. The success of these efforts are evident by recent data from the BDMP. Statewide in the year 2002 alone, there were an estimated 80-90 fewer pregnancies affected by NTDs compared to the number that would have been expected had the rates remained the same as in 1995 (prior to folic acid interventions). More than one-half of these pregnancies probably would have ended in medical termination or fetal/infant death, while the remaining infants would have been born with significant disability and other serious health problems.

The BDMP provides the foundation for the Folic Acid Campaign. The program's surveillance data inform the Campaign regarding populations of greatest need, help the Campaign evaluate its effectiveness, and aid in strategic planning. It is also useful to combine these data with information from the Pregnancy Risk Assessment Monitoring System (PRAMS) and the Behavioral Risk Factor Surveillance System (BRFSS) in order to track trends in folic acid knowledge and consumption. With longstanding support from the March of Dimes, the NC Folic Acid Campaign conducts community and healthcare provider education, vitamin distribution, and media campaigns in its efforts to educate North Carolinians about preventing neural tube defects by taking folic acid daily.

The Campaign has succeeded in raising awareness about the benefits of folic acid. Data from NC PRAMS show that in 2001, 86% of women who gave birth that year had heard or read about folic acid (up from 74% in 1998); however, the fact that still only 27% of women reported taking it every day before becoming pregnant indicates that much work remains to be done before all folic acid preventable birth defects are eliminated. The major challenge now lies in reaching those sociodemographic populations in which the prevalence of NTDs has not declined substantially, and in which multivitamin use remains low. For example, a recent analysis by the BDMP found that the prevalence of spina bifida had decreased very little among women who were less than 25 years of age, who had less than a high school education, and who were on Medicaid compared to their counterparts who were older, better educated, and not receiving Medicaid.[3] Efforts to refocus the Campaign on these populations are already underway.

There is still much work to be done by the Folic Acid Campaign and by healthcare providers. Of the women who know that folic acid prevents birth defects, but do not take vitamins, 89% say they would take vitamins containing folic acid if their healthcare providers recommended they do so.[4] This is a tremendous opportunity for healthcare providers to create public health change by causing a change in the behavior of patients. Every woman who is capable of becoming pregnant should be encouraged by her physician to take 0.4 mg (400 mcg) of folic acid in the form of a multivitamin every day, in addition to eating a well-balanced, healthy diet. Because the development of the neural tube occurs within the first few weeks of pregnancy (often before a woman even knows she is pregnant), it is essential to stress that folic acid must be taken *every day before pregnancy* and continued through at least the first trimester.

In their article elsewhere in this issue of the *Journal*, DeClerque et al.[5] highlight the need for infant mortality prevention efforts to place a greater emphasis on improving the health of women before they become pregnant. Those who have been involved with birth defects prevention have long recognized the fact that the preconceptional period is the only viable window for effective primary prevention, because most major structural congenital malformations occur very early in pregnancy. Although we do not yet fully understand the mechanisms leading to early preterm birth and we do not know when the optimal window for prevention is, it is only reasonable to assume that, in general, the healthier a women is before pregnancy, the better her chances are of having a full-term, healthy infant. In their paper DeClerque and colleagues call for a "paradigm shift" toward focusing on improving preconceptional health—and more generally *women's health*—as a strategy for combating infant mortality. That recommendation, which has the potential for reducing infant morbidity and mortality related to both birth defects and low-birth weight, is a welcome one indeed. **NCMJ**

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Addressing Perinatal Health Disparities:

Another Place for a Paradigm Shift

Vijaya K. Hogan, DrPH

There are persistent racial and ethnic disparities in infant mortality in the state of North Carolina that are preventable and unjust by all standards of social justice. The five-year infant mortality rate (1998-2002) for African American infants was 15.4 compared to 6.3 for white infants—a greater than two-fold excess mortality risk for African American infants.[1]

Prematurity/low-birth weight is the leading contributor to neonatal mortality in the United States,[2] and the leading cause of overall infant mortality in many states including North Carolina.[3] Preterm birth has been the leading cause of death for black infants for more than a decade and is the greatest contributor to the excess mortality experienced by black compared to white infants in this state.

One of the *Healthy People 2010*[†] goals is to eliminate health disparities.[4] Among this goal's objectives is to address the racial and ethnic disparities in all aspects of perinatal health, including prematurity. The *Healthy People 2010* objective is to reduce the rate of preterm births to 7.6 by 2010. Yet, the preterm birth rate continues to increase, both among multiple and singleton deliveries. There has been little progress over time in reducing the rates of preterm births and similarly little sustained progress in reducing the disparity.[5] If we are to begin to make progress toward the 2010 objective, it is critical to step back and assess why we have not made more aggressive progress in eliminating the excess risk of infant mortality and preterm birth experienced by African American infants.

> *"Preterm birth has been the leading cause of death for black infants for more than a decade..."*

Barriers to Reducing Perinatal Health Disparities

One problem lies in the fact that little progress has been made in understanding the etiology of preterm birth. Another problem is the failure to define effective mechanisms to address known risk factors. These problems affect women of all ethnicities, but most acutely, African American women. The third problem—which uniquely affects women of color—rests in a failure to correctly conceptualize the causes of health disparities, and approach their elimination in a logical and scientific way. While discussion and action are needed to address all three of these problems, this paper attempts to focus attention on the latter in order to spur discussion and action toward the needed paradigm shift in disparity elimination.

The existence of a national objective to eliminate health disparities as specified in the *Healthy People 2010* goal effectively charges all of public health and medicine with a responsibility to actively work toward the elimination of these disparities. Receipt of federal funding, such as Title V, often requires that states include strategies for monitoring and addressing health disparities, and states may often additionally require local accountability and plans to address disparities. There is no doubt that the existence of the *Healthy People 2010* objective has elevated the issue of health disparities and their elimination to a higher level of national and state priority. But despite this, there does not appear to be a systematic process for understanding and addressing health disparities.

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[†] *Healthy People 2010* is a set of national health objectives for the first decade of 2000. *Healthy People 2010* builds on initiatives pursued over the past two decades. The 1979 Surgeon General's Report, Healthy People, and Healthy People 2000: National Health Promotion and Disease Prevention Objectives both established national health objectives and served as the basis for the development of state and community plans.

Indicators of the Existing Paradigm's Failure to Reduce Disparities

First, the current approach assumes that everyone in medicine and public health is scientifically prepared to conduct planning and research around health disparities. Second, there is a predominant notion that to address the disparity, one simply needs to target "evidence-based" interventions specifically to African American (or other vulnerable) populations. Neither of these assumptions is necessarily correct.

Not everyone is scientifically prepared to conduct planning and research around health disparities. It would be hard to imagine someone addressing diabetes without having some training it the subject area, yet most in public health and medicine do not have any preparation for addressing health disparities. The curricula of schools of medicine, nursing, or public health do not routinely require study of health disparities.

One of the fundamental components of a prevention approach to any disease is to know its contributing factors and then act to reduce the effects of these factors.[7] Yet, most people either do not know what factors contribute to health disparities or do not act on them. Factors cited in literature as affecting disparities overall include: healthcare, behavior, culture/acculturation, social factors, psychosocial factors, environmental factors, racism, stress, genetic factors, economic factors, socioeconomic position, neighborhood factors, national, state or local policies, historic and life course exposures, weathering, and other intergenerational factors as contributors.[8-11] Currently, there is little empirical data to define the relative contribution of each of these factors to any specific disparity, but for perinatal outcomes, individual studies have shown a persistence of a disparity when behavioral, healthcare, and, in some cases, socio-economic status factors are considered.[12] Genetic factors are unlikely to be a major contributor to health disparities.[13] In fact, in the summer of 2000, the acting director of the National Institutes of Health stated before the US Senate Subcommittee on Public Health that:

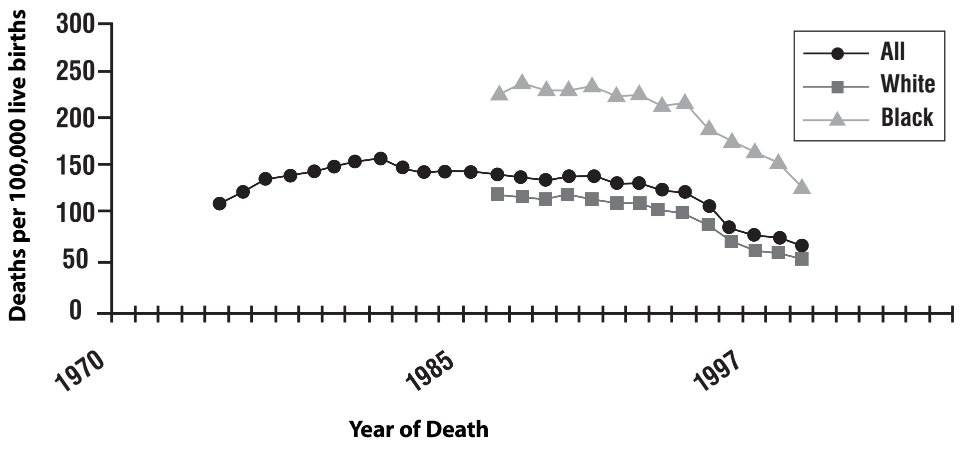
> "The causes of health disparities are multiple. They include poverty, level of education, inadequate access to medical care, lack of health insurance, societal discrimination and lack of complete knowledge of the causes, treatment and prevention of serious diseases affecting different populations. The causes (of health disparities) are not genetic, except in rare diseases like sickle cell... The elimination of health disparities will require a cross-cutting effort, involving not only various components of the Federal Government, but the private sector as well...."[14]

Additionally, a highly touted national Institute of Medicine (IOM) report reviewing evidence on healthcare inequities recognized that:

> "...racial and ethnic disparities in health status largely reflect differences in social, socioeconomic, behavioral risk factors and environmental living conditions. Healthcare is therefore necessary, but insufficient, in and of itself to redress racial and ethnic disparities in health status. A broad and intensive strategy to address social-economic inequality, concentrated poverty, inequitable and segregated housing and education... individual risk behaviors as well as disparate access to medical care is needed to seriously address racial and ethnic disparities in health status"[15]

Yet, recent trends in research and intervention focus on healthcare factors, genetic research, and downstream clinical factors. The language used, and the implicit approaches to disparity elimination, reflect a certain naiveté (or maybe denial) about what it takes to truly eliminate disparities. For example, it is not unusual to hear public health and medical professionals interchange the use of the terms "health disparity" and "healthcare disparity." They are two distinct phenomena, with disparities in healthcare being only one contributing factor to overall health status disparities. Understanding the distinction is not unimportant as it is reflected in subsequent actions to eliminate health disparities. While healthcare factors are estimated to cause 10-30% of the morbidity disparities,[16] we spend 90% of our resources on this one contributor. Some of this spending should be reallocated to address the social determinants of health and to the pertinent research issues that will generate new knowledge to fuel progress toward eliminating disparities.

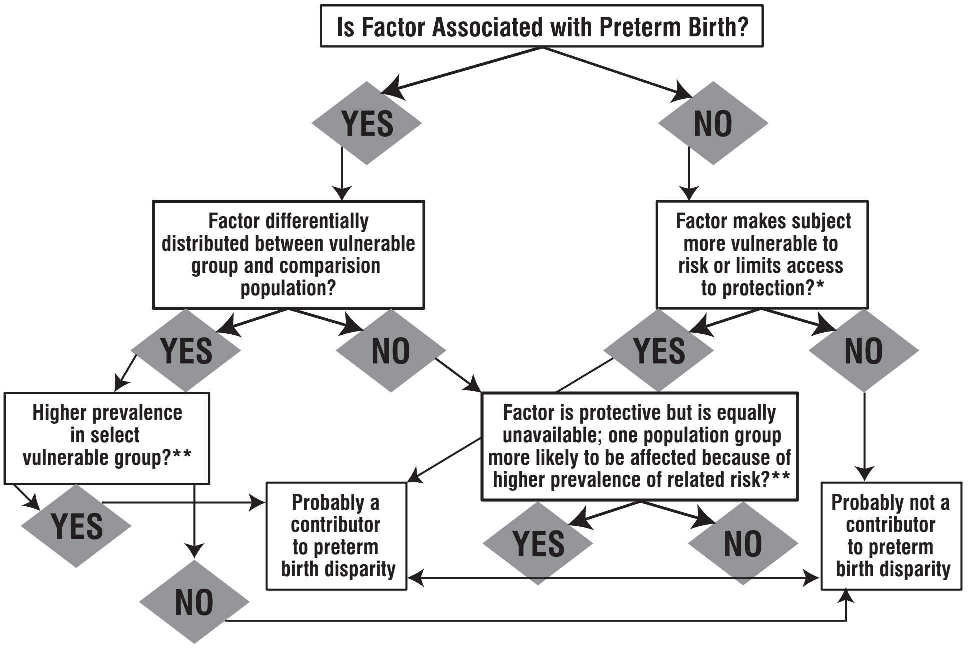
Figure 1.
Infant Mortality Rates Due to SIDS, United States by race, 1973-1998



Another limitation of the current paradigm for disparity elimination is a sole reliance on targeting evidence-based interventions for the disease as a strategy to reduce disparities. Targeting evidence-based interventions as a disparity elimination strategy assumes that reducing specific risk factors for the disease in vulnerable populations is all that is needed to reduce the disparity. Factors that cause the disease are not necessarily the same as those that cause the disparity. Efforts to reduce the disparity may require interventions above and beyond those that reduce the disease. Take for example the decline is Sudden Infant Death Syndrome (SIDS) rates (Figure 1).

The significant declines over the past several years are widely attributed to the impact of one "evidence-based intervention" (i.e., the Back To Sleep campaign). However, these declines occurred among all population groups, including African Americans; yet the magnitude of the *disparity* between African American and white populations remained unchanged. This indicates that something more than the standard evidence-based interventions targeted to vulnerable populations may be necessary. Additional attention needs to be paid to the factors that make some populations more vulnerable to specific health threats. That is, strategies to reduce/eliminate disparities must target the risk factors for the disease as well as risk factors for the disparity. It will take more than business as usual to really get at the causes of the disparity.

Figure 2.
Logic Model: Determining Contributors to Preterm Birth Disparity



* The factor may be an "upstream" contributor that has not been directly associated with preterm birth, but has been associated with increased prevalence of other more proximal risk factors for preterm birth. One example might be "racism."

** Caution is advised in ruling out factors by this criterion. Even if prevalence of a single risk factor is lower, the prevalence of co-existing risks (with which this factor may interact) may be higher and interactive effects may contribute to disparity. For a hypothetical example, smoking prevalence may be lower among African Americans, but a higher percentage of African American smokers may have other co-occurring risks, increasing the risk of disease outcome.

Logic Model: Determining Contributors to Preterm Birth Disparity

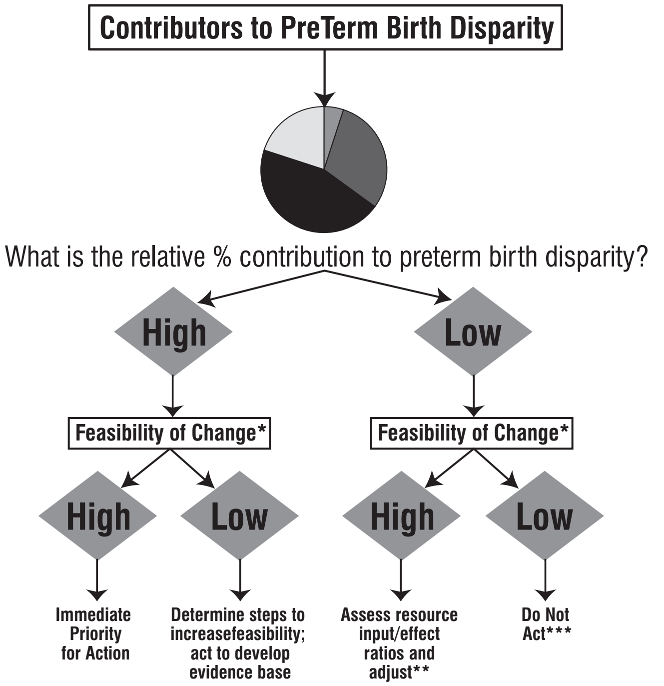
If we want to address the disparity as well as see continued declines in all groups in troublesome perinatal outcomes, we have to take a more strategic, logical, and scientific approach. First, we have to improve the knowledge base within public health, medicine, and society as a whole with respect to what causes, and how we could eliminate, health inequities. Second, we need to focus research more strategically toward the issues that will bring more bang for the buck—that is, to support and conduct research that sheds light on how we can more effectively address social determinants of health, as these factors are acknowledged to be the strongest contributors to the disparities in health status. Third, we need to take a more logical approach with the use of existing knowledge to define strategies, and in defining what the priority research issues should be.

One logic model for determining if a factor is a potential cause for perinatal disparities is proposed in Figure 2. To begin with, we have to determine if a factor is a contributor to the disparity in preterm birth, and if so, include this on the list of factors that need to be addressed (Figure 2). This model is most useful for including additional factors that may not be otherwise considered. To be defined as a contributing factor to the disparity, the variable in question should be a risk factor for preterm birth or affect the distribution of a known risk factor. It should also be more prevalent in the vulnerable group. For example; maternal infection (e.g. bacterial vaginosis) is associated with preterm birth (YES), is differentially distributed between African Americans and whites (YES), and with higher prevalence among African Americans (YES). Therefore, it is very likely a contributor to the disparity. In contrast, smoking is associated with preterm birth (YES), is differentially distributed between these two groups (YES), but the prevalence is higher among whites (NO); therefore, it is probably not a major contributor to the disparity. This does not mean, however, that smoking cessation should not be included in an intervention strategy. Since smoking is a risk factor for preterm birth and other serious diseases, it should be included. Genetic factors are another example. These may be associated with preterm birth, but are not shown to be differentially distributed, and therefore are not likely to be a contributor to the diparity.

Logic Model: Planning Strategies to Eliminate Preterm Birth Disparities

Once a set of factors is determined to be associated with the preterm birth disparity, the factors can then be prioritized to determine where to place resources more effectively. Figure 3 offers a model that can be used to determine intervention priorities. In the model, if prenatal healthcare factors contribute little to the disparity (LOW), but the feasibility of improving the quantity or quality of care was high (HIGH), then one needs to reassess the amount of resources placed on this factor and consider reallocation to a degree proportionate to the relative impact. Maternal infection is considered a strong contributor to preterm birth disparity, with estimates of up to 30% of disparity attributed to this cause (HIGH). The feasibility of mediating this risk is minimal at this time because of the conflicting nature of results from existing treatment trials (LOW). This does not, however, suggest that one should do nothing. In fact, since it is a strong contributor, even more action is needed to develop the evidence base for effective intervention strategies.

Figure 3.
Logic Model: Planning Strategies to Eliminate Preterm Birth Disparities



* *Feasibility of change:* evidence base for best practices to address the factor exists; prevailing economic, political, and institutional climate will be supportive with reasonable effort

** If proportion of resources put toward addressing this factor exceeds its percent contribution to disparities, consider reallocation of resources toward factors with greater importance

*** Spending resources on these factors may be wasteful, counterproductive, and inefficient in efforts to eliminate disparity

A risk factor that is a strong contributor should have higher priority compared to one that is a lesser contributor. If a risk factor is a strong contributor and is relatively easy to change, this should be included in a disparity elimination strategy. If it is not easy to change (e.g., racism), then instead of passing over it, we need to focus attention on increasing the feasibility of change and support the research needed to develop an "evidence base" for successfully mediating these risks. Conversely, if a factor is a small contributor, whether easy or difficult to change, we need to reassess our efforts and the resources spent on these factors. An example might be genetic factors, which are not likely to be strong contributors to the disparity, have a low feasibility of change, thus resources (research and other) would be better placed toward addressing stronger contributors.

Conclusion

Health disparities have not been approached with the same scientific rigor that we use for addressing other health conditions. Before defining strategies to eliminate health disparities, professionals should be required to study or understand the underlying contributors. Assumptions and personal biases about causality also need to be critically examined. The probability of success in eliminating disparities will be affected by the depth of healthcare professionals' knowledge of the causes of health disparity. The responsibility for eliminating health inequities lies with all of society. Thus, it is important for all to have a strong conceptual understanding of: why it is important for the health of all that disparities be addressed, what contributors affect health inequities, how much certain risk factors contribute, and how they exert their effects. This understanding can increase the probability that efforts to eliminate health disparities are realistic and holistic, have a strong conceptual basis, are reasonably keyed to the true causes, and thus have greater probability of successfully reducing inequities. It is important to avoid spending considerable resources on a strategy or intervention that addresses a minor contributor at the expense of large ones, all the while promising to eliminate overall health inequities. In the current political climate, the price of failure to make progress could significantly reduce future prioritization of funding to address health inequities. **NCMJ**

North Carolina Efforts to Address Perinatal Health Disparities

Belinda Pettiford, MPH

The NC Office of Minority Health and Health Disparities (OMHHD), within the Department of Health and Human Services (DHHS), released its health disparities' report in January 2003. In this report, the state received a "D" in perinatal health disparities, specifically infant mortality. As part of the follow-up to this report, the DHHS has made eliminating health disparities a higher priority.

In its ongoing efforts to address perinatal health disparities, the Women's and Children's Health Section (WCHS) of the NC Division of Public Health, DHHS, has implemented several programs within the last 5-10 years.

The state's Minority Infant Mortality Reduction Program, Healthy Beginnings, is a collaborative effort between WCHS and OMHHD. This program provides $50,000 yearly to 13 community-based organizations, faith entities, health departments, and health centers. These organizations provide outreach to bring people into care, education for parents, and support services to primarily African American women, infants, and families within certain geographic areas (one project focuses on American Indian families).

North Carolina's federally funded Healthy Start Program, Baby Love Plus, is also designed to address perinatal health disparities. This program has covered 14 counties with a primary focus on improving birth outcomes in African American and American Indian communities. Services include community consortia development, case management from prenatal to two years postpartum for mother and child, health education, outreach, and perinatal depression screening.

All of these efforts emphasize strong community, family, faith, and health provider relationships, along with a key focus on community leadership development. Due to funding cuts with both programs and other budgetary limitations, WCHS continues to look for resources to expand these efforts as part of the overall DHHS's disparity plan.

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Making a Difference in Infant Survival:

Evidence-based Actions to Reduce Tobacco Exposure During Pregnancy and Infancy in North Carolina

Cathy L. Melvin, PhD, MPH, and Sally Herndon Malek, MPH

Health and Economic Consequences in North Carolina

Three of the top four causes of infant death in North Carolina are directly associated with either maternal smoking during pregnancy and/or infant exposure to tobacco smoke after birth.[1] Rates of preterm birth/low-birth weight, respiratory distress syndrome and Sudden Infant Death Syndrome (SIDS) could all improve dramatically if pregnant women and their partners did not smoke during and after pregnancy, and if infants were always in smoke-free environments, especially in their homes, child care locations, public places and automobiles.

> *"If no pregnant women smoked during pregnancy, the overall infant mortality rate for the state would drop an estimated 10 to 20%."*

In 2002, 15,440 women, or 13.2% of all women giving birth in North Carolina smoked while pregnant. A 2002 report on the association of maternal smoking during pregnancy with infant mortality in North Carolina showed that mothers who smoked had nearly twice the risk of an infant death or low-weight birth as mothers who did not smoke.[1] For SIDS, the risk associated with maternal smoking was more than five times as high.[1] Low-birth weight rates (per 1,000 live births) for smokers were 12.6 compared to 6.4 for non-smokers and 'small for gestation age' rates for smokers were 10.0 compared to 4.0 for non-smokers. When data by cause of death were examined, 50% of the infants who died of SIDS had mothers who smoked during pregnancy.[1]

If no pregnant women smoked during pregnancy, the overall infant mortality rate for the state would drop an estimated 10 to 20%.[1] Furthermore, the mortality rates would improve most in underserved and disadvantaged communities where women are more likely to smoke while pregnant.

Secondhand smoke is a known human lung carcinogen, and there is increasing evidence of its threat to both the short- and long-term health of pregnant women and infants.[2] Regardless of whether mothers smoked while pregnant, infants living in households or being cared for outside the home where they are exposed to secondhand smoke (SHS) may be at greater risk for SIDS.[3,4] These infants are also at greater risk than infants without this exposure for respiratory and growth-related problems.[3,4] In 2001, 11.7% of new mothers in North Carolina reported that their infants were often in the same room with someone who was smoking.[5]

Not only does prenatal exposure and/or exposure to SHS endanger the lives of infants, they also result in higher public expenditures for the care of mothers and infants participating in the Medicaid program in North Carolina. Costs during the first year of life for infants of women who smoked while pregnant were $4,353 compared to $3,769 for infants of non-smoking women.[1] Overall this difference amounts to nearly $6.5 million in excess Medicaid costs during one year for the infants of mothers who smoked.[1]

What Works to Reduce the Impact of Smoking on Infant Death?

A number of strategies have been proven to help pregnant and parenting smokers quit smoking and to increase the number of smoke-free environments for families. *The Guide to*

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Community Preventive Health Services presents recommendations for use by communities and healthcare systems on population-based interventions to promote health and to prevent disease, injury, disability, and premature death. Three strategic areas for intervention in tobacco use and prevention were identified through systematic reviews of the literature: reducing exposure to environmental tobacco smoke; reducing tobacco use initiation by children, adolescents, and young adults; and increasing tobacco cessation.[6] (See www.thecommunityguide.org for a complete listing of proven strategies to prevent and reduce tobacco use.)

Brief clinician counseling with pregnancy-specific self-help materials for pregnant smokers has been found to increase cessation rates by 30 to 70%.[7] Depending on the underlying prevalence of smoking in a particular group, this improvement could double or even triple cessation rates and save $3 for every $1 invested in treatment.[8] Similar counseling interventions along with appropriate pharmacotherapies for non-pregnant smokers have also been shown to significantly increase their chances of quitting smoking.[9]

Telephone support, when combined with other efforts such as educational approaches or medical therapies, is effective in helping smokers to quit when implemented in both clinical and community settings.[6] These help, or quit, lines are a valuable resource for clinicians who may need to refer their patients to external sources of counseling and support during their quit attempts.

Mass media education campaigns when combined with other interventions have also proven to be effective in preventing and reducing tobacco use.[6] Advertisements aimed at promoting cessation coupled with other interventions such as provider cessation services using the "5A's"[10] and full service, proactive quitlines are strongly recommended strategies.[6]

Increasing the numbers and types of smoke-free environments for pregnant women and children can reduce their exposure to SHS and its consequences. Policies and legislation aimed at creating smoke-free environments in worksites and public places have been found to increase cessation rates among smokers and to reduce SHS exposure for smokers and non-smokers alike.[6]

Strategies that increase the price of cigarettes and other tobacco products also have an impact on initiation of smoking and smoking cessation. Pregnant women seem to be especially sensitive to changes in price; for every 10% increase in the price of cigarettes, maternal smoking falls by 5%.[11] Increasing excise taxes on tobacco products in many states has prompted a significant number of smokers to quit smoking altogether.[11] Since many pregnant women are already motivated to quit smoking for their baby's health, the increase in price provides one more incentive to help them quit smoking.

Is North Carolina Using These Strategies?

North Carolina is making substantial progress in some, but not all, of these areas. To help clinicians who care for pregnant women gain the skills, confidence, and materials they need to help pregnant women quit smoking, the state has pursued a number of strategies. The Maternal and Child Health (MCH) Program within the NC Department of Health and Human Services (DHHS) has established a performance standard for treating tobacco use among pregnant clients. MCH programs must identify pregnant smokers and treat them using the Public Health Service "5A's" approach to cessation counseling. Award winning training materials for providers have been developed and training sessions have been held across the state. The Health and Wellness Trust Fund Commission has provided funding to increase tobacco cessation services for pregnant teens. Backup support and consultation is also available for clinicians working with pregnant smokers. Each year, programs compile data to assess their progress and identify areas for improvement in their approach to treating pregnant smokers.

The Women and Tobacco Coalition for Health (WATCH) has been working through a grant from the American College of Obstetricians and Gynecologists to conduct a number of activities designed to increase smoking cessation rates in North Carolina. This group is currently conducting a survey of clinicians providing prenatal care in North Carolina to understand how clinicians currently treat tobacco use among pregnant women they serve and to identify training and other needs that clinicians may have. Information gathered in this survey will help organizations involved in the coalition to develop new programs, materials, and approaches to help clinicians.

As part of an effort to reduce SIDS risk, the NC Child Care Commission recently approved changes to North Carolina's childcare licensing rules to address tobacco use and SHS exposure in child care facilities, including family child care homes. Recognizing that the risk for SIDS is more than doubled when babies breathe SHS and that tobacco products are a leading cause of childhood poisoning, the Commission expanded the prohibition on smoking in family child care homes so that the operator(s) cannot use tobacco products at any time children are in care; and that smoking or use of tobacco products is not allowed indoors when children are in care or in a vehicle when children are transported. Changes in policy and regulations such as these dramatically reduce the exposure of infants and young children to SHS and the risks associated with it.

North Carolina's local school boards are increasingly promoting 100% tobacco free school policies to eliminate secondhand smoke exposure and provide positive role modeling at school and school events. Thirty-six of North Carolina's 117 school districts have 100% tobacco-free schools policies; this is up from six school districts in 1999.

Significant progress has been made in North Carolina's private sector to protect workers from exposure to SHS, however this progress is considerably greater in the white collar sector. Disparities exist in blue collar and service industry sectors where many low-income women work. State law is a barrier to local government protections for secondhand exposure. The 1993 law entitled "Smoking in Public Places" (GS 143-597), states legislative intent "...to address the needs and concerns of both smokers and nonsmokers in public places by providing for designated smoking and non-smoking areas." This law requires state-controlled buildings to set aside 20% of space for smoking and preempts local governments from passing stricter rules.[12]

Are There Other Things North Carolina Can Do?

The state can expand efforts to train all clinicians in evidence-based interventions for pregnant and parenting smokers and take steps to assure adequate reimbursement for these interventions, especially through the Medicaid program and the state employee's health insurance plan(s). One of the barriers clinicians frequently cite as a reason for not providing cessation services is the lack of reimbursement for such services. An investment in the reimbursement of cessation services for pregnant smokers brings short-term cost savings for healthcare systems and the state, and has been shown to increase the likelihood that clinicians will offer these services.

Currently two quitlines are available to North Carolina residents. The American Legacy Foundation Great Start Quitline for pregnant smokers can be reached at 1-866-66-START. The National Cancer Institute Quitline for all smokers/tobacco users at 1-888-44-UQUIT is currently available during weekday hours. Plans are in place to have this line become a full-service, proactive quitline in January 2005. These quitlines bring evidence-based cessation help directly to smokers. They are also an important referral resource to clinicians as they work with pregnant and parenting smokers. Marketing these quitlines in North Carolina will enhance their utilization and result in more successful quit attempts. Mass media campaigns designed to promote quitting and the use of local and national resources such as these quitlines among pregnant women and the members of their households are strongly recommended by the Community Preventive Services Task Force, but currently not funded in North Carolina.

An increase in the state excise tax on cigarettes would also increase the likelihood that pregnant and parenting smokers would quit smoking. North Carolina's tobacco tax is currently five cents per pack, the third lowest in the nation. With an increase to 75 cents, North Carolina's tax would be close to the national average (currently 72.9 cents). And, a 75-cent increase in the cost of a pack of cigarettes would result in a 17.5% decrease in the number of pregnant women in North Carolina who smoke.

Adoption of a 100% tobacco-free school policy by North Carolina school boards would eliminate smoking at school and school events by students, staff, and visitors so that students, faculty and staff are protected from secondhand smoke and nonsmoking is promoted as a social norm. Blue collar and service industry sector worksites should be smokefree in order to provide worker protection from secondhand smoke, a known, preventable health hazard. If private sector worker protections are not adequate, the law prohibiting local rulemaking to protect people from secondhand smoke in public places and workplaces should be reconsidered in light of new evidence of the serious risks of secondhand smoke exposure for pregnant women and other vulnerable populations, and the effectiveness of nonsmoking policies in protecting pregnant women and infants from harm.

Summary

North Carolina faces major challenges in dealing with smoking and its consequences during pregnancy and infancy. Evidence-based strategies exist to help pregnant and parenting smokers to quit, to discourage young people from becoming smokers and to reduce exposure of infants to SHS. North Carolina is making progress in implementing these strategies, but more infant lives could be saved each year if the state adopted a more comprehensive approach to addressing tobacco use by improving cessation services for pregnant and parenting smokers, reimbursing clinicians for providing cessation services, increasing state excise taxes on tobacco products, establishing statewide help or quitline services and adopting tobacco-free school policies. These proven strategies can make a difference. **NCMJ**

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Preterm Birth in North Carolina

Mary Lou Moore, PhD, RN, FAAN

Decreasing infant mortality is closely linked to decreasing preterm births. Unfortunately, the rate of preterm births in North Carolina and in the United States, after declining in the 1980s, has been rising again for the past several years. The goal of this commentary is to examine North Carolina data related to both preterm births per se and to those factors that have been associated with preterm birth.

At times, low-birth weight (LBW) rates will be used in this paper when preterm data are not available. While both rates follow similar patterns, readers should recognize that LBW refers to the birth of infants weighing less than 2,500 grams (5 pounds, 8 ounces), while preterm births are those before 37 weeks gestation. Some of the data reported here (smoking and intimate partner violence, for example) are based on self-report by women who are pregnant or delivering; such self-reporting may result in underestimation of the true rate of the outcome or exposure reported.

> *"...births to teen mothers have dropped each year in both the United States and in North Carolina."*

Preterm births may be medically indicated because of the health of the mother or fetus, may follow preterm premature rupture of the fetal membranes, or may be the result of spontaneous onset of labor. The antecedents of preterm birth are multifactoral and vary from one birth to another. Thus, the reasons for increasing rates of preterm birth are not clear. Two factors have been identified in both national and North Carolina data as potentially contributory: increasing maternal age and an increasing number of multiple gestation births.[1,2]

Maternal Age and Multiple Births

More women are delaying childbearing until their mid-thirties and into their forties than in previous generations. In North Carolina in 1998, 10.5% of all births were to women over the age of 35. By comparison, only 3.6% of births in 1978 and 5.8% of births in 1988 were to North Carolina women ages 35 or greater. The birth rate (births per 1,000 women in a population) for women ages 35 to 39 was more than twice as great in 1998 (32.7%) than in 1978 (13.8%). Although both rates were somewhat lower than comparable rates for the United States (34.7% and 19.0%), the trend is the same. During this same period, LBW rates for mothers in this age group increased from 8.8% to 10.2%. in North Carolina.[1]

Multiple births increased from 2.0 % of live births in 1980 to 2.8% in 1997, a 40% relative increase. Women over the age of 35 naturally have higher rates of multiple births.[2] In North Carolina the 1999-2001 rate was 43.3 for women ages 30-39 and 51.5 for women ages 40 and over, compared to 17.6 for women under age 20.2 In addition, the increased use of in vitro fertilization with the implantation of two or more embryos appears to be a contributory factor. The rate of preterm birth in multiple gestation pregnancies in North Carolina for 1999-2001 was 61.2, slightly higher than the rate of 59.2 for the United States.[3] The increase in multiple births between 1980 and 1997 appears to account for 70% of the increase in the LBW rate in NC during these years.[2]

At the other end of the childbearing age continuum, births to teen mothers have dropped each year in both the United States and in North Carolina. In the ten years from 1992-2001, pregnancy rates for North Carolina teens ages 10-14 decreased from, 3.3 per 1,000 to 1.7 per 1,000, a decrease of 48.5%. For adolescents ages 15-19 rates decreased from 30.7% to 16.4%, a decrease of 46.6%.[4] These decreases surpass the national rate of decrease of 26% since 1991.[5] Nevertheless, rates continue to be higher than in many developed nations.[6] In a review of 14,718 births, teens under 15-years of age were almost 50% more likely to have a preterm infant than adult women. Teens ages 16 and 17 were not found to be at increased risk in this study.[7]

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Cigarette Smoking

Cigarette smoking and preterm labor, addressed in another paper in this issue,[26] has been linked to preterm and low-birth weight births for more than half a century. In a five-year study of low-income women receiving care in a public clinic in Forsyth County, North Carolina, cigarette smoking had a far greater effect on both low-birth weight and preterm births in African American women than in white women, even though fewer African American women smoked. In this study, 21.2% of African American women reported smoking cigarettes. African American women who smoked more than one-half pack of cigarettes a day had a preterm birth rate of 20.4% compared with a rate of 9.2% for non-smokers (p=.003 after adjusting for age and other risk factors).[8]

Physical and Emotional Stress

Stress has been associated with preterm birth in a number of studies.[9] Accumulation of trauma over one's lifetime (allostatic load),[10] job related stress,[11,12] and racism are examples of stresses experienced by many pregnant women in North Carolina. Through a complex physiologic pathway, stress raises levels of corticotropin-releasing hormone (CRH) leading to the production of Adrenocorticotropic hormone (ACTH) and glucocorticoids with subsequent preterm labor. Stress has also been associated with decreased immune competence, increasing the likelihood of infections which, in turn, are associated with preterm labor.

Intimate partner violence, a particular form of stress, was first identified as a correlate of preterm birth in 1989[13] and has since been confirmed in a number of studies. In a study using data from the population-based NC Pregnancy Risk Assessment Monitoring System (PRAMS) for 1997 though 2000,[14] the prevalence of physical violence during the 12-month period prior to pregnancy was 6.9% and 5.5% during pregnancy. These rates decreased from 8.4% and 8.1% for the two periods in 1997 to 6.5% and 5.2% in 2000. Rates of preterm birth were 10.1% for women experiencing violence and 9.6% for those who did not report violence. Rates of LBW were 10.1% for women reporting violence and 7.6% for those who did not. Women experiencing violence were more likely to begin prenatal care after the first trimester; to smoke before, during, and after pregnancy; to report high levels of stress in the 12 months before birth; and to experience postpartum depression.

Infection

Two groups of infections have been associated with preterm birth, infections of the genitourinary tract and periodontal infections. Genitourinary infections have been recognized as important correlates of preterm birth for a number of years. Identification and treatment of these infections necessitates access to and utilization of prenatal care.

Less attention has been given to periodontal disease. In a case control study of 124 pregnant and postpartum mothers, controlling for other risk factors, women with periodontal disease were found to be 7.9 times more likely to have preterm LBW births.[15] In a randomized study of 351 women in Chile, women treated for periodontal disease prior to 28 weeks gestation had a preterm rate of 1.84% compared to 10.11% for untreated women.[16] In North Carolina the availability of periodontal care for low-income women must be examined and, if it is not adequate, this issue must be addressed in plans to reduce preterm births.

Preventive Interventions

Two studies conducted entirely or partially in North Carolina suggest potential preventive interventions. A randomized multisite study of natural progesterone (17 alpha-hydroxyprogesterone caproate: 17P) injected intramuscularly beginning at 16 to 20 weeks gestation until 36 weeks included women from two North Carolina sites. All of the women in the study had experienced one or more previous preterm births. There was a statistically significant difference in births less than 37 weeks (36.3% vs. 54.9%; p=.0001) and less than 32 weeks (11.4% vs. 19.6%; p=.018) with the lower rates in women receiving 17P. There was also a significant difference in infant mortality rates: 2.6% for the 17P group and 5.9% for the placebo group (p=.05), as well as a decreased incidence in morbidity, including necrotizing enterocolitis and intraventricular hemorrhage (p=.05).[17] A study of 17P in Brazil using vaginal progesterone in a population with additional risk factors for preterm birth, also found a statistically significant reduction in preterm births.[18] The American College of Obstetricians and Gynecologists Committee on Obstetrical Practice has stated that "further studies are needed to evaluate the use of progesterone" in women with conditions other than a previous documented history of preterm birth "because unresolved issues remain, such as optimal route of drug delivery and long-term safety of the drug."[19]

In a five-year randomized study of nurse telephone intervention in low-income women receiving care in a public clinic in Forsyth County, North Carolina was highly effective in 759 African American women aged 19 and over with a 34% reduction in LBW births and a 44% reduction in preterm births. There was no difference in younger African American women or in white women.[20] Telephone intervention led to a cessation in smoking in 25%, of participants and reduction in an additional 21%.[21] Specific interventions included two or more phone calls per week with assessment, behavioral suggestions as appropriate (e.g. smoking cessation, need to contact healthcare providers at the clinic), education about preterm labor, and emotional support. When study data were examined by risk for preterm labor using a modification of the risk factors of Papiernik[22] and Creasy,[23] the greatest impact was on women identified at low risk. Previous studies by others have shown that only 50% of women who will have preterm births can be identified in a risk screening; the other 50% will have no identifiable risk factors and will be considered at low risk, but should nevertheless not be ignored in prevention efforts.[24]

A Changing Paradigm for Prematurity Prevention

The data reviewed here suggest several directions that may lead to the reduction of preterm births. As stated in the lead paper in this issue of the Journal,[25] the prepregnancy period is an ideal time for intervention. Unfortunately, all women do not have access to preventive healthcare during this time, and nearly half of all pregnancies are unplanned. Whenever possible, prior to pregnancy, we should:

- Educate women and their partners about the increased risk of preterm birth when pregnancy is delayed beyond age 35;
- Encourage abstinence from smoking at each health encounter and provide specific assistance for smoking cessation;
- Screen women for intimate partner violence at each health encounter and have a protocol for appropriate referral;
- Be aware of the possibility of periodontal disease and refer women for dental care;
- Encourage the use of contraception to reduce the number of unwanted pregnancies.

During pregnancy, we can:

- Support efforts to assure accessibility to prenatal care for all pregnant women;
- Continue assessment and intervention for identifiable stressors, smoking, intimate partner violence, and infection, including periodontal infection;
- Consider strategies such as nurse telephone intervention or other forms of frequent contact for pregnant women, particularly those with limited incomes and education.

Conclusion

Just as many pieces of fabric form a patchwork quilt, many factors contribute to preterm birth in North Carolina. Approaches to prevention of preterm birth must be multifaceted, should begin early in a woman's life, and must continue though the prenatal period, creating an environment in which every woman achieves the best possible pregnancy outcome. **NCMJ**

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COMMENTARY

Expanding Medicaid Income Eligibility for Family Planning:
An Opportunity to Improve Reproductive Outcomes and Lower Medicaid Costs

Joe L. Holliday, MD, MPH

The State of North Carolina is requesting federal approval from the Centers for Medicare and Medicaid Services (CMS) to extend eligibility for family planning services to all women and men from 19 to 55 years of age with incomes at or below 185% of the federal poverty level. Unlike the Medicaid expansions for pregnancy-related care, which are specifically provided for in the federal statute, a family planning expansion must be approved by CMS as a Medicaid Family Planning 1115 Demonstration. To be approved, the proposal must be budget neutral—the added Medicaid family planning costs must be offset by at least a similar decrease in maternity and infant healthcare costs. As with maternity care, services may be offered by both public and private providers.

Current Medicaid regulations provide coverage to pregnant women and to infants (younger than a year) at or below 185% poverty. However, these women are eligible for Medicaid benefits only during the period following the confirmation of their pregnancy through 60 days postpartum. After 60 days postpartum, women who no longer meet the state's more stringent financial criteria for participation in the Medicaid program lose eligibility for all benefits, including family planning. It has been estimated that more than two-thirds of the approximately 45,000 women eligible for Medicaid each year due to pregnancy lose their Medicaid coverage after 60 days postpartum, leaving them without family planning or preventive health services coverage.

Among all North Carolina women of childbearing age, there are estimates that more than 318,000 women aged 20-44 are in need of publicly supported contraceptive services and do not have Medicaid coverage for these reproductive health services.[1] Although the 170 publicly supported family planning clinics in North Carolina serve 125,500 women aged 20-44, this represents only 39% of all women in need. Publicly supported contraceptive services are provided to 179,340 low-income women of all ages each year in North Carolina, and these women avert over 41,000 pregnancies each year.[2]

Unintended Pregnancies

A key goal of the Medicaid Family Planning 1115 Demonstration is to reduce the rate of unintended pregnancies within a state's low-income female population. Unintended pregnancies are those that are unwanted or occur before a woman intended to become pregnant (i.e., mistimed). More than half of all pregnancies in the United States and North Carolina are unintended.[3] In North Carolina, an estimated 45% of the more than 115,000 live births each year were unintended at the time of conception.[4] In addition, there are approximately 27,000 induced abortions each year in North Carolina, and presumably the vast majority of those result from unintended pregnancies. Women ages 20 and older account for over 85% of all unintended pregnancies.[5] More than three out of every five (61%) pregnancies to low-income women (income less than the federal poverty level) are unintended, compared to 41% of pregnancies for higher-income women (income more than double the federal poverty level).[6] They also are less likely to use effective contraceptive methods and to use contraception consistently.[7] Women whose prenatal care is paid for by Medicaid are significantly more likely than other women to report an unintended pregnancy resulting in a live birth.[8] The national *Healthy People 2000* goal was to reduce unintended pregnancies to 30% of all pregnancies, while the *Healthy People 2010* goal is to increase intended pregnancies to 70%.[9]

Reproductive Outcomes

Unintended pregnancy is associated with delayed entry into prenatal care as well as low-birth weight, poor maternal nutrition, smoking, and use of alcohol and other drugs.[10,11,12] Additionally, the opportunities and benefits of preconceptional healthcare are lost. As reported in the Running the Numbers column in this Journal (page 177),[4] North Carolina Pregnancy Risk Assessment Monitoring System (PRAMS) data from

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1997-2000 showed a strong association between an unintended pregnancy and low-socioeconomic status, never taking a multivitamin (folic acid) before pregnancy, late entry into prenatal care, smoking during pregnancy, postpartum depression, and not breastfeeding.[13,14]

The overall premise for the Medicaid Family Planning 1115 Demonstration supports the concept that providing Medicaid coverage for family planning services increases the likelihood that low-income women will use these services and thus be less likely to have unintended pregnancies. In turn, fewer pregnant women and subsequent infants and children will need Medicaid coverage. Also, fewer of these pregnant women, infants, and children will have complicated medical conditions, because women with unintended pregnancies are at a higher risk for preterm delivery and other complications. Moreover, improving the spacing of births among the low-income, postpartum population will result in reductions in the overall number of births that will be supported by Medicaid funding.[15] The provision of this benefit might also be expected to reduce the number of low-birth weight and premature deliveries and infant deaths attributable to closely spaced pregnancies among those families whose poverty limits their access to health services. This, in turn, impacts the costs that are incurred for the lifetime care of infants who are born with a disability due to their premature and/or very low-birth weight. Additionally, expanding coverage for family planning and related preventive services offers a major health benefit to low-income populations.

Proposed Family Planning Services

The proposed family planning demonstration will cover family planning clinical services currently covered by Medicaid as well as some limited sexually transmitted disease (STD) treatment for STDs identified during the initial family planning visit. Additional covered clinical services could be added in the future if funds were available and budget neutrality could be maintained. Services recommended for coverage are the following:

- Family planning initial or annual examinations (including appropriate physical exams)
- Family planning counseling and supply visits
- All FDA-approved and Medicaid covered methods of birth control (including removal of implants/inserts)
- Tubal ligations and vasectomies and necessary post-procedure follow-up (upon receipt of proper federal sterilization consent form per current Medicaid regulations)
- Laboratory tests that are in conjunction with the family planning visit, including STD screening tests, pregnancy tests, and Pap tests
- Antibiotics for STDs detected during a family planning initial or annual visit
- HIV testing including pre- and post-test counseling visits
- Referral to a primary care physician or clinic, when needed

Abortion services will not be covered under this program nor will infertility services and related procedures. Unfortunately, except for treatment of some STDs, treatment will not be covered for medical conditions/problems discovered during screenings (e.g., urinary tract infections, diabetes, or hypertension) or caused by or following a family planning procedure (i.e., medical complications from family planning procedures). Treatment for AIDS and cancer will not be covered.

Projected Cost Savings

The purpose of family planning demonstration waivers such as the one North Carolina has requested from CMS is to prove that approaches that expand family planning services to low-income adults will ultimately reduce Medicaid costs for maternity and infant care. Other states (including South Carolina and Arkansas) have already demonstrated that significantly expanding family planning services to low-income populations results in savings greater than the government expenditures needed to provide the family planning services. This is true because the annual cost of family planning services per participant is approximately $350 while the average cost of prenatal, delivery, and infant healthcare is almost $9,000. In addition to savings for maternity and infant healthcare costs, reducing the number of unintended pregnancies will result in savings in future government expenditures for social services, public assistance, and other healthcare costs.

The match for Medicaid family planning services is an especially favorable one for the state—$1.00 in state match for every $9.00 in federal Medicaid expenditures. The favorable Medicaid match will allow existing state family planning funds, when used as the state match, to expand family planning services nine-fold. No additional state funding will be required to fund the Medicaid Family Planning 1115 Demonstration. Thus, even with the State's current budget shortfall, the importance of implementing this waiver—with support and involvement of both the public and private sectors—cannot be overstated.

Evaluation of Efforts by Other States

The first national evaluation of the Medicaid Family Planning 1115 Demonstrations funded by the CMS has just been completed.[16,17] There are currently 18 Medicaid Family Planning 1115 Demonstrations located throughout the United States.[18] Some have operated longer than others. The South Carolina demonstration, which began in 1993, was first, Rhode Island followed in 1994, and demonstrations in Virginia, Mississippi, and Illinois are the most recent to be approved. This evaluation concluded that all of the state programs evaluated were budget neutral. Savings from averted births exceeded the cost of expanded family planning coverage when the proposed model budget neutrality formula was applied.

Timeline

Preparations to expand Medicaid income eligibility for family planning services in North Carolina are well underway. The proposal has been approved by the NC General Assembly.

Once CMS approval is obtained, implementation can begin within three to four months. Within the NC Department of Health and Human Services, the Division of Medical Assistance, with support from the Division of Public Health, will be responsible for the Medicaid Family Planning 1115 Demonstration. Postpartum women, especially those at high risk for poor pregnancy outcomes, will be given priority for enrollment. Approximately 4,000 women and men will be provided family planning services during the first full year. This annual number will increase each year, with 20,000 people being served by the fifth year.

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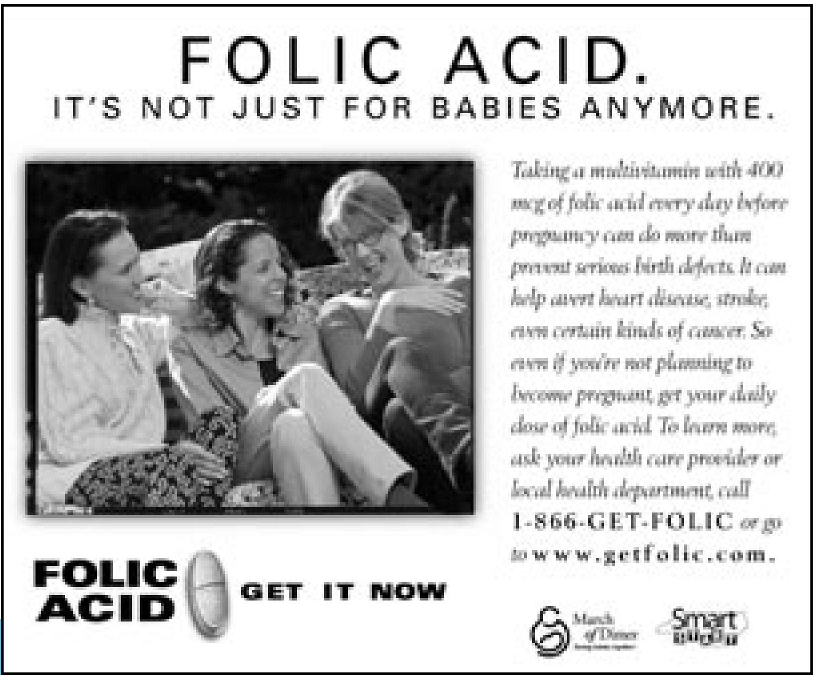

There Is Life (and Death) Beyond the Infant Year:

North Carolina's Recent Experience in Reducing Child Deaths

Tom Vitaglione, MPH

The 1990s witnessed a significant reduction in infant mortality in North Carolina, and this success has continued into the new millennium. For several years this success was guided by the NC Governor's Council on the Reduction of Infant Mortality, established in response to the dreadful news that the state had experienced the worst infant mortality rate in the nation in 1988.

Traditionally, the infant mortality rate has been considered a key indicator of the overall status of children within a society. Thus, it deservedly receives significant attention in public policy-making and in the media. Interestingly, the death rate of children after their first birthday receives less attention, perhaps because there are fewer of them (in 2001, for example, there were 1,005 infant deaths in NC and 524 deaths in children ages 1-17), or perhaps because the loss of an infant engenders a greater sense of tragedy. Nevertheless, an important measure of a society is the protection it affords its most vulnerable citizens, and especially its children of all ages.

This brief article is thus focused on North Carolina's experience in reducing death rates in children ages 1-17 in the period 1991-2001, a period in which the infant mortality rate declined by 22%. What progress did North Carolina make with regard to older children, and how did this progress occur?

Introduction

The road to progress in reducing deaths in older children began much the same way it began for infants: with bad news.

In 1991, a series of child abuse homicides in North Carolina received wide publicity. Data reviews indicated that this was an all too common phenomenon. Further reflection revealed concerns about all child deaths in the state. A few years earlier, North Carolina had achieved the distinction of having the worst infant death rate in the nation. It was now becoming apparent that, while the state's ranking in overall child deaths was not that bad, preventable child deaths were a tragically large problem.

As a response, the NC General Assembly held hearings on child abuse homicide, and interest grew in having an ongoing study of its cause and possible prevention. The interest then expanded to cover all child deaths, culminating in a watershed legislative decision to adopt an initiative known informally as the "child fatality prevention system."

The Child Fatality Prevention System

Three critically important components of the child fatality prevention system were established:

- Local Child Fatality Prevention Teams, with multi-agency membership established by statute, were directed to review all child deaths in each county. (A prior Executive Order had established similar teams to focus exclusively on deaths suspected to have resulted from abuse or neglect. Under the new legislation, counties were given the option of combining these teams or operating them separately.) Teams make recommendations to change local procedures, policies and ordinances aimed at preventing future deaths. Recommendations with statewide ramifications can be referred to the other components of the prevention system described below.
- A State Child Fatality Review Team, with statutory multi-agency membership and chaired by the Chief Medical Examiner, was directed to assist in the review of unexplained, unexpected child deaths, with particular focus on those suspected to be the result of abuse or neglect. Once again, the purpose of the reviews is to develop recommendations that could prevent future child deaths. The State Team is specifically required to report its findings and its recommendations to the Child Fatality Task Force described below.
- The NC Child Fatality Task Force is the lynchpin of the entire system. It is a 37-member legislative study commission, including legislators and multi-agency membership, with the overall charge to study the incidence and causes of child deaths, as well as to make recommendations for changes in legislation, rules and policies that would prevent deaths and promote the safety and well-being of children. It is responsible for assuring that multidisciplinary reviews of child deaths

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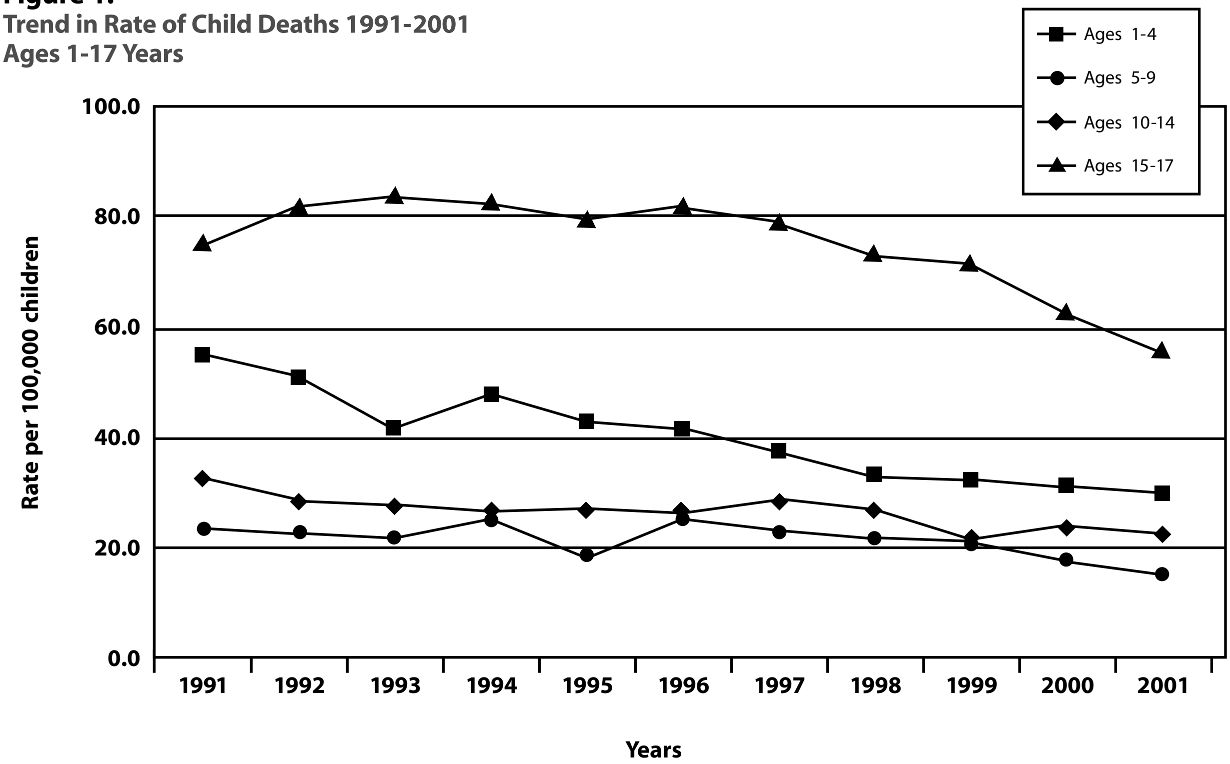
Figure 1.
Trend in Rate of Child Deaths 1991-2001
Ages 1-17 Years



are taking place, and is also responsible for assuring that, as noted above, local and state recommendations to reduce child deaths are studied and transmitted to state agencies and the NC General Assembly.

A Decade of Activity

All three components of the child fatality prevention system have been very active since inception. Though virtually the entire system is volunteer-based, the objective of saving children's lives and promoting their well-being stimulates a high degree of participation.

It is not possible to document all of the many accomplishments of local teams in changing local procedures, policies and ordinances. Changes in medical referral systems and emergency responses, heightened collaboration among child-caring agencies, street signs and traffic signals at hazardous intersections, and swimming pool safety ordinances are just some of the highlights that have made a difference in protecting children. In addition, many problems noted locally were referred to the State Review Team and the Child Fatality Task Force for review and action.

Because it operates in a more public venue and focuses on fewer, but more far-reaching issues, the activities and legislative accomplishments of the Task Force are more easily recounted. Since even these accomplishments would create a very lengthy list, below is a non-exhaustive list of highlights:

- Child passenger safety laws were strengthened twice.
- A Graduated Drivers License System was adopted.
- Smoke detectors are now required in all rental property.
- The sale of fireworks to youth under age 17 is now prohibited.
- "Zero tolerance" for alcohol in drivers less than 21 was adopted.
- Comprehensive kindergarten health screening is now required statewide.
- Numerous measures were adopted to reduce infant mortality, including expansion of Medicaid services for pregnant women and infants, a birth defects monitoring system, a folic acid awareness campaign, "safe sleep" practices in child care facilities, and overall awareness efforts under the auspices of the Healthy Start Foundation.
- Bicycle helmets for riders less than 16 are now required.
- The Infant Homicide Prevention Act, providing a "safe haven" for abandoned infants, was adopted.
- The penalty for illegally selling firearms to a minor was changed from a misdemeanor to a felony. In addition, safe storage of firearms is now required in homes where children reside.
- NC General Statutes, Chapter 7A was re-written to strengthen the protective services system.
- State funds for additional child protective services workers were appropriated at least twice.
- Protective services "hot lines' were established in each county.
- Additional funds were appropriated for the medical evaluation of children suspected to have been abused.

The Outcomes

All of the above, as well as all of the local efforts, were intended to reduce child deaths in North Carolina. As the child fatality prevention system reached its tenth birthday in 2001, some remarkably good news was reported in this regard.

Figure 1 depicts the steady decline in the child death rate for each age group since 1991.

Table 1 compares the percentage decline in death rates in the period 1991-2001 for each age group, including infants. The percentage decline in each of the older age groups exceeded that for infants, producing a remarkable overall decline of 28% for all groups birth through age 17 combined.

Table 1.
Death Rates By Age

Age	Death Rate*		% Change
	1991	2001	
Infant	10.9	8.5	**- 22%**
1-4	54.0	30.1	**- 44%**
5-9	22.8	15.0	**- 34%**
10-14	32.8	21.7	**- 34%**
15-17	74.9	57.6	**- 23%**
Overall	107.0	76.4	**- 28%**

* For infants, the death rate is the number of deaths per 1,000 live births. For all other groups, the death rate is the number of deaths per 100,000 children.

Table 2 depicts another startling outcome. For each and every major category of death, there was a substantial decline in the death rate in the period 1991-2001. (Beyond the infant year, injuries in their various forms are by far the leading causes of death.)

Discussion

The data depicted in the figure and tables taken together, are a firm indication that the remarkably good news about the decline in North Carolina's child death rate is not the result of happenstance. The overall decline has been steady and significant, the declines were enjoyed by all age groups, and the declines occurred in all cause of death categories.

It would not be scientifically accurate to conclude that the implementation of the child fatality prevention system in 1991 is solely responsible for the ten-year decline in child death rates. However, considering all the state and local activity generated by this system, it must surely be highly correlated with the positive outcomes.

North Carolina's success in reducing death rates for both infants and older children offers some interesting comparisons.

First, enhanced attention to both areas (with concomitant attraction of resources) was the result of media coverage. For infant deaths, it was the coverage of the state's last place national showing; for older children, it was coverage of a series of child abuse homicides. The state's infant and child death rates had not been previously ignored by public health officials, and proposals to reduce those rates had frequently been made. It took media coverage, however, to create a political environment that would entertain these proposals.

Second, the establishment of public commissions—the Governor's Council on the Reduction of Infant Mortality and the Child Fatality Task Force—was critical to the success of prevention efforts. Though these commissions have had neither administrative authority nor funding for services, they have exerted influence on the development and coordination of services. Perhaps most importantly, they have enhanced awareness of the critical issues, and have not been tethered by the administrative bureaucracy in advocating for solutions. (Note: The Governor's Council was dissolved in 1995, and its functions were undertaken by the Task Force.)

Third, the causes of death for infants and older children are quite dissimilar. Almost all infant deaths are attributable to birth defects, sudden infant death syndrome, and perinatal conditions related to low-birth weight and prematurity. Indeed, the underlying causes of many infant deaths are still not well understood. On the other hand, most deaths in older children are due to injuries, both intentional and unintentional. The specific causes of these deaths are well-understood.

Table 2.
Death Rates By Cause

	Percentage Change from 1991 - 2001
Cause of Death	Children (1-17)
Birth Defects	- 25.6%
Perinatal Conditions	- 29.6%
SIDS	N/A
Illness	- 39.4%
Motor Vehicle	- 13.8%
Bicycle	- 61.3%
Fire	- 80.2%
Drowning	- 40.3%
Other Injuries	- 52.0%
Homicide	- 51.0%
Suicide	- 17.9%

Fourth, because of the differences in causes, the interventions-educational, medical and political-are also quite different. For infant deaths, interventions focus on education during the preconceptional, prenatal, and postpartum periods; access to prenatal care; and newborn intensive care. Interventions are

"Beyond age one, injuries in their various forms are by far the leading causes of death."

fairly costly, and political support is usually a function of awareness and the availability of public funds. For deaths in older children, interventions focus on injury prevention, which is largely a function of education to guide and/or change behaviors. These interventions are often at low or no public cost. However, legislation is often sought to reinforce educational/behavioral messages (e.g., the safe storage of guns, or requirements for bicycle helmets and smoke alarms). These proposals usually engender much political debate, for they are often viewed as an infringement on individual rights or on the rights of the family to make decisions on behalf of children.

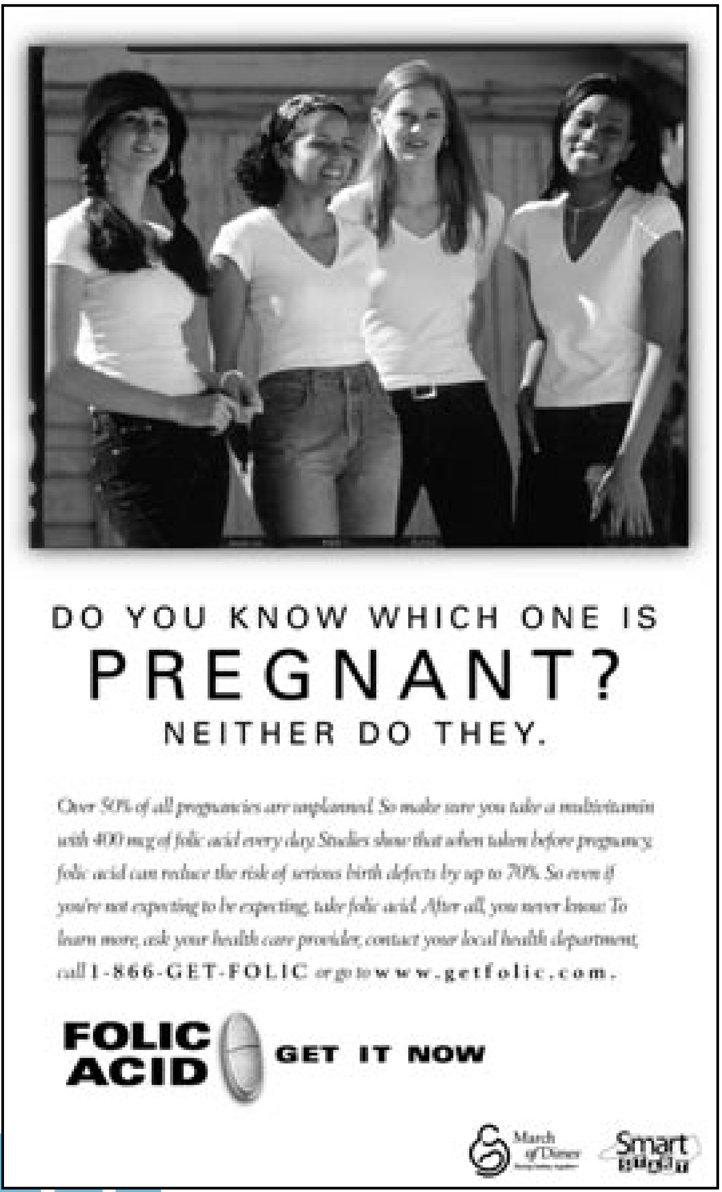
An Invitation to Physicians

As noted above, most of the deaths in children beyond the infant year are not related directly to the provision of hands-on medical care. This does not mean, however, that physicians do not have a large role to play in reducing such deaths. Health education and behavior-risk counseling are the critical interventions needed at the child/family level, and advocacy is often needed at the state and community level to enhance child safety.

At both levels, physicians can use their expertise and their positions of respect to raise awareness of issues and to effect remedies that will enhance the health and safety of children and youth. Physicians are encouraged to become involved with the efforts of the local child fatality prevention team in their respective counties. (Information can be obtained from the local health department.)

While North Carolina's progress in reducing infant and child death rates has been remarkable, there is much more progress to be made. Physicians are invited to increase their participation in these efforts. **NCMJ**

Acknowledgement: The author would like to thank Fatma Simsek and her collegues in the State Center for Health Staticstics for their assistance in compiling the data for this article.



Running the Numbers

A Periodic Feature to Inform North Carolina Healthcare Professionals
About Current Topics in Health Statistics

From the State Center for Health Statistics, North Carolina Department of Health and Human Services
www.schs.state.nc.us/SCHS

Unintended Pregnancies in North Carolina

More than half of all pregnancies in North Carolina and the United States are unintended. Unintended pregnancies are those that are unwanted (now or at any time in the future) or occur before a woman wanted to become pregnant. In North Carolina, an estimated 45% of the more than 115,000 live births each year were unintended at the time of conception. In addition, there are approximately 27,000 induced abortions each year in North Carolina, and presumably the vast majority of those result from unintended pregnancies.

Among live births, women with unintended pregnancies are less likely to seek early prenatal care, more likely to smoke during pregnancy, less likely to breastfeed, and more likely to have a low-weight birth. Women with unintended pregnancies are likely to also have other risk factors (such as low-socioeconomic status), but the evidence suggests that a well-timed pregnancy in itself leads to better health behaviors and improved infant health.

The North Carolina Pregnancy Risk Assessment Monitoring System (PRAMS) is a mail and telephone survey of a random sample of North Carolina women who have recently had a live birth. It is supported by the Centers for Disease Control and Prevention (CDC) and is currently conducted in more than 30 states. In North Carolina, approximately 1,800 women are interviewed each year. Pregnancy intendedness is captured from the PRAMS survey question that asks mothers to indicate how they felt about becoming pregnant just prior to conception. Those who answered that they wanted to be pregnant "'sooner" or "then" were categorized as intended; those who answered "later" or "not then or at any time in the future" were categorized as unintended.

Forty-five percent of 1997-2000 PRAMS survey respondents indicated that their pregnancy was unintended, with 34% saying that they wanted to be pregnant later and another 11% saying that they did not want to be pregnant then or at any time in the future. The following categories of women had a particularly high percentage of live births that were unintended: age less than 20 years (76%), less than a high school education (61%), household income below $14,000 (66%), and unmarried (73%). Having a live birth that was unintended was strongly associated with never taking a multivitamin (folic acid) before pregnancy, late entry into prenatal care, smoking during pregnancy, domestic violence, postpartum depression, and not breastfeeding.

A planned pregnancy gives women the opportunity to prepare for a healthy pregnancy. Healthy behaviors before and during pregnancy reduce the risk of a low-weight birth. Though the risk of unintended pregnancy is higher among younger women, more than 75% of all unintended pregnancies are to women ages 20 and older. Therefore, efforts to reduce unintended pregnancies must include all age groups. Access to appropriate contraceptive services is certainly very important. Many family planning programs also provide a broad range of preventive health services such as patient education and counseling; breast and pelvic examinations; cervical cancer, STD, and HIV screenings; pregnancy diagnosis and counseling; and referral to appropriate medical and social services.[1] This emphasis on pre-conceptional health means that women who do choose to become pregnant are better prepared physically and mentally. Federal funds from the Title X program and Medicaid support family planning services for low-income individuals. These publicly-funded services are available on a voluntary and confidential basis.

The full report from which these results were taken was published by the State Center for Health Statistics in November 2002 (SCHS Studies No. 136) and can be accessed at http://www.schs.state.nc.us/SCHS/pubs/title.cfm?year=2002

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Contributed by Paul A. Buscher, PhD
State Center for Health Statistics, North Carolina Division of Public Health

Letters to the Editor

Latino Health in North Carolina

To The Editor:

In your May/June 2003 issue, you focused on Latino health in North Carolina—a subject in need of attention. The issue did not mention domestic violence and I wanted to share some information with you and your readers about this serious problem. The following paragraph is an excerpt from a client's story (with names changed). It paints a picture of the issues battered Latinas face.

> *"I remember once when I was three or four months pregnant with my second child, he beat me. I was crying and begging him not to hit me, but he kept on and his mom and step-dad did nothing. After he beat me, he left the house like he always does. When I asked his mom to call the ambulance she said she was not going to get her son, José, in trouble. His mother threatened to call immigration and said she would keep my son, José, Jr., because I would be taken back to Mexico."*

Numerous organizations, such as the American Medical Association, the American Nurses Association and the Joint Commission for the Accreditation on Healthcare Organizations, endorse addressing domestic violence through the healthcare system. Domestic violence has serious physical and mental health consequences and healthcare visits may be among the few opportunities for isolated victims to receive the support they need. However, in accessing the healthcare system, battered Latinas face multiple barriers in North Carolina. In general, the Latino population faces greater challenge accessing the healthcare system due to language barriers, cultural differences, immigration status and a lack of awareness of services. For Latinas who are victims of domestic violence, these barriers are increased by the isolation that is endemic to being a domestic violence victim. To further complicate matters, other common tactics by abusers such as threats of deportation, use of children and economic abuse hinder the ability of battered Latinas to access services.

"Language barriers first and foremost result in deterring a victim from obtaining necessary assistance."

Language barriers first and foremost result in deterring a victim from obtaining necessary assistance. Although linguistically accessible healthcare services should be provided by recipients of federal funding pursuant to Title VI of the Civil Rights Act of 1964, few such services exist. Several of our clients have feared getting medical help on their own because they are monolingual and were used to relying on the abuser for interpretation. One battered Latina client told us "[h]e was the only person who helped me in situations where I needed to communicate, and in this situation I could not rely on him." Even if the battered Latina is actually able to get to a healthcare provider, if the batterer acts as the interpreter, the information given health workers may be skewed.

Since not all Latinas in North Carolina are US Citizens, immigration status is also a barrier for many battered Latinas. Some immigrants are not eligible for Medicaid or Medicare except in life threatening emergencies, thereby limiting their access to healthcare. Domestic violence victims may choose to avoid receiving healthcare because they do not know how they can pay for such services and fear reprisals from the abuser. Furthermore, it is not uncommon that abusers will threaten an undocumented victim that a phone call to 911 for emergency services will result in her deportation and removal of children from her custody. Finally, cultural differences create an additional barrier for battered Latinas to access relevant services, although defining cultural differences can be a tricky enterprise. We know that cultural differences operate on both ends of the system. Healthcare providers may lack culturally competent staff. From the perspective of battered Latinas, they may be surprised to learn that they may be eligible for services. Many of our clients, for example, are unaware that they can receive mental health counseling as victims of domestic violence. One client informed us that in her home country, there were no services available for "women who are abused by their husbands." Many women, therefore, do not attempt to obtain assistance due to a lack of familiarity with the system especially since it may be quite distinct from the system in their home country.

Taken all together, the power and control dynamics inherent in a domestic violence situation further aggravate the cultural isolation created by language barriers, cultural differences, and immigration status. These dynamics create special difficulty for battered Latinas in accessing medical assistance.

Special Laws Applicable to Battered Latinas Who Are Immigrants

There are certain laws that offer battered immigrant Latinas some assistance from the extreme isolation created by their situation. The Violence Against Women Act (VAWA) can help certain battered immigrants obtain lawful immigration status and employment authorization—both crucial to a victim's ability to survive independently.[1] If an undocumented immigrant is married to a Legal Permanent Resident or to a US Citizen, she may have remedies under VAWA. Normally, the undocumented immigrant would get immigration status through the traditional family-based immigration process, where the spouse with legal status would control the application process. In domestic violence situations, the abusive spouse often exploits the family-based immigration process by refusing to apply for lawful status in order to exert further control. VAWA was passed to remedy the traditional family-based immigration process so that the victim herself could apply for legal immigration status by filing a Self-Petition.

The VAWA Self-Petition process not only allows victims to obtain lawful immigration status, but it also may make some battered immigrants eligible for important federally-funded benefits, such as Medicaid.[2] Battered immigrants can qualify for federally-funded benefits it they have filed a VAWA Self-Petition and can show a substantial connection between the abuse and the need for the benefit. The victim is required to show: (1) a prima facie determination or an approval of a VAWA Self-Petition or a Family-Based Petition; (2) battery or extreme mental cruelty; (3) a substantial connection between the abuse and the need for the benefit; and (4) that she no longer resides in the same household as the abuser. Children of VAWA Self-Petitioners will also be eligible. Many of our clients have been able to show a substantial connection between the need for medical attention or mental health counseling and the effects of the abuse.[3] Unfortunately, not all VAWA Self-Petitioners will automatically be eligible for Medicaid since they are still subject to the complicated restrictions facing non-US Citizens who apply for federally-funded benefits.[4] This exception, however, at least places VAWA Self-Petitioners on the same footing with Lawful Permanent Residents in terms of accessing federally-funded benefits.

Moreover, there are certain federally-funded benefits that are available to all battered Latinas regardless of immigration status, since many battered Latinas are otherwise ineligible to file a VAWA Self-Petition. Some federally-funded benefits that are especially relevant to the health and safety of victims are: emergency Medicaid, crisis counseling and intervention programs, public health assistance for immunizations, treatment of symptoms of communicable diseases, violence and abuse prevention, medical and public health services and mental health, disability or substance abuse assistance necessary to protect life or safety.[5] Finally, battered Latinas, regardless of immigration status, have the right to access important criminal and civil court remedies necessary to protect their health and safety.

Suggestions for Healthcare Providers

Healthcare providers can take steps to increase battered Latinas' access to the healthcare system and to identify and assist victims. Common recommendations for increasing access for the Latino population generally are to offer bicultural and bilingual services and to conduct community education and outreach about available services. To serve battered Latinas as well, providers should be trained about the issues that are particular to battered Latinas, including the extreme isolation aggravated by their domestic violence situation and legal options for battered immigrants. Having some understanding of these issues is significant because it will shape how healthcare practitioners understand and choose to pursue treatment.

Healthcare providers should also have an adequate referral system in place for when they encounter a battered Latina who needs assistance. A good starting point is to establish contact with the local domestic violence program. Many programs are increasingly facing populations of battered Latinas and are learning about the special intricacies in assisting this population. Several of the programs within the state have also made a special effort to hire someone on their staff who is bilingual and/or bicultural; however, only a minority of the programs has bilingual staff. In addition, it is important to connect with the other local community-based organizations that serve Latinos. Many of them, particularly in communities where the domestic violence program does not have bilingual staff, serve as a de facto domestic violence program for Latinas.

Finally, a couple of statewide coalitions have worked on issues facing battered immigrants. These coalitions bring together individuals from a variety of backgrounds, including law, social work, public policy, law enforcement, and academics, in order to facilitate cooperation and the exchange of knowledge about the barriers faced by battered Latinas. Project Esperanza focused on issues relating to battered Latinas across the state. For more information, please contact the Coalition for Family Peace in Siler City, North Carolina: (919) 742-7320. There is also a larger statewide coalition called the NC Network on Behalf of Battered Immigrant Women, which addresses issues facing battered refugee and immigrant women generally. To subscribe to their list serve, please e-mail NCNetworkforBIWsubscribe@yahoogroups.com.

These coalitions would welcome the participation of healthcare practitioners who could bring to the table their unique perspective on this very important issue.

Acknowlegement: Thanks to Jan Capps and Mara Deutsch for help with this letter.

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1 Violence Against Women Act of 1994, Pub. L. No. 103-322, 108 Stat. 1902, subsequently amended, Victims of Trafficking and Violence Prevention Act of 2000, 114 Stat. 1464, Pub. L. No. 106-386 (2000). There is also a more limited immigration remedy for victims of crime (U Visa) that could aid domestic violence victims who are otherwise ineligible for VAWA.

2 8 U.S.C. § 1641(c). This same provision applies to other federally-funded benefits such as Work First, Food Stamps, Public Housing and Section 8 Assistance.

3 Despite federal law, our battered Latina clients were being told by the local divisions of the Department of Health and Human Services that they were ineligible for Medicaid and other federally-funded benefits. Only with persistent advocacy on a case-by-case basis were we able to get our clients access to Medicaid and other benefits. In 2003, the Department of Health and Human Services modified their manuals to reflect federal law with more specific guidance to their workers. See “Citizen/Alien Requirements: Battered Alien (Violence Against Women Act),” Family & Children’s Medicaid Manual, MA-3330, Section VI; “Immigrant Access to Benefits,” DMA Administrative Letter, No. 19-03 (April 1, 2003). Similar clarification was made in the Manuals for Work First and Food Stamps.

4 All Lawful Permanent Residents who entered after August 22, 1996, for example, are subject to a five-year bar for Medicaid benefits. There is no exception from this requirement for battered immigrants. Other such restrictions were enacted by the Personal Responsibility and Work Opportunity Reconciliation Act of 1996, Pub. L. No. 104-193, 110 Stat. 2105, and the Immigration Reform and Immigration Responsibility Act of 1996, Pub. L. No. 104-208, 110 Stat. 3009.

5 8 U.S.C. § 1611; 66 Fed. Reg. 3613 (January 16, 2001), A.G. Order No. 2353-2001, Final Specification of Community Programs Necessary for Protection of Life and Safety Under Welfare Reform Legislation. Federally-funded community health centers which provide primary and preventative healthcare serve all people regardless of immigration status or ability to pay. Mental health centers do not have restrictions on who can receive services based on immigration status; however, individual centers may have funding restrictions that are linked to immigration status.

Mental Health Reform

To The Editor:

In several of the analyses of the State Mental Health Reform Plan published in the September/October 2003 issue of the *North Carolina Medical Journal*, veteran observers of the reform effort raised concerns about the capability of the state mental health workforce to meet the challenge. Basic elements in the Plan—conservation of resources for the most severely mentally ill, increased accountability of clinicians and communities for mental health policy, consumer involvement, transfer of service delivery to the private sector and provision of evidence-based best practices for the targeted populations—pose challenges to the clinicians in the workforce as it is currently configured. The limitation of the most expensive forms of public mental healthcare to all but the most severely ill citizens will exclude some consumers from public sector facilities where they are currently being served, requiring that they seek care in different settings. Care of the uninsured and indigent citizens who do not meet target criteria is still undetermined.

Furthermore, by downsizing public mental hospitals and shifting public funding to community-based services for severely mentally ill citizens, the Plan inherently calls for a compensatory array of primary mental health services that are characterized by easy access, quick, comprehensive response, and that use an arsenal of interventions to restore normal function and divert hospitalization or incarceration. A shift to more primary mental health services means that the traditional equation of incremental intensity of services is reversed. Consumers, whether mildly or severely mentally ill, currently have access to intensive intervention immediately through multiple portals to care. Evidence-based early intervention precedes tertiary care, a wider array of clinicians are empowered to make gate keeping decisions and service authorizations, and relationships among individuals and institutions are collegial, not hierarchical. These elements require a level of seamless integration among frontline systems (e.g., emergency departments), mid-level systems (e.g. community mental health providers, clubhouses) and tertiary systems (e.g. inpatient facilities and mental healthcare hospitals). If a commitment is made to truly change mental healthcare, this necessary configuration must be addressed honestly rather than “patching” the current system in a way that preserves existing interests. As the Plan and the Journal analysis noted, meeting the reforms in the Plan is beyond the composition and configuration of the current state workforce.

In that same issue of the Journal, Schwartz and Morrissey called for bold training and recruitment and retention initiatives to intensify clinicians’ skills, while Bacon and Stallings proposed increased use of advanced practice psychiatric nurses, in particular, the psychiatric nurse practitioner (PMH-NP). We would like to focus on this one role, not as a solution to the challenges of reform, but as an exemplar of the way in which existing clinicians within the mental health system could be prepared to bring the innovative elements that were in the Plan closer to reality.

The PMH-NP, a relatively new face on the mental healthcare team in North Carolina, has proven to be a cost-effective, quality-enhancing addition to mental healthcare in other states. Currently, there are almost 3,000 registered nurses working in mental health in North Carolina—more than 300 have a master’s or doctoral degree. Most of these clinicians were prepared as

PMH Clinical Nurse Specialists with advanced practice preparation in psychotherapies and primary mental healthcare, but without prescriptive authority in North Carolina. As the state mental health hospitals are downsized and consolidated, some of these experienced nurses could help meet the mental health workforce needs if they were prepared as PMN-NPs to provide the right care at all levels of acuity in these ways:

- As independent practitioners, PMH-NPs could widen the portals of immediate mental healthcare through the provision of individual, family and group psychotherapeutic interventions for less-severely mentally ill adults and children in the community and, in collaboration with a physician, prescribe and maintain psychotropic medication, thus helping to prevent progression of disorders.
- As community-based providers of care for severely mentally ill adults and children in conjunction with local managing entities (LMEs), PMH-NPs could coordinate multiple care systems and construct support systems for families and community groups who will be the primary caregivers of these citizens, and in collaboration with a physician, provide medication prescription and ongoing maintenance and education.
- As institutionally-based providers of care to severely mentally ill citizens in crisis, the PMH-NP could collaborate with physicians to manage complex physical and mental health conditions and psychiatric crises that require readjustment of psychotropic medications and alterations in care treatment plans required to maintain them once they have returned to their communities.
- As institutionally-based providers of care to medically-ill citizens, the PMH-NP, in a consult and liaison role, could collaborate with physicians to correctly identify mental health issues when appropriate, secure early intervention when appropriate and assist in correct placement in community-based treatment facilities.

Nationally, and in North Carolina, existing advanced practice nurse educational programs prepare PMH-NPs to be cost-effective, multi-skilled providers. These programs already have mechanisms such as online courses, executive formats and AHEC liaisons through which many nurses who already have psychiatric experience could be supported to return to school. Through partnerships with existing facilities, faculty can work with LMEs to place these students in preceptored experiences that will prepare them to meet the newly-evolving service roles. With additional preparation enriching their years of experience in the provision of mental healthcare, these PMH-NPs could provide cost-effective, high quality care to North Carolinians based on best-practice evidence. The model that is already in progress for nursing could be adapted by other disciplines, thus creating an exemplar of interdisciplinary care to meet the challenge of mental healthcare reform in North Carolina.

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New Directions in **End-of-Life** and **Palliative Care** in North Carolina

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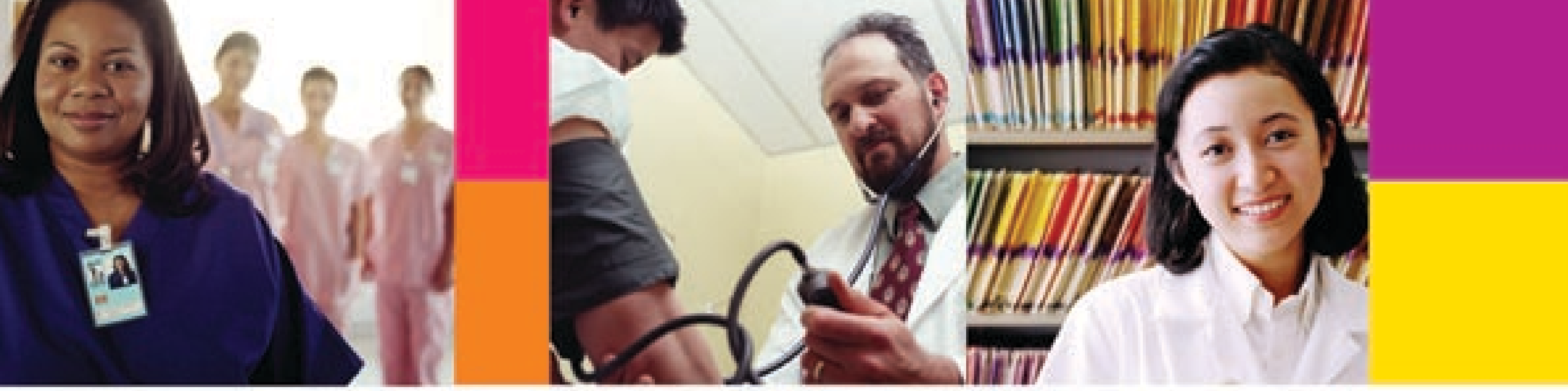

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"When chances for cure and survival diminish, most dying patients and their families prefer an approach to medical treatment that emphasizes comfort and quality of life."

African American Elders' Perceptions of the Influenza Vaccine in Durham, North Carolina

Sohini Sengupta, PhD, MPH, Giselle Corbie-Smith, MD, Angela Thrasher, MPH, and Ronald P. Strauss, DMD, PhD

Abstract

Objective: *To qualitatively explore community perceptions among elderly African Americans about what makes it easy or difficult to get vaccinated for influenza.*

Sample: *A total of 28 elderly (age 65 years or older) African Americans living in Durham County, North Carolina, participated in this study.*

Data Collection Methods: *In-person, open-ended interviews were conducted to perform a content analysis on factors influencing influenza vaccination use, or lack thereof, in an elderly African American population. Interviews were conducted in participants' homes and at senior centers in Durham County, North Carolina. Interviews were transcribed and analyzed to identify themes.*

Principal Findings: *Ten facilitators to encourage obtaining vaccinations were identified, including reminders from a doctor to get the influenza vaccination and the perception that the vaccination prevents influenza. Eight barriers were identified, including community perceptions to not get vaccinated and the fear of getting the "flu" from the vaccination itself.*

Conclusion/Relevance: *The study identified community perceptions of what makes it easy or difficult for elderly African Americans to get vaccinated for influenza. The findings will be useful to design and implement programs targeted to improving vaccination rates in health clinics or private physician's offices since the elderly are more likely to receive influenza vaccinations in primary care settings.*

Key Words: *Aging, Access to Care, Immunization/Vaccines, African Americans/Blacks, Qualitative Research*

Introduction

Every year influenza epidemics cause more than 20,000 deaths and 110,000 hospitalizations in the United States.[1-4] Specific target groups, such as elderly persons (≥ 65 years), young children, and persons with underlying diseases (who are often elderly) are at highest risk of influenza-related complications and hospitalizations.[5] Mortality associated with influenza, however, disproportionately affects the elderly. In a recent study, influenza mortality correlated with age, with persons ≥ 85 years old being 32 times more likely than persons 65-69 years old to die of influenza-related complications.[6] Given that the average life expectancy at birth for men and women in the United States now exceeds 74 and 80 years, respectively,[7] annual influenza vaccination is, and must, remain among the most important public health priorities to control the healthcare burden associated with influenza morbidity and mortality.

The United States Preventive Service Task Force and the CDC's Advisory Committee on Immunization Practices recommend that elderly Americans get vaccinated against influenza as a preventive measure annually.[8-9] The 1996 Medicare Current Beneficiary Survey and the 2002 Behavioral Risk Factor Surveillance Survey—nationally representative surveys to assess influenza vaccination usage and reasons for not getting vaccinated among elderly Americans—demonstrated, however, that influenza vaccination rates differed among elderly racial/ethnic groups; approximately 68%-69% in whites, and 47%-50% in African Americans.[10,11] Furthermore, not getting vaccinated was associated with not perceiving influenza to be a health risk, regardless of race.[12] In *Healthy People 2010*, one of the objectives is to increase the proportion of all elderly Americans vaccinated annually against influenza to 90%.[13] "Eliminating," not just reducing health disparities, is one of the nation's goals for the next decade.

It will be a particular challenge to increase influenza vaccinations in elderly African Americans from 47% to 90%. The Medicare Current Beneficiary Survey provided little evidence as to why elderly African Americans are disproportionately not

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getting vaccinated for influenza other than they may not know about the benefits of getting vaccinated.[14] Before we can wage a campaign to increase the proportion of elderly African Americans vaccinated against influenza, we must first understand the structural and interpersonal factors influencing their behaviors (i.e., getting or not getting vaccinated). The purpose of this qualitative study is to explore community perceptions of what makes it easy, as well as what makes it difficult, for elderly African Americans to get vaccinated for influenza.

METHODS

The target population was non-institutionalized, community dwelling elderly (≥ 65 years) African Americans living in Durham County, North Carolina. We recruited our convenience sample from senior centers, referrals from study participants already interviewed, as well as from a list of elderly African Americans through the University of North Carolina at Chapel Hill/North Carolina Central University Center for Minority Aging. Of the 41 potential participants approached or contacted over the telephone by our interviewer, 13 (31.7%) refused to participate. Reasons for refusal included that individuals were not interested, did not have the time, or they were not in good health. Our final sample was 28 participants, which was sufficient in achieving data saturation with respect to the expected and emergent issues associated with our research objectives.

Data Collection

The interviewer scheduled a one-hour interview with each of the 28 participants. Interviews were conducted either at the participant's home or at one of the senior centers where recruitment occurred. Written informed consent was obtained, followed by the interview. All interviews were audiotaped, and participants received financial compensation for their participation. The interviews were completed between May and October 2002. The Institutional Review Board of the University of North Carolina School of Medicine approved this study's protocol and consent form on October 19, 2001.

Qualitative Interview Guide

An interview guide was developed for this study to explore three main open-ended questions:

- What are the benefits (or risks) of getting vaccinated for the flu?
- What kinds of things do you think would help older African American adults get the flu shot?
- What makes it difficult for older African Americans to get the flu shot?

The interview concluded with a set of sociodemographic questions, including race/ethnicity of their main physician, age, education level, main source of income, health insurance status, whether or not they lived alone, whether or not they ever had the flu, whether or not they received a flu shot consistently on an annual basis, and whether or not their physicians offered them the flu shot during office visits.

Data Management and Data Analysis

Audiotapes of the interviews were transcribed into a word-processing program. The interviewer checked the accuracy of the transcripts by listening to, and reading along with each tape. Any identifying information in the transcripts was supplanted with generic references (e.g., Person A, Senior Center B) to protect confidentiality. The transcribed interviews were then imported into Ethnograph© v5.07, a qualitative software program for the purposes of content analysis.

For the Likert-type, and sociodemographic questions, data were entered into SPSS© 11.0.1. Frequencies were calculated for categorical variables, and medians were calculated for continuous variables. Content analysis involved the development of a thematic coding structure representing a hierarchy of codes.[15] Level 1 codes reflected each of the open-ended questions asked. Sub-codes reflected themes identified from answers to these questions. For example, *What are the benefits of getting vaccinated for the flu?*, was a theme earmarked by a level 1 code, and a sub-code for this theme was, *Protect myself from getting the flu.* We addressed validity systematically by first developing a codebook through an iterative process that delineated each

Table 1.
Sociodemographics

Variables	(N=28)
Gender	
Male	6 (21.4%)
Female	22 (78.6%)
Marital Status	
Married	12 (42.9%)
Widowed	11 (39.3%)
Other	5 (17.8%)
Income Source	
Social Security	18 (64.3%)
Retirement/Pension	10 (35.7%)
Education	
≤ High school	9 (32.1%)
Trade school	8 (28.6%)
College education	6 (21.4%)
Graduate degree	5 (17.9%)
Health Insurance	
Medicare + Private	19 (67.9%)
Private only	5 (17.9%)
Medicare only	1 (3.6%)
Other	3 (10.7%)
Lives alone	9 (32.1%)
Had the flu in the past	20 (71.4%)
Personal doctor offered vaccine in the past	24 (85.7%)
Personal doctor offered vaccine in Winter 2002	21 (75.0%)

Note: "Not sure" responses were excluded from totals that do not equal N = 28.

code (level 1 and sub-codes), their definitions, when is it appropriate to use each code, and when is it not appropriate to use each code after the research team had read a first passing of all of the interviews. The codebook provided the coders a framework of mutual understanding about each of the themes. The second step involved having coding teams independently read and code each interview for intercoder reliability. Percent agreement was compared for each code across interviews for the purposes of assessing intercoder reliability. Any code having less than 80% agreement was discussed, and discrepancies were resolved to improve agreement.

RESULTS

Description of the Sample

The 28 participants were all African American, 65 years of age or older, and living in Durham County, North Carolina (see Table 1). The mean age was 74.9 years, with the oldest participant being 86 years old. Overall, the majority of the participants was female, living on Social Security, and had both Medicare and private health insurance. Twenty (71.4%) of the participants had the flu in the past, and 13 (61.5%) of these participants received the annual flu shot consistently (data not shown in table). For 24 (85.7%) of the participants, a personal physician offered the vaccine to them in the past, and for 21 (75.0%), the personal physician offered the vaccine to them in winter 2002.

Facilitators and Barriers Affecting Influenza Vaccine Usage

To better understand why African Americans are getting or not getting vaccinated for influenza, we asked three open-ended questions to elicit what makes it easy and what makes it difficult for elderly African Americans to get the influenza vaccine. The three questions we asked were intended to improve understanding of community perceptions of the facilitators and barriers to influenza vaccine use. Tables 2 and 3 present the themes for facilitators and barriers, respectively, and quotation examples for each theme.

Facilitators Associated with Influenza Vaccination

All participants were asked about what makes it easy for members of their community to get vaccinated for influenza. Responses were categorized as either structural facilitators or personal factors (e.g., knowledge, attitudes, or health status) facilitating influenza vaccine usage (see Table 2). For structural factors, the predominant facilitator reported was receiving a reminder from their doctor to get a flu shot (N = 19). Reminders could range from an informal postcard in the mail, to a conversation with their personal doctor about the benefits for older African Americans to get vaccinated for influenza. Another important source of external information that facilitated vaccine usage was word-of-mouth from the community that getting the influenza vaccine is an important health behavior (N = 14). The "community" generally referred to other African Americans with whom they had discussed the influenza vaccine, such as friends, relatives, or church and religious leaders who were perceived as a source of positive information that older African American adults could trust. Lastly, it helped that the influenza vaccine was primarily covered by participants' health insurance (N = 7).

Several personal facilitator themes were identified. Seventeen (60.7%) participants strongly felt that being knowledgeable about influenza, its symptoms, and the possibility that it could be fatal, was a strong motivator to get vaccinated. Participants also described their own health conditions (e.g., heart disease or hypertension) as susceptible to the flu (N = 6), or the fact that they were getting older (N = 11), resulted in the need for getting a flu shot. Lastly, participants identified three main benefits about the influenza vaccination. The predominant perceived benefit given was that the influenza vaccination was effective in preventing individuals or communities from getting sick with the flu, or getting sick from cold-related illnesses (N = 24). The second most common benefit was the perception that the vaccine would diminish the severity of flu symptoms if the individual became infected with the flu (N = 12).

Barriers Associated with Influenza Vaccination

All participants were asked what makes it difficult for members of their community to get vaccinated for influenza. As in the analysis of facilitators, responses were categorized as either structural or personal factors (e.g., knowledge, attitudes, or health status) that posed as barriers to influenza vaccine usage (see Table 3). The predominant structural barrier was word-of-mouth from the community to not get a flu shot (N = 20). Within this context, "community" included community leaders, or relatives and friends, but this theme also reflected conversations individuals may have had, or might have heard at the barber shop, eateries, or other public places that were construed as dissuading elderly African Americans from getting a flu shot. Although not frequently mentioned, the theme, lack of access (N = 6), incorporated a number of different issues that prevented elderly African Americans from getting vaccinated, including not enough venues where individuals could go to get a flu shot. Lack of access also related to the issue of influenza vaccine shortages, which were salient even for participants who had regular primary care and could have received the vaccine through their physician's office.

Thirteen (48.1%) participants felt that not knowing about the severity of the flu was a personal barrier for most elderly African Americans. Participants also were influenced by what they perceived to be the risks of the influenza vaccination itself, focusing particularly on the contents of the vaccine. A predominant belief was that the flu shot itself could cause the flu (N = 21).

DISCUSSION

Our study demonstrated that participants' knowledge and attitudes about the severity and likelihood of getting influenza did not explain fully why elderly African Americans are getting or not getting vaccinated. Instead, exploring knowledge and attitudes in concert with structural facilitators and barriers provide a better picture of the challenges health professionals confront to improve influenza vaccination rates in this underserved racial group. We set out to understand the factors affecting influenza vaccination use in one elderly African American sample and to provide recommendations on how to remedy some of the key factors identified.

The study findings focused on the facilitators and barriers affecting influenza vaccine usage among elderly African Americans in Durham County, North Carolina. Interestingly, some themes were identified as both facilitators and barriers to getting vaccinated for influenza. One of these themes was word-of-mouth from the community highlighting both the pros and cons of getting vaccinated. Although more participants expressed this theme within the context of what discourages individuals from getting vaccinated, it raises an important issue about how negative experiences with the influenza vaccine are emphasized, spread, and can linger within a community. Similarly, a predominant perceived risk was that the vaccine itself causes the flu. Most likely, what participants experienced

Table 2.
Facilitators to Getting the Influenza Vaccine

Theme	Text Example	(N=28) N (%)
STRUCTURAL		
Reminder from the doctor to get a flu shot	"...and pamphlets that they [doctor's office] send you in the mail to get the flu shot. And, they [doctor's office] do write you ...And tell you the flu shot will be given such and such a time." (Female, 73 years old)	19(67.9)
Word-of-mouth from the community to get a flu shot	"And that's where a lot of people gather, so around the flu time send notices or information to the churches and the schools informing people about this flu shot and sometimes people in the church will listen if it's coming from somebody else in the church." (Female, 73 years old)	14(50.0)
Written or visual media promoting flu shot use	"I think when you get information when you go to get your flu shot, they also give you pamphlets to hand out and things like that, I think that all is a good awareness." (Female, 67 years old)	11(39.3)
Vaccine is free or low cost	"Also cost, better health insurance for, insurance making it [flu vaccine] available that way." (Female, 65 years old)	7(25.0)
PERSONAL		
Being knowledgeable about the severity of the flu	"I have had the flu, and I know how sick you can get from it." (Female, 77 years old)	17(60.7)
Having a chronic condition that puts them at higher risk for getting the flu	"See I didn't have any serious medical problem. But since I had heart disease, he [doctor] encouraged it [getting flu shot]." (Female, 75 years old)	6(21.4)
Having (Had) a job that puts them at a higher risk for getting the flu	"Because it was part of the hospital's routine, the nurses there had to take, they had to take different vaccinations and all that kind of stuff." (Female, 66 years old)	8(28.6)
Getting older	"And the reason why I took the flu shot this year is because for the last—since I've made sixty five—I see that my resistance to colds and flus are getting worse." (Female, 68 years old)	15(53.6)
Benefits of the flu shot		
* Prevention	"I think it prevents you from being miserable during the winter." (Female, 68 years old)	24(85.7)
* Decreases symptom severity of the flu	"I guess stave, stave off colds, other diseases that might be connected with the flu." (Female, 78 years old)	12(42.9)
* Greater ability to do day-to-day activities	"Because my doctor is still telling me that if I have a breathing condition, that if I got the flu, it would be milder than if I did not take the flu shot." (Female, 73 years old) I think it [flu shot] keeps my immune system stronger, so therefore I feel better, and I'm able to do the things that I enjoy doing and not have to spend time laying around, sneezing, coughing...so it really helps me so I can be more active." (Female, 67 years old)	8(28.6)

Note: Values represent the number (and %) of participants who reported each theme listed.

and were describing was an immunological response or side effects to the vaccine that they interpreted as the flu. Nevertheless, their negative experiences with taking the influenza vaccine will affect their future usage. In attempting to change behaviors among elderly African Americans, and in this case improve annual vaccination usage, we recommend the need to address historical, collective experiences (e.g., being exposed to a "bad batch" in early vaccination efforts), as well as urban myths (e.g., the vaccine causes the flu), in any targeted program developed.

Several other recommendations can be noted with respect to increasing knowledge and awareness of influenza and its vaccine in African American communities. A majority of the participants identified reminders from healthcare providers to get vaccinated

Table 3.
Barriers to Getting the Influenza Vaccine

Theme	Text Example	(N=28) N (%)
STRUCTURAL		
Word-of-mouth from the community to get a flu shot	"Those are the ones that are scared of, of getting the flu [from the flu shot]. They heard from somebody who heard from somebody else that it can give you the flu. It's hard to convince folks once they start thinking that." (Male, 72 years old)	20(71.4)
Irregular or lack of preventive healthcare	"When you're talking about medical visitation, regular visitations, a lot of people my age don't go to a doctor until they're sick. And the doctor, when they find out what's the matter with them, you know where they go first, the Emergency room." (Male, 76 years old)	7(25.0)
Lack of access	*Regarding vaccine shortage:* "When I went to the health department, they said it was somewhat late that they couldn't get the vaccine or something. I went there three times, you know. But anyway she said, 'I'll call you,' but when I did go back there was, something didn't come in... and I was interested in getting my flu shot." (Female, 77 years old) *Regarding location access:* "I think it's access to health, to places where you know the flu shot is given. There may be not as many clinics or places that you know that they can go to, or the distance that they may have to travel." (Female, 77 years old)	6(21.4)
PERSONAL		
Not knowledgeable about the severity of the flu	"Some of them are not knowledgeable enough to know what it can do for you. They don't realize the risks or the advantages." (Female, 76 years old)	13(48.1)
Fear	"I think some people are afraid. They're afraid that they're going to get sick or something from it." (Female, 79 years old)	13(46.4)
Risks of the flu shot		
* Side effects	"I think when they give you the shot, they're giving you part of that, parts of flu? And, if you're not strong enough or you can't fight it off, that's the way I feel about it. Your body's not strong enough, then I guess you just have the flu, it will give you the flu." (Female, 80 years old)	21(75.0)
* Getting the flu from from the flu shot	"My arm swolled up and I had chills and fever. Just like I was having, just like flu. And, I was just sick. And so, that stopped me from taking them [flu shots]." (Female, 80 years old)	18(64.3)
* Past problems with flu shot batches	"...sometimes the flu shot can, depending upon the batch of the flu shots that's being given sometimes they can have adverse effects and that is something I do think about." (Female, 65 years old)	5(17.9)

Note: Values represent the number (and %) of participants who reported each theme listed.

as a facilitator. The reminders can lead to elderly patients asking for the vaccine or just asking questions about the vaccine should they have concerns. Through simple reminder systems, providers can play an important role in reducing racial/ethnic disparities in vaccine use,[16] not to mention encouraging more patient education about influenza and its prevention. A second recommendation is to educate African American communities about the fact that an annual influenza vaccine is covered under Medicare, to which all over the age of 65 are entitled, and cost should not be a barrier to getting vaccinated. Lastly, since influenza immunization is seasonal, it would be useful to develop local media campaigns notifying the public in a timely and coordinated fashion when and where the vaccine will be available. This will most likely target individuals who have a desire to get vaccinated, but have had access difficulties due to vaccine shortages, late arrival of the vaccine, or not knowing locations where to get the vaccine, particularly in cases where individuals do not have a regular healthcare provider and rely on chain pharmacies or health departments for their vaccine source.

Our study has two primary limitations. First, our convenience sample was not heterogeneous with respect to socioeconomic status and gender, i.e., low-income and male participants were not equally represented. Second, our findings have limited generalizeability only to elderly African Americans with similar population characteristics to our sample living in Durham, NC. Further research would need to be conducted on a national sample of older African Americans to determine whether the same facilitators or barriers may apply in other regions of the United States. Despite its limitations, the findings demonstrate what works, and what factors pose as obstacles for elderly African Americans to get the influenza vaccination.

The public health benefits of improving influenza vaccination rates among the elderly include primary prevention, preventing secondary complications, and reducing hospitalizations and deaths associated with influenza.[9] These actual benefits, unfortunately, are not translating into increased vaccination use among the elderly, particularly elderly African Americans. In order to improve vaccination use, any public health intervention should have a multi-system approach that emphasizes what facilitates and overcomes the barriers to vaccine use at the individual, provider, community, and healthcare system levels. In so doing, eliminating health disparities, at least for influenza morbidity and mortality among elderly African Americans, could be a possibility. **NCMJ**

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POLICY FORUM

> *"...a good death [is] 'one that is free from avoidable distress and suffering for patients, families, and caregivers; in general accord with patients' and families' wishes; and reasonably consistent with clinical, cultural, and ethical standards.'"*

INTRODUCTION

Policy Forum:
End-of-Life and Palliative Care

The Policy Forum section of this issue of the *North Carolina Medical Journal* gives attention to one of the most complex sets of problems in American healthcare—end-of-life and palliative care. Few topics addressed in this Journal have such profound and relevant implications for healthcare quality and to the lives of all Americans, regardless of social class, gender, religion, race, or ethnicity. The inevitability of death forces all of us to think about the choices we would make at the end of life. But, as these articles make clear, all too often the family and friends of those who are dying are faced with limited choices because few of us make adequate plans for these inevitable circumstances.

In this issue of the Journal, an outstanding group of healthcare professionals, lay activists, and policy analysts with broad-reaching involvement in end-of-life and palliative care have offered a comprehensive overview of the major problems and issues in this field. Geriatrician and medical ethicist, Laura Hanson, MD, MPH, offers a panoramic overview of these issues. Other authors provide detailed analyses of the care and services provided by hospice and hospital-based palliative care organizations and some of the dilemmas of clinical decision making, including a review of current approaches to pain control and the circumstances under which feeding tubes (percutaneous gastrostomy tubes or PEGS) should be used for nutritional supplementation. In addition, we have an explaination of the legal and ethical issues associated with do-not-resuscitate orders (DNR) and the designation of healthcare power of attorney. We have also included reprints of formal statements from the North Carolina Medical Board and the North Carolina Medical Society on these issues, which can serve as useful guidelines and assurances to practicing physicians who care for dying patients.

As one reads these articles, it is clear that despite the complex issues in this field, there are some remarkable successes and indications of a growing professional concern about how we care for dying patients and their families. Given the rapid growth of North Carolina's elderly population, we are likely to see an increase in the demand for more and better trained healthcare professionals who can provide end-of-life and palliative care. Though there are healthcare professionals who have denied the need for a specialized approach to the care of the dying patient, the many facets of end-of-life care described in these articles surely underscore the contrary point of view. There is great need for professionals in a number of disciplines who are dedicated to providing the care and services needed to assure the opportunity for a "good death" when that time comes.

As always, we await your letters and other comments on these issues as we continue to bring you reviews of some of the more important and far reaching health and healthcare policy issues affecting the lives of North Carolinians.

Gordon H. DeFriese, PhD
Editor-in-Chief and Publisher

Kristie K. Weisner, MA
Managing Editor

ISSUE BRIEF

Palliative Care:
Innovation in Care at the End of Life

Laura C. Hanson, MD, MPH

What is Wrong with Healthcare at the End of Life?

Americans benefit from rapid innovation in medical therapies to prolong life and ameliorate disease, but innovation in care of dying patients has not kept pace. When efforts to cure or to manage diseases reach their inevitable limits, patients, families, physicians, and nurses question continued use of treatments designed to prolong life. Many physicians and nurses recall using life-sustaining treatments for terminally ill patients—treatments that they considered to be inappropriate at the time.[1] In extreme cases, beginning with the court battle over life support treatment for Karen Ann Quinlan, these poignant personal decisions have become public narratives of suffering. When chances for cure and survival diminish, most dying patients and their families prefer an approach to medical treatment that emphasizes comfort and quality of life. Discerning and then communicating this transition is one of the central dilemmas of end-of-life care.

> *"Palliative care is comprehensive, interdisciplinary care designed to promote quality of life for patients and families living with a serious or incurable illness."*

Good care at the end of life is not accomplished by simply stopping traditional modes of treatment. The alleviation of suffering is one of the primary goals of medicine, yet emerging research in the care of dying patients demonstrates high rates of untreated pain and other physical symptoms. New forms of treatment and care are needed to control symptoms associated with dying. Decisions to withhold or withdraw life-sustaining treatments do not address the needs for effective treatment for pain and other symptoms. The crisis of impending mortality triggers additional emotional and spiritual suffering.[2] Forty percent of conscious patients have moderate-to-severe pain and more than half have moderate-to-severe dyspnea during the last two-to-three days of life.[3] Patients dying in hospitals and nursing homes have high rates of unmet needs for physical symptoms, emotional suffering, personal care services, and communication about treatment options.[4,5] Patients do not suffer alone; during the dying process and after a death, family caregivers experience significant emotional, physical, and financial stress.[6,7,8] Patients, families, and healthcare providers acknowledge profound deficiencies in current end-of-life care, and the need for improved palliative care services that are well matched to the needs of dying patients.

Palliative care is an emerging field in United States healthcare. Palliative care is comprehensive, interdisciplinary care designed to promote quality of life for patients and families living with a serious or incurable illness.[9] Because it is a comprehensive approach to care, providers of palliative care offer expert pain and symptom management, supportive care for emotional and spiritual distress, and bereavement support for surviving family. Palliative care includes and expands on the expert care of dying patients found in hospice services.

How Do Americans Die?

More than two million deaths occur in the United States each year. Depending on the underlying cause of death, a dying patient's "death trajectory," or their functional decline prior to death, may follow a brief or prolonged course. The trajectory of illness before death may have a recognizable terminal phase, or a more uncertain and unpredictable course prior to death. The underlying cause of death and resulting death trajectory strongly influence the quality of the dying experience, the certainty that a patient is dying, and the physician's ability to discuss options for medical treatment.[10,11,12]

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Progressive chronic diseases—heart disease, cancer, stroke, chronic lung disease, and neurodegenerative disease such as Alzheimer's and other dementias—cause the majority of adult deaths. Among these causes, cancer patients have a more precipitous functional decline near death, which may facilitate recognition of a terminal phase of illness. Patients with chronic heart or lung disease have a more uncertain trajectory of worsening and remitting symptoms over months to years prior to death. Elderly nursing home residents with neurologic diseases and varied other chronic illnesses may have a very slow functional decline for many years, with no recognizable terminal phase. These individuals often die of an acute illness such as pneumonia or hip fracture. In the context of advanced dementia, these treatable acute illnesses have a 50% mortality risk at six months.[13,14]

Because Americans expect to live into old age, deaths early in life are especially painful. Premature deaths among children and teens are more often caused by relatively sudden events such as accidental injury, homicide, suicide, or complications of HIV infection or congenital abnormalities.[16] Racial and ethnic minority groups have higher rates of death at younger ages from these traumatic or sudden causes. The national Institute of Medicine's report, *Approaching Death: Improving Care at the End of Life*, emphasizes the need for overall improvements in end-of-life care and lends attention to the diverse needs of these subgroups of dying patients.[15,16]

Where Do People Die?

The site of death may be one of the most important structural determinants of the experience of dying.[5,17] Patients and their families say they prefer terminal care at home,[18] but four of five deaths in the United States take place in hospitals and nursing homes. After-death interviews with bereaved families show an association between site of death and satisfaction with terminal care. Surviving family are consistently more satisfied with hospice and are least satisfied with conventional nursing home and hospital care.[5,17,19] Hospice services, which can be provided in private homes or long-term care facilities, now support one-in-five dying Americans. In 1989 the Medicare hospice benefit was extended to nursing home residents. Hospice has since been added to usual nursing home care for 5.6% of deaths in long-term care facilities.[20] The site of death and use of hospice care varies by state. Oregon, after its highly publicized debate on assisted suicide legislation, has achieved the highest rate of hospice enrollment in the nation (31% of all deaths), and is able to provide terminal care at home for 42% of its citizens who die. North Carolinians' healthcare experiences at the end of life are very similar to the majority of decedents in the nation (See Table 1).

Table 1.
Site of Death in North Carolina, 2001

	NC	US
Site of death		
Hospital	54%	49%
Nursing home	22%	24%
Home	25%	23%
With Hospice	21%	19%

As the population ages, and as economic pressures cause reduced hospital lengths of stay, nursing homes are becoming a more common site of death. Data from the National Mortality Followback Survey, a representative sample of United States deaths in 1986 and 1993, show that the proportion of deaths that occur in hospitals decreased from 65% to 56%, while the proportion of deaths in nursing homes increased from 17% to 19%. By helping frail elders receive treatment and supportive care outside of hospitals, community-based, integrated eldercare programs such as the Programs of All-Inclusive Care for the Elderly (PACE)[22] can result in increased use of nursing homes (34%) and private homes (45%) as sites of death.[23] The availability of services within one's local health system, including readily available hospital beds, nursing home beds, and hospice services are likely to influence where people die, perhaps more than their own preferences about site of terminal care.[24,25]

How Do Patients and Families Define a Good Death?

Most medical treatments are judged to be effective if they are proven to prolong life or to reduce the risk of adverse health events or functional impairments. Good end-of-life care can only be defined by its ability to promote a "good death," or good dying experience for patients. As the potential for medical treatment to improve function and survival diminishes, patient- and family-centered outcomes become paramount. An expert consensus panel convened by the national Institute of Medicine has defined a good death as "one that is free from avoidable distress and suffering for patients, families, and caregivers; in general accord with patients' and families' wishes; and reasonably consistent with clinical, cultural, and ethical standards."[15]

Several well-designed studies explore domains defined as important to seriously ill and dying patients and their professional and family caregivers (See Table 2).[26,27,28,29,30,31] Dying patients and those who provide their care consistently value: (a) relief from pain and other physical symptoms, (b) attention to emotional, psychological, and spiritual needs, (c) compassionate communication, (d) involvement in critical healthcare decisions, (e) affirmation of personhood and dignity, (f) support for family caregivers, and (g) coordination and continuity of care.[32,33]

Innovations in End-of-Life Care

Public demand for appropriate care at the end of life emerged in the controversy surrounding dramatic "right-to-die" court cases. It has been fuelled by the debate over assisted suicide, and by descriptive studies of pain and suffering experienced by dying patients and their families. These problems are well defined, and new approaches to the delivery of medical care to seriously ill and dying patients are beginning to improve care.

Strategies to improve end-of-life care can be conceived as targeted or comprehensive interventions. Targeted interventions

Table 2.
Patient and Caregiver Perceptions of Quality in End-of-Life Care

Study Population	How do patients, family, and healthcare providers define a "good death"?
N = 126 chronically ill patients (Singer, 1999)	Receiving adequate pain and symptom management Avoiding inappropriate prolongation of dying Achieving a sense of control Relieving burden on loved ones Strengthening relationships
N = 137 chronically ill patients, family members, and healthcare providers (Curtis, 2001)	Physician access and continuity Team coordination Communication with patients Patient education Inclusion of family Medical competence Pain and symptom management Emotional support Personalization Attention to patient values Respect and humility Support of patient decision making
N = 75 healthcare providers, patients, and family caregivers (Steinhauser, 2000)	Pain and symptom management Clear decision making Preparation for death Completion of spiritual or meaningful final tasks Contribution to others Affirmation of the whole person

are designed to influence one aspect of the dying experience. Examples could include programs to improve physician communication skills, to implement pain management protocols, or to provide grief counselling for parents of dying children. Comprehensive clinical services such as hospice or palliative care units are designed to improve the overall quality of care for dying patients and their families. These comprehensive services typically include healthcare providers who can address a wide range of communication and symptom management needs for dying patients and their families.

Making Advance Directives Work

Given evidence that patients and families were dissatisfied with current end-of-life care, concerned clinicians and bioethicists reasoned that increasing patient control over major clinical decisions would result in more appropriate forms of treatment. Advance directive documents emerged, in which a patient gave prior direction about who could make decisions on his or her behalf (Healthcare Power of Attorney) and how life-sustaining treatments were to be used in the event of terminal or incurable illness (Living Will). Research on advance directives has shown that education and provision of advance directive forms can increase documentation of patient preferences. Patients generally welcome these conversations, and many are willing to record their wishes in some form.

Unfortunately, advance directives may be necessary but not sufficient to change the experience of care at the end of life. Living wills and other advance directive documents have not had a significant impact on the medical care received by dying patients.[34] In 1995, the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment randomized seriously ill patients with limited life expectancy to a nurse-facilitated, written communication of prognosis and treatment preferences. The aim of the intervention was to inform and facilitate decision-making by patients and physicians. This intervention, like similar smaller studies, had no impact on pain treatment, life-sustaining treatment use, or cost of care.[35] Advance directives have the potential to promote communication among patient, family, and provider, but are not sufficient to change care at the end of life.

In retrospect, it is not surprising that advance directives alone are not sufficiently powerful to change care at the end of life. These documents may not be immediately available when patients become acutely ill and are unable to speak for themselves. Living wills are subject to interpretation and may be difficult to apply to specific clinical circumstances. Is a patient with advanced Alzheimer's and a hip fracture "terminally ill"? Is the treatment of pneumonia in a patient with end-stage cancer "life-sustaining treatment"? Another limitation is that traditional advance directives focus on withholding or withdrawing treatments, rather than a positive choice for an overall plan of care.

Advance directive documents are most useful when they serve as an invitation to conversations about patients' real concerns and values, goals of treatment, and a plan of care serving those goals. Some newer advance directives promote more comprehensive advance care planning. One example, The Medical Directive, requires a median time of 14 minutes to discuss, and allows the physician and patient to cover a broad range of health scenarios and treatment options.[36] In the mid-1990s Oregon adopted a portable physician order form which promotes discussion of preferences for resuscitation, overall level of medical treatment, and use of antibiotics, feeding tubes, and intravenous fluids. The form, Physician Orders for Life-Sustaining Treatment (POLST), is a physician order that is portable between healthcare sites.[37] The POLST has been widely accepted in Oregon, and evaluations suggest that it lowers the use of life-sustaining treatments and hospital admission among nursing home residents. A randomized controlled trial of a similar comprehensive advance directive in six Ontario nursing homes had a marked effect on hospital use and cost of treatment at the end of life.[38]

Improving Communication

Meaningful and compassionate communication is the core skill in end-of-life care. Absent this skill, physicians will be unable to help patients decide on appropriate treatments, assess physical symptoms, or address emotional and spiritual suffering. Patients facing the crisis of their own mortality require time to express fears and to seek reassurance of continuing physician attention to their spiritual and emotional needs, in addition to medical aspects of their care.

Family perspectives on the quality of the dying experience are independently important. While the patient lives, physicians must be skilled in communication with family members who make decisions for incapacitated patients, and serve as physical and emotional caregivers. Although they may not accurately represent patient treatment preferences or symptoms, family members are the ethical surrogate for incapable patients, and they will evaluate the quality of care after the patient's death.[39,40] In one study of recently bereaved family members in North Carolina, their most common recommendation for improved care at the end of life was to improve physician communication skills.[17] Their recommendations emphasized the need for communication beyond medical treatment choices, including a desire to talk more about prognosis, and about the humanity and dignity of the patient.

Communication of prognosis is essential if patients and families are to participate in informed decision-making. Prognostic models are accurate for populations, but challenging to communicate to individual patients. In the SUPPORT study population, a patient with a 50% chance of living two weeks also had a 20% chance of living six months.[41] Physicians and patients alike respond to prognostic information with optimism born of hope for survival. Physicians systematically overestimate their patients' life expectancies, and communicate even more optimistic data than they believe.[42] Patients who have cancer and an average life expectancy of six months will nearly all expect to live longer than six months.[43]

Compassionate communication about prognosis seeks to balance optimism with a gentle respect for patients' right to know the truth about their illness. Probabilities are confusing, but physicians can often tell patients whether life expectancy is measured in days to weeks, weeks to months, or months to a year or two. Patients and physicians can travel a careful middle ground together, where they "hope for the best, and prepare for the worst."[44] Prognosis is not simply a question of communicating life expectancy. Patients and family members also need information about what is likely to happen during the dying experience. Their ability to understand and anticipate the natural history of disease, its symptoms, and possible treatments will allow time for practical and spiritual preparation for more serious illness or death. It may also relieve unspoken fears.

Physician training includes little experiential learning about these essential communication skills. However, physicians who have worked to become expert in this aspect of medical practice are demonstrably more capable of comprehensive, patient-centered communication. This communication can be accomplished even within the time constraints of an office visit.[45] Experts in end-of-life communication have published useful examples of the words and approaches they use to promote continued practice of this vital skill.[44,46,47,48,49,50] Innovative continuing education programs that expand didactic education to include experiential learning techniques have a positive effect on physicians' communication skills.[51,52]

Communication about end-of-life treatment decisions may also be improved using ethics consultations for intensive care unit (ICU) patients. In a multi-site randomized controlled trial, ethics consultants led family meetings when value-laden treatment decisions were imminent. These consultations result in high levels of satisfaction, reduced use of life-sustaining treatment and ICU days, and yet had no adverse effect on the length of patient survival.[53,54]

Individualizing Care for Diverse Populations

End-of-life care varies for patients of minority, ethnic, and cultural backgrounds. Terminally ill African-American or Hispanic patients are less likely to receive effective pain treatment or to enroll in hospice than their white counterparts, and are more likely to die in hospitals.[55, 56] Physicians seeking to provide excellent care for dying patients must consider whether these differences in treatment are driven by patient values, or by failed access to or understanding of treatment options. Knowing that African-American patients generally enroll less often in hospice should not lead physicians to assume an individual patient's preference, but it may allow for more sensitivity in discussions of treatment decisions.

Patient characteristics such as education, race, and cultural or religious background may also influence values about patient and family involvement in medical treatment decisions. For example, traditional Navajos may perceive that speaking of potential bad outcomes may cause them to occur; a value quite distinct from a Western European emphasis on truth telling.[57] Patients from some cultural traditions, including African American, Hispanic, and some Asian countries, may place a greater emphasis on the importance of family involvement in medical treatment decisions even when the patient is capable of making his or her own choices.[58] Use of written advance directives and orders to limit life-sustaining treatment vary by patient insurance status, educational attainment, and racial background.[59,60] Dying patients and their caregivers desire spiritual care, and this aspect may engender particular concern among patients from minority, ethnic, or religious backgrounds.[61] Spiritual care, when available for dying patients and their families, needs to be consistent with individual faith traditions and cultural expression of spiritual practices.[62] Understanding these patterns of historical differences may allow for more nuanced communication with patients who do not share the physician's cultural heritage.[63]

Comprehensive Strategies: Hospice

Palliative care is comprehensive, interdisciplinary care designed to promote quality of life for patients and families living with a terminal or incurable illness. Hospice agencies, modelled on the inpatient treatment approach pioneered by Dame Cicely Saunders in Britain, have delivered palliative care in private homes in the United States since the creation of the Medicare hospice benefit in the 1980s. In 1989 Medicare expanded this benefit to nursing home residents, and hospice is now offered under most state Medicaid programs and many forms of private health insurance.

Patients are eligible for hospice if a physician certifies that they have a life expectancy of six months or less "if the disease follows its expected course." Patients are also expected to agree to forgo "curative treatment for their terminal illness." Patients with uncertain disease trajectories may find it difficult to meet the six-month criterion, although non-cancer diagnoses are increasingly represented within the hospice population. For many diseases, curative and palliative treatments overlap and access to specific treatments may vary by provider. For example, patients with cancer may or may not be able to continue transfusions for anemia and patients with chronic obstructive pulmonary disease (COPD) may or may not be able to continue intravenous antibiotics for pneumonia.

For patients who can qualify, hospice improves satisfaction with end-of-life care. After death, family caregivers rate hospice services more positively than any other aspect of terminal care.[5,17] In early studies, hospice inpatient units showed improved satisfaction despite modest impact on symptom scores.[64,65] In nursing homes, family caregivers believe that adding hospice care improves the quality of care for physical symptoms and emotional needs.[66] Comparison of nursing home decedents who do or do not receive hospice care shows increased use of pain medication and decreased use of tube feeding and hospitalization for those enrolled in hospice.[67] Hospice delivered in private homes can reduce the total cost of care for younger patients and those who die from cancer, but not for other dying patients.[68]

Many patients who might benefit from palliative care do not currently access hospice, or do so within only days of death. The length of stay in hospice has slowly decreased over the past decade. Patients may deny they are nearing death, or have an uncertain trajectory of illness that does not fit the six-month criterion. They may be unwilling to forego treatments, such as palliative radiation, that are prohibitively costly to include in the hospice per diem payment. Many individuals may face terrible pain and suffering, but have a cultural or personal imperative to "fight until the end." Hospices and other healthcare organizations are creating newer forms of palliative care services to match the needs of these patients.

Comprehensive Strategies: Palliative Care Programs

New model palliative care programs have increased significantly during the past decade, in response to needs for palliative care outside the traditional hospice enrollment population. Palliative care programs may be affiliated with an acute care hospital, a hospice agency, or with innovative elder care services that provide a continuum of health services.[69]

The number of physicians seeking palliative care certification is rising rapidly. The American Board of Hospice and Palliative Medicine incorporated in 1995, and began administration of its board exam in 1996. By August 2003, there were 43 active or emerging United States fellowships in Palliative Medicine, and over 1,200 physicians have met qualifications for certification in this field.[70]

Seventeen percent of United States hospitals currently house a palliative care service. Unlike hospice, palliative care programs do not yet offer a standardized array of clinical services. Hospital-based palliative care may include a variety of healthcare providers who offer inpatient consultation, outpatient consultation, dedicated inpatient beds, or bereavement programs for families. For example, the Pain and Symptom Care Program at UNC Hospitals, initiated in 2001, now provides inpatient care on 23 different hospital units. Using a consultation model, this interdisciplinary service reaches a diverse patient population; half are under age 65, one-third are African American, and one-third have terminal illnesses other than advanced cancer. Patients' average ratings of pain and other symptoms improve, and 80% of patients and families receive counselling about end-of-life issues.

Table 3.
Internet Resources for Palliative Care

Organization	Website
American Academy of Hospice and Palliative Medicine	www.aahpm.org
American Board of Hospice and Palliative Medicine	www.abhpm.org
Carolinas Center for Hospice and End-of-Life Care	www.carolinasendoflife.org
Center for the Advancement of Palliative Care	www.capc.org
Duke Institute on Care at the End of Life	www.iceol.duke.edu
End-of-Life Palliative Education Resource Center	www.eperc.mcw.edu
Last Acts Partnership	www.lastacts.org
Midwest Bioethics Center	www.midbio.org
National Hospice and Palliative Care Organization	www.nhpco.org
National Resource Center on Diversity in End-of-Life Care	www.nrcd.com

Because palliative care programs are changing rapidly and are not yet standardized, studies of its impact on care quality and cost are just beginning. One systematic review of 16 relatively well-established services found that these hospital-based inpatient services improved family satisfaction, reduced symptoms of distress, and decreased the intensity or cost of inpatient services for the patients they serve.[71] Like many labor-intensive healthcare services that do not emphasize procedures, palliative care is valued for its ability to reduce costs while improving quality of care.

Conclusion

For several decades, the medical literature has been filled with evidence of shortcomings in end-of-life care. Patients who have acquired the disease that will cause their death receive the same approach to medical care in early and advanced stages of incurable disease. Physicians fail to discuss prognosis, and patients retain hope for cure rather than hope for comfort and quality of life during their remaining days. In recent years palliative care practice and research have stimulated new programs and new clinical approaches to the care of dying patients and their families. Hospice, long the only repository of expertise in palliative care, is now joined by physicians, nurses, and other healthcare providers who have made a career commitment to excellence in healthcare for patients in the final phase of life. **NCMJ**

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COMMENTARY

Hospice:
A Vital Service Facing Increasing Demands

Judith Lund Person, MPH

Introduction

For three decades hospice providers in the United States have been changing the care for dying Americans and their families by providing options and choices that enable patients to be in control of their care at the end of life. Yet, hospice faces a number of challenges. The healthcare landscape is changing along with the demographic profile of the nation. In order to meet present and future challenges relating to end-of-life care, it is imperative that hospices build on the successes of the past and carefully listen to the needs of the changing populations served.

The Care Americans Want

The hospice movement in the United States can be traced back to the work of Dame Cicely Saunders at St Christopher's Hospice in the United Kingdom. Hospice care in America grew out of the need for more compassionate care for dying persons. In the American paradigm, hospice is not a place, but an interdisciplinary offering of palliative and support services that allows the terminally ill to be cared for primarily at home. 'Home' is defined by the patient, this may be: the patient's own home, the home of a loved one, an assisted living facility, a long-term care facility, or a hospice residence. The care that the hospice provides reflects the specific care that is in demand. Nearly 90% of adults reported that they would prefer to be cared for in their own or a family member's home if they were terminally ill and had six months or less to live.[1]

Many studies[1-4,23] have documented that when considering issues of death and dying, the American public's chief priorities and concerns include:

- home-based care;
- patient control and choice about the services available to them;
- emotional and spiritual support for patients and families;
- pain control customized to the patients wishes; and
- freedom from financial worry.

In 1982, Congress voted to support the Medicare Hospice Benefit (MHB). In providing a government funding mechanism, Congress established an all-inclusive benefit for hospice that has enabled millions of Americans to receive quality end-of-life care. More than 96% of hospices in the United States are Medicare-certified and just over 80.9% of patients claimed Medicare as their payment source in 2002.[5] Most private insurance plans, health maintenance organizations, managed care providers, and Medicaid in the majority of states also cover hospice services.

The Nation's Demographics Are Changing

Availability of hospice and palliative care is a critical issue as many more Americans begin dealing with end-of-life care decisions, for themselves and older family members. The aging post-World War II generation is bringing on a significant demographic shift that is unprecedented. The elderly population in the United States is expected to double between 2000 and 2030. By 2030, there will be approximately 70 million Americans over the age of 65. The proportion of the elderly falling into the 85 years of age and older category is increasing. This group is expected to increase from 4.2 million in 2000 to 8.9 million in 2030. Never have the chances of reaching 100 years of age been better. It is estimated that more than 72,000 people in the United States are over 100 and by 2050 that number is expected to be 834,000.[7]

As our population ages and life expectancy increases, more sophisticated and costly medical interventions will be required to provide for the nation's healthcare needs. More people will live with long-term illness that requires significant care. The number of deaths will also increase. In 2001, 2.4 million people died in the United States from all causes. The National Center for Health Statistics estimates that the number of deaths per year will grow at such a rate that in 57 years, the number will be almost 5.7 million people annually.[7] These statistics demonstrate a need to prepare for a patient base that is already changing. In order to adequately provide care, access to hospice and palliative care must expand and capacity must increase. An

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understanding of how hospice has successfully served the dying in the past will provide a foundation for future care.

Three Decades of Growth

By virtually any measure, the system of hospice care provided in the United States has been successful. One of the most dramatic measures of success has been the growth in beneficiaries. In 1975, there were 1,000 hospice admissions in the United States. By 2002, that number had grown to 885,000 annually. Over 95% of hospice patient visits are for routine home level of care reflecting Americans' preference to be in a home environment at the end of life.[6]

Today's hospice must address a broader range of terminal disease states and a wider range of palliative care services.[10] Hospice providers in the mid-1970s primarily served cancer patients, and the demographic profile of the patient population was almost entirely white and middle-class.[9] By 2002, cancer patients accounted for 50.5% of admissions. Hospices are also serving patients with end-stage heart, kidney and liver disease, along with dementia, lung disease, and other conditions (see Table 1).[8] America's hospices have taken a leadership role in the care of patients with HIV/AIDS as well.

Treatments such as chemotherapy and radiation, traditionally associated with curative care, are being increasingly used in hospice for pain and symptom management. In fact, advances in medical practice and technology for palliative, end-of-life care have prompted a significant increase in the intensity and frequency of services delivered to the hospice patient.[11] Outreach and increased access for diverse populations is also necessary. In 2002, 9.2% of hospice patients were African-American, 4.3% were Hispanic or Latino, 8% were Asian or Hawaiian/Pacific Islander, and 3.7% were classified as multiracial or 'another race.'[8]

Table 1.
Hospice Deaths in the United States, 2002

Diagnosis at admission	2002
Cancer	50.5%
End-stage heart disease	10.7%
Dementia	8.3%
Lung disease	6.7%
End-stage kidney disease	3.0%
End-stage liver disease	1.6%

More Americans Could Benefit from Hospice

Statistics suggest that more terminally ill Americans could gain access to the benefits of hospice. The United States General Accounting Office reported in 2000 that, while more beneficiaries are choosing hospice, many are doing so closer to the time of death. Half of Medicare hospice users are enrolled for 19 or fewer days, and service periods of one week or less are common. This study and other reports attribute this phenomenon to a variety of factors, including physician practices, patient preferences, concerns about compliance with Medicare eligibility requirements, and lack of awareness of the MHB among both the public and professionals.[12] A closer look at the trend toward shorter hospice service periods shows that the average length of service (ALOS) in hospice has declined dramatically since the initial Medicare demonstration project of 1983. The median length of service (MLOS) illustrates the effect of enrollments taking place days before death, and in 2002, 34.7% of those served died in seven days or less.[8]

The trend toward shorter lengths of service, combined with the greater intensity of today's hospice services, is also creating severe financial pressures for hospice providers. The government's original reimbursement mechanism under the MHB assumed a 70-day average length of service, with a per-patient, per-day rate that spread total cost over that 70-day period. With the drop in ALOS, hospices have a shorter period of patient stability over which to spread the high front-end and back-end costs that are unavoidable with hospice care.[11]

Cost of Care

A 1994 Lewin-VHI study found that Medicare saved $1.52 in Medicare Part A and Part B expenditures for every dollar it spent on hospice. That 1995 study also showed that in the last month of life, per-patient savings totaled $3,192, "as hospice home care days often substituted for expensive hospitalizations."[13]

Other more recent studies suggest that the use of hospice and advance directives saves up to 10% in the last year of life, 10% to 17% in the last six months of life, and 25% to 40% in the patient's last month.[9] The dollar value of such savings is dramatic when one considers the staggering costs that can result from efforts to extend life futilely through hospitalization in an intensive care unit (ICU). It has been estimated that the cost of caring for certain categories of cancer patients in an ICU can range from $95,000 to as much as $450,000 per patient for each year of life gained.[13]

Methods of reimbursement for services that are outside current hospice reimbursement streams must be explored and developed. Providers should not depend on the Medicare Hospice Benefit as the only source of reimbursement. Alternative funding sources include foundation grants, research projects, physician fellowships, charitable contributions, and institutional subsidies. These must all be aggressively explored. Providers must think beyond billing income to cover costs of care and operation.[22]

The cost of caring for the terminally ill is a critically important public policy issue, given the fact that one third of all federal Medicare dollars are spent on patients who are dying.[14] However, increasing hospice referrals is not just an economic measure. Hospice provides compassionate, high-quality care with consistently high patient approval ratings. [15,16]

Public Policy Changes

Congress has recognized the need to improve access and care through adjustments to the Medicare Hospice Benefit. While recent legislative changes may not address all the concerns related to access and capacity, they should prove beneficial. In

December 2003, Congress approved a far-ranging package of Medicare reforms, the Medicare Modernization Act of 2003.

There are a number of provisions designed to improve access and make hospice care more available to patients and families earlier in their illnesses. These include an educational consult for patients who would be appropriate for hospice care but have not yet been referred, the ability for hospices to contract for core or specialized services, a provision for nurse practitioners not employed by hospice to continue caring for patients under hospice, and a rural hospice demonstration project to evaluate care delivery.

Demonstration Projects

Additional methods to improve access, capacity, and ensure financial viability could be identified through national and community demonstration projects. Demonstrations that could lift current reimbursement guidelines, offset patients with very short stays, or examine how hospice patients could benefit from higher cost treatments would provide data that would potentially improve access to care for all. Projects that explore ways in which service providers can combine hospice and disease-modifying therapies at the same time must also be examined. There has also been much debate regarding Medicare eligibility requirements—currently, a physician must certify that a patient could die within six months if the terminal illness follows its expected course. Eligibility has often been confused with limits in length of service. A better understanding of how this has become a real and perceived barrier to care should be researched, ultimately leading to improved public and professional outreach and engagement.

> *"Nearly 90% of adults reported that they would prefer to be cared for in their own or a family member's home if they were terminally ill and had six months or less to live."*

Public and Professional Education

Another recognized barrier to greater public education about hospice is the character of American society, with its emphasis on youth, curative treatment, and the reversal of aging.[17] While not everyone with a terminal illness may be receptive to hospice, research suggests that most Americans—including physicians—are not sufficiently educated about hospice to make an informed choice. Also, within the physician community, studies indicate an aversion to the open discussion of death with patients and a lack of medical education about end-of-life issues.[3,18,19,21] An article in the *American Journal of Hospice & Palliative Care* reported that physicians often withhold the truth of a terminal diagnosis from their patients, resulting in the patient not realizing that death is likely until the last month of life.[20]

The national Institute of Medicine published a 1997 study, *Approaching Death: Improving Care at the End of Life*, that reported "the education and training of physicians and other healthcare professionals fail to provide them the attitudes, knowledge and skills required to care well for the dying patient."[9]

Hospital-Hospice-Palliative Care Partnerships

Important opportunities for hospice providers and hospitals in the United States can be found in hospital-hospice partnerships. A report released by the National Hospice and Pallative Care Organization (NHPCO) and the Center to Advance Palliative Care, *Hospital-Hospice Partnerships in Palliative Care*,[19] explores the relationship between hospitals and hospices that actively collaborate in providing appropriate care. The report indicates that partnerships tend to move in two directions. First, an enhanced utilization of the Medicare Hospice Benefit is seen as closer relationships between the hospice and hospital develop. Also, education surrounding hospice care, the creation of in-patient units, and reduction in barriers to hospice admission are documented.

The second trend is the development of palliative care services. In April 2004, the Clinical Practice Guidelines for Quality Palliative Care[24] were released by the National Consensus Project, a consortium of five national organizations in the field intensely interested in improving care for patients and their families at the end of life. The consortium includes the American Academy of Hospice and Palliative Medicine, the Center to Advance Palliative Care, the Hospice and Palliative Nurses Association, Last Acts Partnership, and the National Hospice and Palliative Care Organization. These Guidelines describe core precepts and structures of clinical palliative care programs and are the culmination of more than two years of work. They provide guidance for the assessment and treatment of pain and other symptoms; help with patient-centered communication and decision-making; and coordination of care across settings and through serious illness and are written for any healthcare provider who is interested in a developing palliative care program. More information on these guidelines can be found at www.nationalconsensusproject.org.

Building on What Works

The success of hospice is well documented, yet ongoing challenges in the field are recognized. End-of-life care providers must respond and adapt to the changing environment. The general public has an awareness of hospice, but the vast majority of people lack the specific understanding and knowledge to gain full access to hospice benefits. Physicians are also reluctant to discuss the specifics of death with their patients, and they lack the comprehensive medical education in end-of-life care that would lead to more referrals (and earlier referrals) to hospice. Changing demographics will greatly impact the number of Americans who must be served and the care that must be provided at the end of life.

It is critical that hospice and palliative care providers take their full knowledge and expertise regarding care at the end of life and make it available further upstream, reaching more Americans much earlier in the course of a life-limiting illness. The hospice philosophy of care should be utilized to help patients make the transition from more aggressive therapies to holistic palliative care services. Increasingly, hospitals and critical care units are using the skills of palliative care to more appropriately serve patients in their care.

The National Hospice and Palliative Care Organization (NHPCO) is the oldest and largest non-profit membership organization representing hospice and palliative care programs and professionals in the United States. The NHPCO is committed to improving end-of-life care and expanding access to hospice care with the goal of profoundly enhancing quality of life for people dying in America and their families.

More information is available at www.nhpco.org. **NCMJ**

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COMMENTARY

Palliative Care:

More than Just Care from a Friendly Relative

Richard C. Stephenson, MD

Overview

A well-meaning board member of a large home health and hospice organization once shared that he thought palliative care must mean, "care from a friendly relative." While half-heartedly playing on the words "pal" and "relative," he was not far from the truth. From a literary point of view, palliative care means care intended to "cloak" symptoms as opposed to curing disease. But most imagine it to be just comfort care only, very supportive and very hospice-like.

For more than a decade, the World Health Organization (WHO) has defined palliative care as active total care of patients not responsive to curative treatment where control of pain and other symptoms and of psychological social and spiritual problems is paramount and the goal is the best possible quality of life for patients and their families. More recently, Diane Meier, at the Center to Advance Palliative Care and others have shied away from this concept of switching from curative to palliative and embraced a concept of palliative care as interdisciplinary care that aims to relieve suffering and improve the quality of life for patients with advanced illness and their families, *offered simultaneously with all other appropriate medical treatment.*[1] From this point of view, palliative care may be present from the time of intensive care unit (ICU) admission, help manage the transition as curative therapies fail, and become the predominant mode of care as terminal illness becomes apparent.

In this issue of the Journal, Laura Hanson has done an excellent job of reviewing existing shortcomings in end-of-life care. She has also reviewed comprehensive strategies such as hospice and palliative care to address these problems and innovations to make advance directives work and other strategies to improve communication and access.[2]

In fact, palliative care may be one of the most rapidly developing service lines in United States hospitals. As Dr. Hanson points out, almost one in five hospitals now has a palliative care service and many more have plans to create them. More than 1,500 physicians are now certified in Hospice and Palliative Medicine.[3] The specialty is in the process of becoming certified by the American Board of Medical Specialties (ABMS) and the Accreditation Council for Graduate Medical Education (ACGME). Palliative care fellowship programs are rapidly developing to meet these growing needs. Existing palliative care and hospice programs have created a more extensive body of evidence-based literature in palliative medicine and achievable, meaningful outcomes are being realized within committed institutions.

All of this must sound very exciting and academic! But from a much more practical point of view, does your institution need palliative care? What can a palliative care service actually do for you? And if you want one, how can you develop one? Many concerned healthcare providers, hospitals, and hospices are asking these same questions. Fortunately, there are tremendous resources available through the Center to Advance Palliative Care (CAPC), a national initiative supported by the Robert Wood Johnson Foundation with direction and technical assistance provided by the Mount Sinai School of Medicine.

The Center to Advance Palliative Care[4]

Diane Meier, Director of CAPC, and staff have created a wide variety of resources to assist institutions with the entire process of developing palliative care services from needs assessment to sustaining and growing existing programs. Resources include conferences, website, monographs, and leadership centers available for site visits and ongoing mentoring. These leadership centers include a variety of settings where palliative care has developed and flourished, i.e., academic medical centers, private hospitals, healthcare systems, and home health and hospice organizations. The process begins with building a case specific to the institution including needs assessment, securing support and financial considerations. While there are formulas that are specific and data driven, it is far from a "cookbook" approach. The CAPC process goes on to help design a program specific

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> *"Palliative care services provide 'specialized care through specific knowledge and skills, including communication with patients and family members; management of pain and other symptoms; psychosocial, spiritual, and bereavement support; and coordination of an array of medical and social services.'"*

to the institution, develop a business plan, implement services, measure quality and impact, and even market the program.

Critical to the success of the CAPC process is the development of a core team, which includes a medical staff leader, nursing leader, hospice representative, and an administrative champion. CAPC is quick to point out that this is an ideal opportunity for hospital/hospice collaboration.

Is this a formula for guaranteed success? Of course not, but generally expected and accepted, evidence-based outcomes include reduction in symptom burden, improved patient and family satisfaction, and reduced costs. Other highly likely outcomes, but less evidence-based, suggest care concordant with patient/family wishes, patient/family/professional consensus on the goals of care, and improved continuity of care.[5]

Local Hospital-based Palliative Care Initiatives

Forsyth County, North Carolina, demonstrates two distinctly different approaches to palliative care programs developed with local initiative, but also tutored by CAPC programs. The local area hospice, a private, independent not-for-profit hospice and home health organization enjoys a longstanding, collaborative relationship with both the academic medical center and the large tertiary care private hospital in Winston-Salem. The hospice owns and operates a 20-bed freestanding inpatient hospice facility, and has an average daily census of 260 patients at home, in nursing homes, and in the facility. Hospice employees include a full-time medical director, a second full-time physician, and a geriatric nurse practitioner.

Over the past five years, the hospice has embraced the concepts of palliative care. Central to their view of palliative care and mission, the hospice strives to improve the quality of care for patients and families facing life-limiting illness across the continuum of care, regardless of diagnosis, prognosis, or treatment.

During this same time period, both the academic medical center and the private hospital responded to needs within their institutions and began to consider the development of palliative care services. Of interest, their approaches were distinctly different if not frankly opposite. The private hospital quickly developed a palliative care unit, whereas the academic medical center conducted a detailed needs assessment and gradually developed a consult service. However, both engaged medical, nursing, and administrative leadership as well as the hospice to collaboratively develop these diverse approaches to meeting palliative care needs within the two institutions. Each has relied on hospice expertise and, under both circumstances, representatives have attended CAPC conferences and relied heavily on CAPC developed tools.

The Acute Palliative Care Unit (APCU) at Forsyth Medical Center (FMC)

Forsyth Medical Center has been a major supporter and referrer to the Kate B. Reynolds Hospice Home in Winston-Salem. Oncologists and hospitalists at FMC became concerned by the development of a waiting list for their patients in need of inpatient hospice referral. This led to the rapid development of the Acute Palliative Care Unit (APCU) to provide quality end-of-life care for hospitalized patients and their families. Hospital staff collaborated with hospice staff in planning, development, and implementation and attended CAPC conferences together. Tools for assessment and treatment were shared, and hospice staff continues to supply clinical expertise and medical direction.

The APCU admitted over 600 patients in 2003 and has achieved superlative results in family satisfaction, while simultaneously demonstrating significant cost savings once patients are transferred to the unit. Their data reflect a cost/day saving of over $1,800 once patients are transferred into their unit from elsewhere in the hospital. In addition, APCU is the focal point for improving end-of-life care in the hospital and provides leadership for quality initiatives surrounding pain and symptom management. In direct contrast to the academic medical center, FMC quickly developed a palliative care unit to meet the needs of patients, families, and physicians. FMC is now taking steps to formally develop a consult service to identify unmet palliative care needs for patients throughout the hospital. The APCU remains one of the major referral sources for the hospice home.

The Palliative Care Consult Service (PCCS) at Wake Forest University Baptist Medical Center (WFUBMC)

The academic medical center took a different approach to meeting palliative care needs within their institution. Not surprisingly, the approach began with a detailed needs assessment to support both the educational and clinical mission of the hospital. The

Figure 1.
Palliative Care Consults by Month at WFUBMC, July 1 - May 31, 2004 = 263 pts.

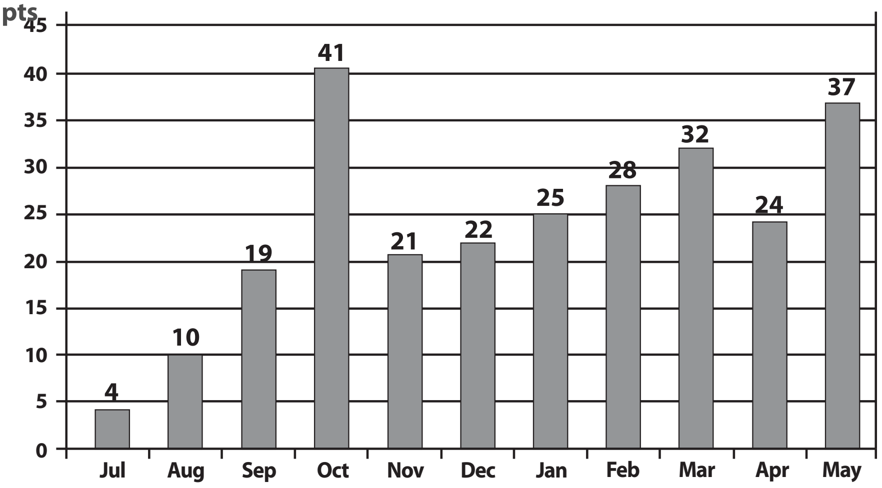


Figure 2.
Service Requesting Pallative Care Consult at WFUBMC

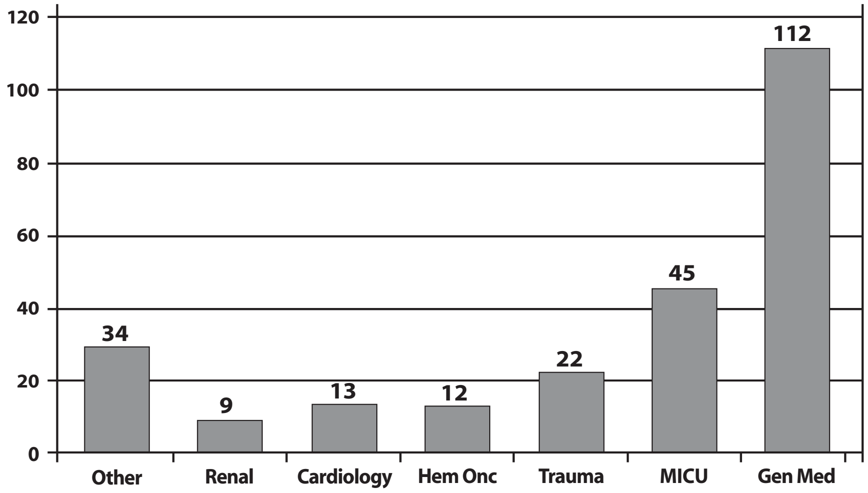
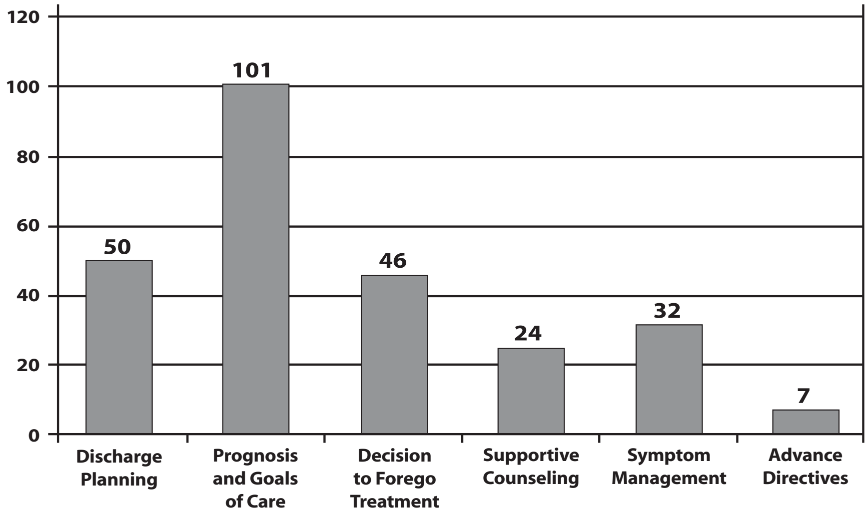


Figure 3.
Reasons Pallative Care Consults Were Requested at WFUBMC



needs assessment relied heavily on tools developed by CAPC, and medical center and hospice staff jointly attended CAPC conferences. A palliative care consult service began with voluntary attending support from the Department of Medicine and the hospice. While needs assessment progressed and administrative support was fostered, consultation progressed slowly. Within the last year, the PCCS at WFUBMC formally began with enthusiastic administrative support, including a full-time nurse coordinator and half-time support for medical direction outsourced to the hospice. Once a "face" became associated with the PCCS, the service has grown rapidly to capacity. Plans now include hiring a second nurse coordinator and additional physician resources as well as ultimate development of a palliative care unit.

The PCCS at WFUBMC demonstrates typical growth of a consult service in an academic medical center. Figure 1 demonstrates consults by month. Figure 2 shows the wide variety of services requesting palliative care consultation. While one might expect the general medical service to be the highest, it is clear that palliative care has become a regular part of ICU care. The most common reasons consultations are requested are shown in Figure 3. Communication issues such as establishing goals of care and understanding prognosis clearly lead the way. In fact, the most common interventions of the PCCS are not changes in symptom management, but family conferences. The PCCS has also demonstrated significant cost savings for WFUBMC through decreased length of stay and decreased ICU length of stay, as well as through more appropriate resource utilization. Recently an outside reviewer suggested cost savings based on the current number and type of consults per year will be at least $1 million and are more likely to approach $2 million.

Discussion

Palliative care is clearly more than "care from a friendly relative." Palliative care has unabashedly adapted and adopted principles of care firmly rooted in the hospice movement and applied them to patients with advanced illnesses and their families. Palliative care services provide "specialized care through specific knowledge and skills, including communication with patients and family members; management of pain and other symptoms; psychosocial, spiritual, and bereavement support; and coordination of an array of medical and social services."[1]

The long list of shortcomings in end-of-life care may seem daunting. With the rapid development of palliative care services across the country, it may seem like something hospitals *should* or *must* do. Indeed, developing standards from the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) and other accrediting organizations may make it a "have to" in the near future. There is an old anonymous saying that suggests, "you can't do everything at once, but you must do something at once." As these two examples in Forsyth County demonstrate, it may not matter how you start, as long as you start.

There are individuals within every hospital and community who "want to" develop models and standards of care that could become palliative care services. It is important to find that core group of leaders and champions and start somewhere. A palliative care program will follow; the wheel need not be reinvented. It will become the standard of care and succeed in improving both end-of-life care and care for all seriously ill patients and their families. It may be wise to simply take a deep breath, a leap of faith, and follow the CAPC motto: "Just do it!" **NCMJ**

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COMMENTARY

Hospital-Based Palliative Care Units:

Answering a Growing Need

Anthony N. Galanos, MA, MD

The central question confronting healthcare professionals and institutions with regard to end-of-life and palliative care is: How do we relieve the suffering that patients and families experience as they struggle to know what to do with serious and possibly terminal illness when it occurs? How do they navigate a medical system that offers few options if cure is not possible, cannot prognosticate with any certainty, and does not allow for the natural ebb and flow of uncertainty in medical decision making? It would seem that "palliative care," with its attention to caring, as well as curing, and its comfort with aggressive, as well as hospice care, is the philosophy of care that can best assist patients and families as they traverse the continuum from diagnosis through symptoms and treatment to an eventual outcome that may include hospice and bereavement.

There are two ways to look at palliative care: it can be seen as the natural extension of where aggressive, cure-oriented conventional therapy ended, i.e., what do you do for people for whom no evidence-based cure or therapy is available? Or, secondly, palliative care can be conceptualized as hospice, but much further upstream. Indeed, hospice and palliative care are not mutually exclusive. Hospice is ultimate palliative care, but is defined by a time limit and regulations surrounding a Medicare benefit. Palliative care, by contrast, can begin at the time of diagnosis, or any point thereafter, when patients and families may have already begun to suffer secondary to physical symptoms, anxiety and uncertainty, and have needs outside of the traditional biomedical model of care. The clinical events that lead people into the hospital have no predetermined outcome, and there the sorting out process must begin.

As an illustration, Morrison and Meier[1] describe the case of an 85-year-old man with class IV heart failure, hypertension, and moderate Alzheimer's disease who is admitted to the hospital after a hip fracture. This is his fourth hospitalization in the past year and his 84-year-old wife feels overwhelmed by his medical and personal care needs. The question becomes what might his doctor do to address his needs, alleviate his suffering, and facilitate discharge from the hospital and subsequent care at home? While this patient may eventually choose hospice, it is his current dilemma, blossoming in the hospital, which creates the need for palliative care services.

Indeed, when problems with end-of-life care are described, reference is often made to situations that occur in the acute care hospital setting. Concomitantly, while place of death is shifting more and more away from the hospital, it still remains the most likely site of death for North Carolinians and for Americans in general. It is important to ask why the hospital is seen in such a negative light when one has a terminal illness and why there is a need for concentrated palliative care efforts in these facilities. Aren't hospitals the very places where high-quality care at the end of life would be expected?

Why the Focus on the Hospital in Discussions of Palliative Care?

Noting that as many as 50% of patients currently die in acute care hospitals, the Acute Care Hospital Working Group, one of eight working groups convened as the National Consensus Conference on Medical Education for Care Near the End of Life, delineated a host of barriers to good end-of-life care in the acute care hospital:

- Shorter lengths of stay; hence, health professionals being trained in these settings do not see the trajectory of end-stage illnesses and fail to appreciate the needs of dying patients.
- Multitude of specialist physicians, with no one seemingly responsible for the integration of care needs in a patient-centered way.
- Emphasis on the "great case" with an accent on the disease and technical procedures at the expense of the bigger picture of the impact of the illness on the patient and family.
- Subtle messages such as death as a medical failure and that physicians should not express personal emotions, and other negative attitudes about dying.

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- Lack of essential communication and symptom-control skills among supervising physicians.
- Few end-of-life educational resources available for health professionals.[2]

Why Should Hospitals Respond? And in What Ways?

Hospitals should respond because the people they serve and the people who work in them want a better response to incurable disease. Data from public opinion polls and the lay press are unequivocal. The majority of Americans (74%) expect their physicians to be confident and competent in providing them with care when they do develop a life-threatening illness.[4] The public expects that the problem of suffering has been addressed directly in medical education[5] and is not uniformly in favor of aggressive care at the expense of comfort and functional status. For example, an American Association of Retired Persons (AARP) *Modern Maturity* survey of people's attitudes about death and dying, based on 1,800 interviews of Americans 45 years of age and older found that the older you are, the less afraid you are of dying and being in pain at the end of life. In the overall sample, 71% of people believe there is a point at which costly health treatments should be stopped and the numbers were even higher among people in higher income brackets, with 77% of those who earn $50,000 or more a year agreeing that at some point aggressive treatments may do more harm than good.[6]

> *"Palliative care is not a way* out, *but a way* through, *and it allows patients to have hope and an opportunity to live as fully and functionally as they can for as long as they can. Hospitals are a place of miracles and cures, but when that can not be the outcome, we '...palliate often, and comfort always.'"*

Closer to home, the AARP North Carolina End-of-Life Care Survey[7] sampled AARP members age 50 and older and had a response rate of 45%. Of the end-of-life concerns, almost 90% say that total physical dependency would be worse than death, and 70% say that not being able to communicate their wishes or that living with great pain is worse than death. More than 90% had heard of hospice, though only a quarter were aware that Medicare pays for it. Among those who know about hospice, three-quarters reported they would want hospice support if they were dying.

In addition, the national Institute of Medicine report, *Approaching Death: Improving Care at the End of Life*,[8] and policy statements from various clinical organizations, such as the American Board of Internal Medicine and the American Geriatrics Society[9,10] have advanced the argument that the public is better informed with regard to issues pertaining to end-of-life and palliative care through community organizations such as Project Compassion in Chapel Hill, North Carolina[11] or through media such as *Time* magazine,[12] the *Wall Street Journal*,[13] ABC's *NIGHTLINE* with Ted Koppel,[14] and National Public Radio.[15] One outcome of such public discussion of death, dying, and the relief of suffering is that hospitals are now being judged by their ability to provide palliative and or hospice services.[16,17,18] Ultimately, hospitals must listen to the Joint Commission on Accreditation of Healthcare Organizations (JCAHO), which has issued a set of standards/guidelines regarding care at the end of life:

> *"The patient at or near the end of his or her life has the right to physical and psychological comfort. The hospital provides care that optimizes the dying patient's comfort and dignity and addresses the patient's and his or her family's psychosocial and spiritual needs... and staff is educated about the unique needs of dying patients, their families and caregivers."*[19]

This last comment regarding "staff" is significant. Caregivers in the hospital need support and guidance as they care for patients for whom there is no cure. Nurses and physicians have voiced concerns over the lack of patient involvement in treatment decisions and the overuse of mechanical ventilation, dialysis, and resuscitation.[20] Our own research at a tertiary care teaching center has shown that among attending physicians, house officers, nurses, and family members, no two of these four groups saw the last week of life in the hospital in the same way, and levels of satisfaction differed among the four groups.[21] It behooves hospitals to provide better advice and support to those front-line professionals responsible for caring for the terminally ill. A palliative care team can provide the support needed for end-of-life care and aggressiveness of care.

How Should the Hospital Respond? Is the Hospital-based Palliative Care Team Part of the Answer?

In response to the 1998 American Hospital Association Survey, 30% of hospitals that responded to the survey reported having a hospital-based palliative care program with another 20% planning to establish one.[23] Palliative care programs have been based primarily in medical oncology or general medicine divisions and a consultation service was the most common clinical entity. Another report based on the same data concluded that, given the need, palliative care services were slow to be institutionalized in the hospital setting.[24] As Hanson concludes elsewhere in this issue of the *North Carolina Medical Journal*,[30] there are multiple models of palliative care services affiliated with hospitals and the process is "not yet standardized," but outcome data are now starting to build.[25,26]

The Essentials of Palliative Care

Palliative care, by definition, is an interdisciplinary team event. Depending on available resources, most palliative care teams have a nurse practitioner as the hub of the team to assure continuity of care. The nurse practitioner is backed up by an attending physician and, in some centers, a geriatric medicine or oncology fellow. It should be noted that there are roughly 43 active or emerging United States fellowships in palliative medicine and Duke University Medical Center will offer a program as of July 1, 2005.[25] Critical members of a palliative care team include a chaplain, a social worker, and rehabilitation specialists if increased function is needed for quality of life. In some cases, a psychiatrist may be needed to address issues such as depression and delirium if the team is not comfortable with the complexity of these issues at the end of life. It is not the composition of a palliative care team that is important, but rather that personnel with appropriate skills are available to meet the needs of a particular patient at a particular time in his/her continuum of care. The most important player on the team will vary by the patient and by patient need. "No man can be rendered pain free whilst he still wrestles with his faith. No man can come to terms with his God when every waking moment is taken up with pain or vomiting."[28]

Some potential roles of the clinical palliative care team include offering advice and support to the patient's caregiving team on symptom control and psychosocial and existential issues. This kind of support is clearly needed for the patient's family as well. Another role is educating hospital staff (pursuant to the JCAHO standard) and serving as a liaison between the hospital, hospice, or other facets of the continuum of care. This role would suggest that the palliative care team is present to reduce symptoms and suffering, to meet family and patient preferences, and to help negotiate goals of care. Meeting these needs should lead to improved patient and family satisfaction, as well as that of the hospital staff, while improving utilization of hospital resources, e.g., length of stay, number of intensive care unit (ICU) days, readmission rate, unnecessary emergency room use, and the timing and appropriateness of hospice referrals.

Institutions that have a designated geographic area and a defined palliative care unit have demonstrated incredible outcomes.[26] Having the designated area allows for total management of the patient, and for an atmosphere of enlightened patient-centered care. A step down from this level of care that still allows primary care of the patient, but does not entail a separate palliative care unit, is the "scatter-bed" model. In hospitals where beds may be at a premium, the "scatter-bed" model allows the palliative care team to take over the patient's primary care in the same bed that he or she was residing in at the time of initial consultation. In other words, when the palliative care consult team visits a patient in the hospital and finds that the needs of the patient can be better met by the palliative care team, then the patient will stay in that unit bed, but the primary care will be provided by the palliative care team. While it has its disadvantages, one clear advantage of the "scatter-bed" model is that multiple units in the hospital are exposed to and learn the fundamental principles of palliative care. In some arenas, primary care of patients may not be an option, so a "consult-only" service is the best mode of operation.

Whatever model of care is feasible at a particular institution, it is important not to approach the staff with an attitude of "we are here to show you how to do it, because you have been doing it poorly," but rather to provide added value to what is in place. Our experience has shown us that once nurses, chaplains, and physicians working on the unit understand the palliative care clinical team's role and purpose, they welcome our intervention and often participate with us in family meetings and discussions of care goals. While these activities clearly lead to better patient, family, and staff satisfaction, we are collecting data on cost savings to the institution. As in the example of the palliative care unit at Medical College of Virginia,[26] to collect data on patients that are matched on diagnosis and other variables, and then to compare cost and other data for those with and without palliative care intervention, can be a powerful argument to hospital administration and to those who may not be familiar with this type of care.

In essence what we have been talking about is that an either/or (cure or not) approach to medicine does not work for patients, families, and hospital staff. We can expand the options and choices of the people we serve by employing palliative care in the hospital. That way, we relieve suffering and change the

Sources Relevant to Initiating a Hospital-based Palliative Care Unit/Program

The Hospital and Healthsystem Association of Pennsylvania has expanded its Hospital-Based Palliative Care Consortium to serve hospitals nationwide and can be accessed via its website at http://www.hbpcc.org. The Center to Advance Palliative Care, a national initiative supported by The Robert Wood Johnson Foundation with direction and technical assistance provided by Mount Sinai School of Medicine, has produced an outstanding monograph: "The Case for Hospital-Based Palliative Care," that outlines the rationale for starting such a program with an emphasis on data that would appeal to hospital administrators.[22] Readers are directed to the Center to Advance Palliative Care (CAPC) website where voluminous amounts of information are available, eg, "Palliative Care in Hospitals: Making the Case," www.capcmssm.org.

focus from the hospital, to the patient and those close to him or her. It is the patient and family who have come to the hospital for answers to their conundrum. In response, the hospital-based palliative care team does not emphasize what will be taken away, but what will be done *for* the patient and family despite a life threatening illness. Palliative care is not a way *out*, but a way *through*, and it allows patients to have hope and an opportunity to live as fully and functionally as they can for as long as they can. Hospitals are a place of miracles and cures, but when that can not be the outcome, we "...palliate often, and comfort always."[29] **NCMJ**

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COMMENTARY

A Brief Review of North Carolina's Law on Dying[1]

Anne Dellinger, JD, and Aimee Wall, JD, MPH[1]

Ten years after Oregon voters first approved the "Death with Dignity Act,"[2] contentious debate continues throughout the country regarding the legal and ethical issues surrounding end-of-life care, particularly on the issue of assisted suicide.[3] Just last year, the North Carolina General Assembly considered legislation proposing to criminalize assisted suicide.[4] The bill did not pass, but the issue is likely to arise in future legislative sessions. In considering how North Carolina should approach end-of-life issues, it is useful to review our state's current law and policy regarding life-sustaining treatment, euthanasia, suicide, assisted suicide, and pain relief. The summaries below are not intended to be comprehensive, but rather provide a basic overview of the legal environment surrounding each of these important issues.[5]

Life-Sustaining Treatment

Refusal, withholding, and withdrawal of life-sustaining treatment all are legal choices under federal and state law. A patient has long had the ability to express his or her wishes regarding life-sustaining treatment orally or in the form of a written document often referred to as an "advance directive" or "living will." Refusal of life-sustaining treatment and advance directives are governed primarily by state law, but the federal government has weighed in on a few important points. While not directly stating it, the United States Supreme Court seems to acknowledge that competent people have a constitutional right to refuse medical treatment.[6] Also, Congress recognized the concept of advance directives in 1991 when it enacted the Patient Self-Determination Act.[7] The law requires health facilities, as a condition of Medicare or Medicaid participation, to ask every patient about advance directives and to explain the options available under state law for creating them. The law does not require providers to comply with advance directives, but they must at least initiate conversations with patients about their wishes.

North Carolina's history of recognizing patient autonomy in end-of-life decisions goes back even further. The state enacted the Right to Natural Death Act[8] in 1978, not so much to create new rights related to advance directives as to recognize existing ones.[9] The law includes a form by which a person may express his or her preferences regarding extraordinary medical interventions, including artificial nutrition and hydration.[10] State law also permits residents to name an agent to make those decisions on their behalf in certain circumstances.[11] In 2001, the state enacted two laws related to patient autonomy. The first is a law that shields providers from liability if they withhold cardiopulmonary resuscitation from a person having a "portable do-not-resuscitate order" on a form developed or approved by the state.[12] The second is a law establishing a voluntary state registry for advance healthcare directives.[13]

Whether North Carolina doctors and hospitals or other facilities must carry out a patient's stated wishes is not settled. Some states require this by statute, subjecting noncompliant providers to criminal or civil penalties and/or professional disciplinary actions.[14] A North Carolina attorney general's opinion advises that a physician or a facility need not follow a patient's wishes or transfer the patient to caretakers who will. But the opinion also says that providers may be civilly liable for assault and battery if they force treatment on a patient.[15] The North Carolina Medical Board, on the other hand, states that "physicians are ethically obligated to follow the wishes of the terminally ill or incurable patient as expressed by and properly documented in a declaration of desire for a natural death" or transfer the patient to another physician's care.[16] Based on this statement, a physician could be subject to disciplinary action if he or she refuses to follow the patient's wishes and fails to transfer the patient.

Euthanasia

"Euthanasia" may be defined as "the intentional putting to death of a person with an incurable or painful disease intended as an act of mercy."[17] This act very likely is murder under North Carolina law. North Carolina's highest court has dealt very harshly with "mercy killing." For shooting his father in a

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hospital bed, a man was convicted of first-degree murder and received a mandatory life sentence, which was upheld on appeal. At trial the judge told the jury that they could infer malice[18] (though they did not have to do so) from the defendant's use of a deadly weapon, and further instructed that the defendant's knowing that his father was at the brink of death was not a defense (though they could consider that knowledge). Both instructions were challenged on appeal. The Supreme Court upheld them, but not unanimously. The chief justice urged a lesser sentence than that for first-degree murder because the son's intentions were good.[11]

Personally administering lethal medication to a patient could be first-degree murder, either as "murder by poison" or simply as deliberate and premeditated killing. Like the man who shot his father, a doctor or a nurse would likely not escape punishment because she or he meant to help the patient—not even if the patient had asked for death.

Suicide

"Suicide" is "the act or an instance of taking one's own life voluntarily and intentionally."[19] It is surprising how recently suicide and suicide attempts were crimes in this state. In fact, North Carolina was the last of the states to prosecute an attempt at suicide. In 1961 the state Supreme Court found the act criminal,[20] as it had been for centuries under the common law of England and was later in the American colonies and states. Because suicide was a crime, helping someone carry it out was as well.[21] In 1973 the North Carolina General Assembly abolished the crime of committing suicide and thereby, implicitly, the crime of attempting suicide. The status of providers' acts assisting patients to commit suicide is more complicated.

Assisted Suicide

A leading treatise on death and dying discusses at length what "assisted suicide" means and how it differs from euthanasia and homicide (if it does).[22] Much of the public and a significant minority of physicians do not distinguish meaningfully between assisted suicide and euthanasia.[23] Most people, however, continue to draw a moral distinction between responding affirmatively to "Help me kill myself" and responding affirmatively to "Kill me."[24] How to treat the two acts, and what constitutes each, are problems for all interested parties [patients, health providers, courts, district attorneys, health licensing boards, legislatures, the United States attorney general, and the Drug Enforcement Agency (DEA)]. For present purposes, though, a loose definition of "assisted suicide" may be helpful: it can be thought of as the act of providing a competent person with the means to take his or her own life.

In general, assisting someone in committing suicide is legal. That is, an ordinary person who hands a knife to a desperate stranger or holds a ladder for that person to reach a window ledge should have no legal problem. The situation can be more complicated if there is a special, legally recognized relationship between the helper and the person wanting to die. In certain relationships—such as parent and minor child or doctor and patient—one party is legally obligated to protect the other to some extent.[25] Based on the current state of the law, we simply do not know whether or when a healthcare provider in North Carolina will be seen as failing to protect a patient if she or he helps the patient die. In other words, we do not know whether a provider's decision to help a patient die will subject the provider to civil or criminal liability.

> *"Pain management is probably the most important of the end-of-life issues because of the effect of pain on dying people and the fear it engenders in nearly everyone who contemplates dying in the United States today."*

The means of assistance most often discussed is providing medication for a patient to administer to herself or himself.[26] As discussed above, Oregon law now authorizes a physician to prescribe a lethal dose of medication for a person suffering from a terminal disease if the person requests the prescription and certain other requirements are met.[27] This law came under attack recently when United States Attorney General John Ashcroft issued a directive explaining that assisting a person to commit suicide does not qualify as a "legitimate medical purpose" under the Controlled Substances Act (CSA) and therefore a physician who prescribes, dispenses, or administers a controlled substance for such a purpose would be in violation of federal law.[28] The attorney general directed the DEA to enforce the CSA in Oregon despite the existence of the state law authorizing such prescriptions. In May of this year, however, a federal court of appeals invalidated the attorney general's directive on the grounds that Congress did not provide him with the authority to make such an expansive interpretation of the CSA.[29]

While it appears (for the time being) that terminally ill Oregon residents may be allowed to request physician assistance for suicide, many other states have expressly prohibited providers from providing such assistance.[30] The United States Supreme Court has upheld such prohibitions in two states, finding in both cases that the state laws did not infringe upon constitutional rights.[31] It is not clear, however, how North Carolina courts would interpret and apply this state's law in such a situation. No law expressly prohibits assisted suicide, as was proposed this past legislative session. In laws governing living wills, however, the North Carolina General Assembly declared that the state does not "authorize any affirmative or deliberate act or omission to end life other than to permit the natural process of dying."[32] The state courts have not been called upon to review this statement, but it may be possible to infer from the language that suicide assistance by a healthcare provider is illegal in this state.

It is also possible that a physician or pharmacist providing medication to assist a suicide could be found in violation of the state's controlled substances law. Like the federal CSA, the state law provides that a prescription must be for a "legitimate medical purpose."[33] While the recent federal court of appeals decision invalidated Attorney General Ashcroft's interpretation of that language, it did not place any limits on the states' ability to interpret and apply the same or similar language in their own laws. The North Carolina Department of Justice has not released a formal opinion on this issue.

Based on the policies, position statements, and resolutions adopted by many national and state professional organizations, it appears that many members of the medical profession in this country object to the principle of assisting a person in committing suicide.[34] While these policies do not have the force of law, they are likely to be persuasive to healthcare professionals in states, such as North Carolina, where clear legal guidance is lacking. In some instances, such policies could form the basis for disciplinary action by licensing boards.

Pain Management

Pain management is probably the most important of the end-of-life issues because of the effect of pain on dying people and the fear it engenders in nearly everyone who contemplates dying in the United States today. Despite efforts from several directions to clarify the legality of giving pain-relieving medication that may shorten life or even kill, the matter is not yet clear enough.[35] Health professionals know that a number of drugs may depress breathing, especially opioids (derivatives of opium or similar, synthetic narcotics), which are among the most effective painkillers. They also know that relieving pain is among the highest goals of their professions, that United States medicine has been widely criticized by its practitioners and others for failing in that regard,[36] and that a major malpractice suit for failure to relieve pain succeeded in North Carolina. In that case a Hertford County jury returned a verdict of $15 million against Hillhaven Corporation for a nursing home's refusal to administer pain medication ordered by a physician for a man dying of cancer.[37]

There is clear support for pain management at the federal level. Federal law encourages the use of controlled substances to relieve pain, even if doing so jeopardizes the patient's life. The law requires doctors who prescribe medication for purposes of treating a drug addict to register with the DEA,[38] but regulations state that the act is not meant to limit a physician who prescribes opioids for intractable pain when no relief or cure is possible or has been found after reasonable effort.[39] In his 2001 directive, Attorney General Ashcroft reiterated the distinction between assisted suicide and "providing sufficient dosages of pain medication necessary to eliminate or alleviate pain."[40] National professional organizations, such as the American Medical Association and the American Nurses Association, also support and encourage active management of pain in dying patients.[41]

At the state level, the scope and type of legal guidance related to pain management varies. Many states expressly approve the use of pain-relieving medication, even though it may shorten life.[42] Some states do this by amending their controlled substances laws while others enact freestanding statutes. North Carolina has done neither. In the absence of state law on the issue, providers may rely on guidance from their licensing boards. In the fall of 1999, North Carolina's Boards of Nursing, Pharmacy, and Medicine issued a joint statement on pain management in end-of-life care. The statement identified issues of concern to members of the three professions. Of particular interest is the section of the statement directed toward physicians. It expressly provides that:

> "Opioid use... is appropriate if the responsible physician is familiar with and abides by acceptable medical guidelines regarding such use, is knowledgeable about effective and compassionate pain relief, and maintains an appropriate medical record that details a pain management plan. Because the Board is aware of the inherent risks associated with effective pain relief in such situations, it will not interpret their occurrence as subject to discipline by the Board."[43]

The Medical Board also adopted two other statements discussing opioid use for the management of pain; one applies to pain during end-of-life care[44] and the other applies to chronic non-malignant pain.[45] The Board took care to assure physicians that they will not be disciplined for pain management, saying "no physician need fear reprisals from the Board for appropriately prescribing...even large amounts of controlled substances indefinitely for chronic non-malignant pain."

Even in the absence of state statutes or regulations on the issue, these strongly worded position statements from professional licensing boards should go a long way toward encouraging healthcare providers in North Carolina to provide adequate pain relief in end-of-life care. Without further action by the North Carolina General Assembly, though, providers (and their attorneys) will likely continue to be concerned about potential liability under the state controlled substances law and basic tort law.

Conclusion

North Carolina is clear on a few issues related to end-of-life care: an individual has the right to refuse life-sustaining treatment; euthanasia (or "mercy killing") would likely be considered murder; and suicide is not a crime. The law related to two of the most controversial issues—assisted suicide and pain management—is less clear. Healthcare providers, patients, advocates, and policymakers interested in continuing to develop the state's legal landscape related to end-of-life care have a tremendous opportunity to provide guidance and clarity in these essential components of patient care. **NCMJ**

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7 42 U.S.C. §§ 1395cc (Medicare), 1396a (Medicaid).

8 N.C. Gen. Stat. Art. 23, Ch. 90 (hereinafter N.C.G.S.).

9 Formal Opinion of Attorney General to C. Robin Britt, Sr., Secretary, N.C. Dept. of Human Resources. Ref. No. fop11. Jan. 5, 1995. (Accessed July 7, 2004, at http://www.ncdoj.com/DocumentStreamerClient?directory=AGOpinions/&file=fop11.pdf). The act and its amendments emphasize that North Carolinians retain additional common-law rights to control the circumstances of their death. N.C.G.S. § 90-320.

10 N.C.G.S. § 90-321. While the law refers to a written document and includes a statutory form, it provides that the law establishes a "nonexclusive" method for creating such a directive. N.C.G.S. § 90-320(a). For a discussion of oral advance directives, see Meisel, A, Snyder, L, and Quill, T. Seven Legal Barriers to End-of-Life Care: Myths, Realities, and Grains of Truth. JAMA 2000;284:2495-2501.

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regulations (incorporated into the state's code at 10A N.C. Admin. Code 26E .0301) provide:

> A prescription for a controlled substance to be effective must be issued for a legitimate medical purpose by an individual practitioner acting in the usual course of his professional practice. The responsibility for the proper prescribing and dispensing of controlled substances is upon the prescribing practitioner, but a corresponding responsibility rests with the pharmacist who fills the prescription. An order purporting to be a prescription issued not in the usual course of professional treatment or in legitimate and authorized research is not a prescription within the meaning and intent of section 309 of the Act (21 U.S.C. 829) and the person knowingly filling such a prescription, as well as the person issuing it, shall be subject to the penalties provided for violations of the provisions of law relating to controlled substances.

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North Carolina Voluntary State Registry of Advance Healthcare Directives

In 2001, the North Carolina General Assembly passed legislation authorizing the NC Secretary of State to create a voluntary on-line registry of advance healthcare directives for the benefit of the citizens of the state and their healthcare providers under circumstances where immediate access to such directives would be needed. Citizens wishing to register their notarized directives may place three types of healthcare directives and an organ donor card on the Internet web site maintained by the Office of the Secretary of State at the following Internet location:

http://www.secretary.state.nc.us/ahcdr/

Those wishing to take advantage of this service by filing their information by mail may get information to facilitate their registration by calling 1-919-807-2000. Forms are provided for:

- Health Care Power of Attorney
- Declaration of Desire for Natural Death (Living Will)
- Advance Instruction for Mental Health Treatment
- Organ Donor Card

COMMENTARY

Spiritual Care at the End of Life:
What Is It and Who Does It?

Keith G. Meador, MD, ThM, MPH

The inclusion of "spirituality" in medical practice and research has become increasingly commonplace in recent years. Although clarity as to exactly what is meant by this term continues to be elusive, acceptance of its significance in the care of patients has increased as we continue to gain a better understanding of its role and develop related standards of practice. End-of-life care has incorporated some consideration of spiritual care since the advent of the modern hospice movement within the vision of Dame Cicely Saunders in England approximately 40 years ago.[1] Her vision of a community of caring that would attend to the spiritual needs of dying patients, along with addressing their pain management and other medical needs in a more humane fashion, was the foundation for the modern hospice movement. Although much of current end-of-life care has evolved from the challenge extended by Saunders regarding appropriate care of the dying, her commitment to meeting the spiritual needs of dying patients continues to be a challenge for healthcare providers.

These challenges grow out of a number of exacerbating factors concerning the diverse understandings of spirituality in a culturally pluralistic society, as well as the complexities of contemporary healthcare delivery systems. While recent evidence[2] indicates that both patients and their families consider spiritual care to be important in end-of-life care, the understanding of what this means varies considerably. The breadth of expectations expressed by this desire for spiritual care is expansive. It can include the spectrum from some sense of an emotionally sensitive care of the "human spirit" to a highly ritualized religious care incorporating very specific rites for the dying and a multitude of possibilities in between. Even those healthcare providers most sensitive to the inclusion of spiritual care at the end of life may be daunted by the thought of engaging such a fluid and somewhat nebulous expression of need.

Dr. Hanson's description of palliative care and its significance as a practice of medicine in the lead article of this issue[3] lays the groundwork for our considering the role of spiritual care at the end of life. Two primary aspects of palliative care are (1) an understanding of the virtue of caring (in contradistinction to curing) as a practice of medicine and (2) an appreciation of the art of listening well in the care of patients. Both of these resonate with the provision of spiritual care to the dying, and their central roles in palliative care speak to the potential for palliative medicine to remind all of us of the importance of listening and caring as essential aspects of practice throughout all of medicine, not just with the dying. The resolution of who can best provide intentional listening, as well as interpret the stories and struggle faced by those considering their mortality while reviewing their lives for a sense of purpose and closure, is not the same for every person. Those who render such care must examine themselves regarding their capacities and willingness to engage the rich and textured complexities of those for whom there are no illusions of cure, but who none the less need their undivided attention at the junction of life and death. The development of the skills and capacity to do such work has not been a standard part of medical education in the past and we, as well as our patients, have suffered for this inadequacy. Arthur Frank comments in *The Wounded Storyteller* that, "One of our most difficult duties as human beings is to listen to the voices of those who suffer."[4] I fear that we do not adequately equip ourselves as physicians and other healthcare providers to fulfill this "duty" and all that it entails.

Voices of suffering—especially the voices of those who know they are dying and their families—become poignantly focused. Along with asking challenging questions regarding prognosis and other "medical" inquiries, they become seekers and purveyors of "spiritual" understanding and wisdom. The language used for such communication will frequently be very specific to a particular cultural or religious tradition. While considerable strides are being made in improving communication skills for physicians in the care of the dying, lack of familiarity with such tradition—specific language and metaphors through which a dying person expresses her "soul"—can limit the capacity of the physician or other provider to listen well. This lack of familiarity is not a fault in the provider, but acknowledgement of this lack and seeking the assistance of someone more versed in the tradition of the dying patient can be crucial for providing

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meaningful spiritual care. Awareness of one's lack of familiarity with the religious or cultural tradition and language of a patient may not be readily evident, and patients may be hesitant to point out such gaps of understanding. Only through our attentiveness to the patient's story and the humility to discern our own inadequacies will we best serve the communication needs central to providing optimal spiritual care for dying patients.

The best spiritual care for the dying patient is most likely to be delivered in the same way other types of care are best provided, through partnerships within the team of persons caring for the patient. Although much of medicine is best practiced within a context of teamwork, palliative care particularly denotes a team approach,[5] and vital to a palliative care team is the clergy member of the team or the chaplain. While many physicians, nurses, and social workers have substantial gifts to offer to the spiritual care of patients, the role of a clergy member on the team to give leadership in providing spiritual care cannot be overstated. The other providers on the team may have a greater appreciation of the particular faith tradition of a patient and may serve as the more trusted spiritual confidant and care provider, but the clergy member of the team brings an interpretive, liturgical, and communal sense of spiritual care from her or his pastoral formation unique to that vocational formation. The optimally-trained and wise chaplain provides pastoral services within the entire community surrounding the dying patient and fosters a sense of care for one another that acknowledges the interdependency of the providers, the family, and the dying person in this work of living and dying.

> *"Palliative care informed by spiritual attentiveness allows both the patient and the provider to give up illusions of therapeutic entitlement to cure and at the same time honor the privilege of intentional and reverent caring for the dying."*

We healthcare providers rarely fully attend to the role of this interdependency in forming the health of the community, which ultimately determines how we care for the suffering and dying among us. Wendell Berry provides insight into the shared communal underpinnings of spiritual and palliative care when he says, "Health is not just the sense of completeness in ourselves but also is the sense of belonging to others and to our place; it is an unconscious awareness of community, of having in common."[6] Mindfulness of our interdependence allows us to be less captive to consumerist expectations and their distortion of caring relationships, while nurturing a greater sense of gratitude within an awareness of the limitations and finitude of healthcare. Palliative care informed by spiritual attentiveness allows both the patient and the provider to give up illusions of therapeutic entitlement to cure and at the same time honor the privilege of intentional and reverent caring for the dying.

Good spiritual care is not just calling the chaplain for last rites or prayer with the bereaved family near the time of death. Although these are both valued and legitimate aspects of spiritual care, they fall short of the vision for spiritual care indicated by a comprehensive strategy for palliative care. Spiritual care should inform the practice of palliative care throughout the course of treatment.

There is no substitute for time to do the work of a "good death." While the interpretation of a good death may vary by tradition and culture, most consider the opportunity for a good death to include adequate pain management and the time to make peace with one's neighbor and with God while supported emotionally by family or friends. Adequate spiritual care helps provide the context for such a death for the dying person with an attentiveness to that individual's particular needs. Spiritual care as part of a comprehensive strategy for palliative care provides the opportunity and support to narrate one's story in such a way as to provide a legacy and memory of a "good death" for the family and broader community. The spiritual legacy of such a narrative can be a gift for generations to come and reframes the inevitable experience of loss within death as a reminder of the gift of the life that has been lived.

The importance and value of well-trained clergy as partners in providing the hope of a "good death" and its legacy is evident, but the lack of availability of such persons is all too common. Recent collaborative efforts between the Pastoral Services Department at Duke University Medical Center and the Duke Institute on Care at the End of Life to train specialist chaplains in end-of-life care are an attempt to address this issue. While the equipping of more specialized chaplains for tertiary care centers is helpful, the large numbers of persons dying in smaller hospitals without staff chaplains require our consideration. If we are convinced of the value of spiritual care as a part of palliative care and believe clergy to be important in the rendering of that care, we are challenged to consider how to best address this void of spiritual care providers in smaller hospitals and communities. The Caring Communities Program of Duke Divinity School and The Duke Endowment provides one response to this need in the Pastoral Care in Community program, which offers a curriculum certifying local clergy as Pastoral Care Specialists and equipping them to serve as volunteer chaplains in local hospitals. Although most of these clergy have visited regularly in the hospitals in the past, they are now receiving education in order to more ably partner with healthcare providers as part of palliative care teams in the provision of spiritual care to suffering and dying patients.

Spiritual care is still finding its place as a practice in healthcare.

Standards of practice for spiritual care have not been developed and we are still unsure as to just who should be engaging in its practice. Spiritual care has been part of end-of-life care since the start of the modern hospice movement, but it continues to evolve in content and form in response to increasingly pluralistic societies in the United States and western Europe. Providing spiritual care with integrity to the faith tradition of the dying patient can be challenging, but such care cannot be viewed as an optional luxury within the developing discipline of palliative care. The substantive shared commitments of good spiritual care and palliative care bear witness to spiritual care being inherently constitutive of palliative medicine rightly construed. Support for intentional spiritual care as an integral part of quality end-of-life care should come from many quarters, but support and commitment to spiritual care's place in palliative care at the end of life *must* come from physicians and administrative leaders in palliative care. The health of us all depends on it. **NCMJ**

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COMMENTARY

Opioids in End-of-Life Care:
Promises and Problems

Richard C. Stephenson, MD

Introduction

On the surface, it would seem that appropriate utilization of opioid analgesics to relieve suffering at the end of life is a "no-brainer." Concerns about addiction, diversion, tolerance, and other side effects might impede the use of these powerful medications in chronic nonmalignant pain, but certainly terminal pain and suffering must override these concerns. Tragically, nothing could be further from the truth.

For years, the American Alliance of State Cancer Pain Initiatives has presented convincing data showing that the undertreatment of cancer pain at the end of life is a public health crisis.[1] What an interesting and descriptive phrase, "public health crisis!" Why not tragedy, shame, or outrage? A public health crisis implies the scope of the problem is huge, that it is of concern to us all, and that effective preventive therapies and treatment strategies are available, but are simply not being utilized.

A quick look at the numbers is alarming. More than half a million people will die of cancer each year in this country. About two thirds of patients with advanced cancer have significant pain. Numerous studies confirm that almost half of these patients have unrelieved pain. Clearly these numbers are of public health crisis proportions. But even more poignantly, most experts in pain management would quickly agree that more than 95% cancer pains could be effectively treated with the right medication at the right dose at the right time.

Unfortunately it isn't just cancer pain at the end of life that is under-treated. The well-known and often quoted Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments, SUPPORT, clearly showed that more than half of very sick hospitalized patients were in serious pain during their final days.[2] Unrelieved pain is incapacitating—interfering with the ability to eat, sleep, interact with others, and achieve a satisfactory quality of life.[3] Nothing could be more diametrically opposed to our fundamental promise as physicians, to cure sometimes and to relieve suffering always.

How can we all do a better job and keep the promise? It seems simple enough. Terminally ill patients present with complaints of severe pain and healthcare providers respond by diagnosing and treating with appropriate analgesic medication. So simple that hospice, palliative care programs, and others have applied a set of ABC's to pain management at the end of life (See Table 1). Perhaps thorough reflection on this "simple" process will demonstrate both the barriers and potential solutions to adequate pain relief at the end of life.

Table 1.
ABC's of Pain Management

ASK	about pain regularly; ASSESS systematically.
BELIEVE	the patient and family in their reports of pain and what relieves it.
CHOOSE	pain control options appropriate for the patient, family, and setting.
DELIVER	interventions in a timely, logical, and coordinated fashion.
EMPOWER	patients and their families; ENABLE them to control their course to the greatest extent possible.

Ask and Assess

All too often it seems we fail to ask patients with serious illness about pain. Paradoxically, healthcare providers are expecting patients to complain, while patients are waiting for their provider to ask.[4] A long list of potential reasons cancer patients may not complain about increasing pain can be easily generated. Pain may well have sinister implications, including spread of disease, failure of therapy, lack of further therapies, and imminent death. Pain may interfere with the doctor-patient relationship. Patients in pain may feel burdensome to their doctor if they complain of pain not adequately managed, even fear their pain may distract physicians from the business of curing their cancer.

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After all, patients fundamentally like and respect their doctors and want the same in return. They may not want to be considered weak, whiney, drug-seeking, ungrateful, or even a therapeutic failure to their physician.

Physicians share some of these same concerns that lead to a failure to ask. In addition, pain evaluation and management are not well taught in most medical schools and residency programs. One recent survey reported the average amount of time spent on teaching pain management in American medical schools is one hour; with just four hours for nurses.[5] Failure to ask may also reflect insecurity about what to do with poorly controlled pain and fears of regulatory scrutiny when prescribing controlled substances. Weber and Huber showed that oncologists in a busy clinic setting documented pain severity and opioid dose only 25% of the time in patients known to have significant pain (see Table 2).[6]

Table 2.
Documentation of Severe Pain, Opioid Doses, and Opioid-related Side Effects *adapted from Weber and Huber*[6]

Finding	Frequency Documented
Pain Severity	24.6%
Opioid Dose	26.9
"Rescue" Dose	4.8
Bowel movements	1.6
Laxative Rx	4.2

Asking is a great place to start, but a more formal pain assessment and regular utilization of a pain assessment tool have been shown to improve pain management. While one might argue that various tools are too long, complicated, time-consuming, or subjective, studies repeatedly show that choosing and consistently using one is far better than using none.[7] Most pain scales and tools are actually quite simple, often done by the patient, and easy to incorporate into regular visits. Even patients with mild-to-moderate dementia can respond to at least one of these simple tools.[8] The simplest of tools are scales. The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) now "recommends" the regular use of pain scales to assess pain severity and relief. The two most common scales are either verbal (none, mild, moderate, severe, or excruciating) or numerical (0-10 where 0 indicates no pain and 10 the worst pain you can imagine).[9]

> *"Unrelieved pain is incapacitating—interfering with the ability to eat, sleep, interact with others, and achieve a satisfactory quality of life."*

In some settings and with some patients, particularly at initial assessment, more detailed tools like the two listed below are helpful. Neither of these tools is new and both have been validated in a variety of settings and many different countries. Many more are available and their use is encouraged.

The Memorial Pain Assessment Card (MPAC)

The MPAC[10] uses a 10-cm Visual Analogue Scale to rate not only pain but also relief and mood. A Visual Analogue Scale (VAS) is a simple 10cm line labeled 0 (none) at one end and 10 (severe) at the other. The patient marks the point on the scale that best indicates the severity of the symptom. A VAS can be used to assess any symptom including pain, nausea, dyspnea, anxiety, depression etc. The patient's response to the card also indicates global symptom distress.

The Wisconsin Brief Pain Inventory (BPI)

The BPI[11] comes in both a long and short form. The long form lends itself to initial pain assessment and the short form to follow-up. Both forms establish pain at its recent worst, least, average, and now using a 0-10 scale. They provide descriptive language about the quality of the pain as well as a body diagram to locate and separate pains. The BPI also asks patients to grade their overall pain relief efforts and quantify interference with mood, sleep, and relationships.

One element that has received recent media attention is incorporating pain as the "fifth vital sign." In reality, this may become the standard of care. The United States Department of Veterans Affairs (VA) has initiated an ambitious program to include pain as the fifth vital sign in not only all of its medical facilities, but all patient encounters. A positive pain score then triggers further assessment, prompt intervention, and follow-up evaluation.[12]

Believe

Patients and their families often note that no one seems to believe in their complaint of pain. Physicians are often stuck in a medical model of care that demands a specific diagnosis before treatment. Treatment may be delayed until proof is found by diagnostic testing or even further delayed if our tests fail to confirm a clear etiology of the pain, e.g., a positive bone scan. Hospice nurses often express considerable frustration that patients with diseases like lung cancer, at high risk for painful metastases, often do not receive adequate pain medications until testing proves the existence of disease spread. With proof in hand, most physicians are then more than willing to prescribe whatever is necessary.

It is abundantly clear that many physicians are very concerned about prescribing opioid medication without "proof" of definitive disease. It is appropriate to be concerned; there are patients trying to scam us. Diversion, abuse, and misuse happen, but fears and concerns about these possibilities should not prevent appropriate prescription of pain medications for patients who need them. This is easy enough to say, but with all the media attention and legal activity surrounding opioid diversion and misuse, fear of regulatory scrutiny, and even legal prosecution, often thwarts adequate pain management.

Few physicians will forget the picture of a Florida physician that appeared in papers all across the country with the caption, "Doctor is sentenced in Oxycontin deaths." Careful review of the article clearly showed that this was a "dishonest doctor" dispensing oxycontin for profit. Unfortunately few people get beyond the headlines. Within just the last year, an equally alarming legal advertisement appeared in the *Winston-Salem Journal* that read, "OXYCONTIN: If you have been prescribed Oxycontin for more than six (6) months for something other than cancer, call...(telephone number)...Prescription users only."

It is precisely for these reasons that the Drug Enforcement Administration (DEA) and 21 health organizations felt compelled to issue a Joint Statement Promoting Pain Relief and Preventing Abuse of Pain Medications: A Critical Balancing Act (see page 234).[13] This joint statement clearly reassures us that,

> *"Preventing drug abuse is an important societal goal, but there is consensus, by law enforcement agencies, healthcare practitioners, and patient advocates alike, that it should not hinder patients' ability to receive the care they need and deserve."*

This consensus agreement goes on to enumerate the following facts.

- Undertreatment of pain is a serious problem in this country.
- For many patients opioid analgesics are the most effective and often the only treatment that provides significant relief.
- Opioids are controlled substances and necessarily regulated.
- Drug abusers obtain these medications by diversion.
- Abuse is a serious problem, but focusing only on abuse could erroneously lead to the conclusion that these medicines should be avoided when indicated—generating a sense of fear rather than respect for their legitimate properties.
- Awareness of both use and abuse will enable all of us to make proper and wise decisions regarding the treatment of pain."[13]

Similarly, state medical boards have issued statements to reassure healthcare professionals that they need not fear sanctions for adequate symptom management of seriously ill patients. In fact, just the opposite is true; physicians have been sanctioned for *undertreatment* of pain at the end of life. The North Carolina Boards of Medicine, Nursing, and Pharmacy issued a Joint Statement on Pain Management in End-of-Life Care, adopted on October 21, 1999 that serves as a model for other states.[14] This statement in part reads,

> *"The Medical Board will assume opioid use in such patients is appropriate if the responsible physician is familiar with and abides by acceptable medical guidelines regarding such use, is knowledgeable about effective and compassionate pain relief, and maintains an appropriate medical record that details a pain management plan."*

The physician's fiduciary responsibility to treat pain at the end-of-life is abundantly clear. These statements serve as excellent guidelines to proceed with effective pain management. As long as physicians carefully follow the tenets of appropriate prescribing within an established doctor/patient relationship, we needn't fear regulatory or legal consequences.

Choose

A pain specialist once shared that effective pain management at the end of life was really quite simple. It comes down to using aspirin and/or opioids. There are a myriad of other potential interventions available including adjuvant medication, surgery, radiation, chemotherapy, central nervous system anesthesia, and even complementary modalities. For the vast majority of patients, pharmacologic therapy with aspirin and/or opioids will do the job. Of course aspirin means the broader class of nonsteroidal anti-inflammatory drugs (NSAIDS). And opioids means a thorough understanding of a number of appropriate opioids used at the right dose, in the right dosing form, at the right time, and by the right route. While NSAIDS have a role in pain management at the end of life, for the large numbers of patients with moderate-to-severe pain, opioids are the mainstay of pharmacologic therapy.

There is little doubt that the most important barriers to effective pain management at the end of life are poor assessment and inadequate utilization of opioid medication.[3] "Inadequate utilization" does not assign blame, but refers to a major problem with education and attitude about opioid medications. This is not just a patient or physician problem, it is everyone's problem —nurse, pharmacist, family, friend, pastor, or volunteer. We all share inadequate education and inappropriate attitudes about opioid medication.

Pain and palliative care specialists speak frequently about morphine myths. These are generally held ideas about opioids that have grown to mythic proportion without much substantial proof as to their existence. These misconceptions interfere with the appropriate utilization of opioids and include undue concerns about addiction, tolerance, and uncontrollable side effects like euphoria, vomiting, constipation, sedation and respiratory depression. Numerous studies have shown that the more firmly held the myth, the more noncompliant the patient will be with their pain regimen.[15] Patients who fear addiction resulting from simply utilizing opioids are unlikely to take them as prescribed. Likewise patients who are afraid that tolerance will develop if they start taking opioids early in the course of their disease, rather than "saving" them for when their pain gets "really bad," are unlikely to take medication appropriately. Healthcare providers must assume that these issues are on the minds of most patients as they write an initial prescription for an opioid medication and ensure appropriate education to explore and dispel the myths.

Perhaps more surprising is how these same myths affect physician attitudes about pain and opioids. A remarkable study done here in North Carolina[16] confirmed the findings of others and demonstrated widespread misconceptions among physicians about pain and opioid medications. In one study,[17] 51% of physicians felt that tolerance to opioids was a significant problem and limited their ability to control pain. Most experts would agree that most of the time tolerance is not a clinical issue. Increasing pain means an increase in cancer-related disease processes and can be relieved by increasing opioid doses and/or other measures. On the other hand, 39% of physicians felt that intolerance to adverse effects of opioids made it difficult to control pain. Interestingly, most patients become tolerant of common side effects of opioids (except for constipation), but not to their analgesic effects. An alarming 20% of these physicians felt addiction was a problem for cancer patients treated with opioids and 19% felt poorly controlled pain was inevitable in advanced cancer.

While a detailed review of specific pharmacologic treatment strategies and recommendations is beyond the scope of this article, many monographs and guidelines are readily available. The American Pain Society has recently published the fifth edition of a remarkable pocket-sized set of guidelines for both acute and cancer pain,[18] which can be ordered at http://www.ampainsoc.org/pub/principle.htm. The American Academy of Hospice and Palliative Medicine also publishes a pocket guide to palliative care with up-to-date recommendations covering both pain and a wide range of other end-of-life care issues.[19] The American Geriatrics Society has recently reissued guidelines for pain management in older persons.[20] All of these resources are clear that opioids may well be both the safest and most effective treatment strategy for persons with serious pain at the end of life. All physicians should be familiar with basic opioid pharmacology, dosing strategies, and the role of common adjuvant medications. In addition, physicians must be knowledgeable about resources and pain consultants available in their communities when pain becomes difficult to control.

> *"Indeed, methadone is probably the ideal opioid in end-of-life care."*

Unfortunately, in a distinct minority of patients, pain isn't nearly as difficult to control as the patient and/or their family. Some patients abuse their opioids, and some families divert patients' medications. Physicians must be thoughtful, careful practitioners willing to confront these possibilities and engage the assistance of specialists who commonly deal with these challenging circumstances. Pain clinics often employ effective strategies, like contracting, to deal with these circumstances.[21] Engaging local DEA authorities may even become necessary to ensure both patient and public protection. *Tolerance* may truly be the issue in patients with a history of opioid abuse. These patients are often *tolerant* of opioid medication, in*tolerant* of both physical and emotional pain, and clearly try the *tolerance* of their healthcare providers.

Deliver

Pain interventions should be delivered in a timely, logical, and coordinated fashion. A thorough understanding of the pharmacology of opioids and other medications is essential for good pain management at the end of life. For example, many physicians dose oral opioids every four hours as needed for pain. However, for patients in pain crisis a more aggressive strategy is indicated. Since oral opioids reach maximum serum concentration within an hour, peak effects and peak side effects also occur in that time frame. As long as adverse effects of sedation or respiratory depression aren't observed, additional medication, including breakthrough doses, can be administered every one to two hours.

Similarly aggressive parenteral dosing strategies exist for patients in pain crisis presenting for inpatient care. One such successful strategy describes a dose doubling every thirty minutes.[22] In this study, cancer pain patients already on opioids as outpatients presented for emergent admission with intense pain sustained for at least six hours and escalating over days. Appropriate to their outpatient opioid dose, patients received 10-20 mg of morphine intravenously over 15 minutes. If inadequate relief and no adverse effects were observed 15 minutes later, the dose was doubled and the process repeated every 30 minutes. Satisfactory pain control without adverse events was achieved in a mean time frame of 90 minutes for all patients.

In a similar study, cancer pain patients were treated with one milligram of morphine per minute for 10 minutes, which could be repeated after five minutes if there was no relief.[23] The goal in this study was also similar; to achieve adequate relief (< 5 pain score) not necessarily with complete relief, but without excess sedation or respiratory depression. In this study, the maximum dose was 30 milligrams over 45 minutes. None of their patients required this high a dose. Once relief was achieved, an hourly dose was calculated at approximately one-third to one-fourth of the loading dose.

Both of these studies depend on a clear understanding of opioid pharmacology. Both were also done in an inpatient setting, with experienced personnel, aware of, and prepared for adverse consequences. Nevertheless, innovative or "best-practice" models like this should be carefully reviewed, adapted and adopted in settings where poor pain control is likely to be encountered and effective pain management expected by patient, family, and providers.

A broader view of delivering interventions in a timely, logical and coordinated fashion suggests taking a harder look at what patients and their families need to achieve pain control. A recent review[24] suggests seven areas of difficulty in putting a pain regimen into practice. The primary difficulty is the cost of medication, but also of major concern are accessing information about the medication, tailoring the prescription to meet individual needs, and managing side effects like constipation. Anticipating these concerns is highly likely, and addressing them with all patients will clearly improve pain management. If opioid cost is an issue, methadone must be an option. While methadone has complex dosing problems and should only be prescribed by those thoroughly familiar with them, oral methadone costs only about a penny per milligram. Topical fentanyl patches for severe pain at 150mcg/hour applied every 72 hours may cost as much as $30/day, whereas an equianalgesic dose of methadone may cost as little as 45 cents/day. In addition, methadone has very specific analgesic properties that make it a more potent and effective opioid for complex, chronic cancer pain. Recent reviews of methadone[25] are essential reading for any practitioner providing care for patients with significant pain at the end of life. Indeed, methadone is probably the ideal opioid in end-of-life care.[26]

Empower and Enable

Unrelieved pain is incapacitating, interfering with the ability to eat, sleep, interact with others, and achieve a satisfactory quality of life.[3] Healthcare providers need to empower patients and their families and enable them to control their course to the greatest extent possible. Information is power. Resources abound to provide patients and their families with information with which they can better manage pain at the end of life. From drug companies[27] to end-of-life care advocacy groups,[1] print and Internet resources are readily available. Hospices cover every square inch of North Carolina and probably the entire continental United States. Palliative care services exist in many hospitals and all regions of the country. Both are committed to effective pain management. Use your local hospice and consult your palliative care service.

JCAHO standards, at least the pain control standards, are terrific guidelines and are the rules we must live by in many settings. As much as we often rebel against "have to" standards, these are worth embracing and implementing. Most guidelines and standards "suggest" that institutions should promise excellent pain control, express it clearly in statements of patient's rights and responsibilities, and put mechanisms in place to live up to the promise. One such statement reads,

"As a patient at Rockford Memorial Hospital, you can expect:

- Information about pain and pain relief measures.
- A concerned staff committed to pain prevention.
- Health professionals who respond quickly to reports of pain.
- State-of-the-art pain management.
- Dedicated pain relief specialists.
- Pain expressions will be believed.

As a patient at Rockford Memorial Hospital, we expect that you will:

- Ask your doctor or nurse what to expect.
- Discuss pain relief options with your doctors and nurses.
- Work with you doctor and nurse to make a pain relief plan.
- Ask for pain relief drugs when pain first begins.
- Help the doctor and nurse measure your pain.
- Tell the doctor or nurse about any pain that will not go away.
- Not worry about getting "hooked" on pain medication."[28]

This may not be the exact statement our institutions choose, but it is a great place to start. Individual and organizational commitment to pain relief is truly powerful. Education, attitude, passion, and compassion will overcome all of the barriers to adequate pain relief at the end of life, fulfilling our promise as concerned healthcare providers. **NCMJ**

> *"Paradoxically, healthcare providers are expecting patients to complain, while patients are waiting for their provider to ask."*

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A JOINT STATEMENT FROM 21 HEALTH ORGANIZATIONS AND THE DRUG ENFORCEMENT ADMINISTRATION

Promoting Pain Relief and Preventing Abuse of Pain Medications: A Critical Balancing Act

As representatives of the health care community and law enforcement, we are working together to prevent abuse of prescription pain medications while ensuring that they remain available for patients in need.

Both healthcare professionals, and law enforcement and regulatory personnel, share a responsibility for ensuring that prescription pain medications are available to the patients who need them and for preventing these drugs from becoming a source of harm or abuse. We all must ensure that accurate information about both the legitimate use and the abuse of prescription pain medications is made available. The roles of both health professionals and law enforcement personnel in maintaining this essential balance between patient care and diversion prevention are critical.

Preventing drug abuse is an important societal goal, but there is consensus, by law enforcement agencies, health care practitioners, and patient advocates alike, that it should not hinder patients' ability to receive the care they need and deserve.

This consensus statement is necessary based on the following facts:

◆ Undertreatment of pain is a serious problem in the United States, including pain among patients with chronic conditions and those who are critically ill or near death. Effective pain management is an integral and important aspect of quality medical care, and pain should be treated aggressively.

◆ For many patients, opioid analgesics – when used as recommended by established pain management guidelines – are the most effective way to treat their pain, and often the only treatment option that provides significant relief.

◆ Because opioids are one of several types of controlled substances that have potential for abuse, they are carefully regulated by the Drug Enforcement Administration and other state agencies. For example, a physician must be licensed by State medical authorities and registered with the DEA before prescribing a controlled substance.

◆ In spite of regulatory controls, drug abusers obtain these and other prescription medications by diverting them from legitimate channels in several ways, including fraud, theft, forged prescriptions, and via unscrupulous health professionals.

◆ Drug abuse is a serious problem. Those who legally manufacture, distribute, prescribe and dispense controlled substances must be mindful of and have respect for their inherent abuse potential. Focusing only on the abuse potential of a drug, however, could erroneously lead to the conclusion that these medications should be avoided when medically indicated – generating a sense of fear rather than respect for their legitimate properties.

◆ Helping doctors, nurses, pharmacists, other healthcare professionals, law enforcement personnel and the general public become more aware of both the use and abuse of pain medications will enable all of us to make proper and wise decisions regarding the treatment of pain.

American Academy of Family Physicians

American Academy of Hospice and Palliative Medicine

American Academy of Pain Medicine

American Alliance of Cancer Pain Initiatives

American Cancer Society

American Medical Association

American Pain Foundation

American Pain Society

American Pharmaceutical Association

American Society of Anesthesiologists

American Society of Law, Medicine & Ethics

American Society of Pain Management Nurses

American Society of Regional Anesthesia and Pain Medicine

Community-State Partnerships to Improve End-of-Life Care

Drug Enforcement Administration

Last Acts

Midwest Bioethics Center

National Academy of Elder Law Attorneys

National Hospice and Palliative Care Organization

Oncology Nursing Society

Partnership for Caring, Inc.

University of Wisconsin Pain & Policy Studies Group

Addressing Pain Management and Palliative Care:

The Official Position of the North Carolina Medical Board

Charles E. Trado, MD, FAPA

Dr. Hanson has addressed the subject of palliative care in end-of-life situations, expertly documenting the definitions, statistics, and strategies for dealing with such care.[1] She has made notable references to these issues as confronted by North Carolinians, references that will prove educational to physicians, nurses, and other healthcare providers in our state. It is comforting to know that we in North Carolina are attending to this important issue with some institutional awareness and program implementation such as the Pain and Symptom Care Program at UNC Hospitals. Obviously more needs to be done by our statewide medical community.

Palliative care is a comprehensive approach to end-of-life issues and all aspects of this care need be addressed as discussed by Dr. Hanson. Alleviation of suffering should be a major goal of healthcare providers and should include not only the physical, but also the psychological, spiritual, emotional, and family suffering that takes place in this difficult life situation.

I would direct your attention to the physical suffering that dying patients more often than not experience. For at least the last 10-to-15 years the medical community has been made aware that adequate pain management in the dying patient has been a continuing problem. It has been reported in several studies over the years that 25-to-30% of cancer patients suffer severe pain and 40-to-50% suffer moderate to severe pain. This despite the fact that 90% of cancer pain can be relieved with current pain management protocols. One such protocol is presented comprehensively in The Clinical Practice Guideline, "Management of Cancer Pain," published by the Agency for Healthcare Research and Quality (AHRQ).[2] This publication is readily available to professionals and to the public alike from AHRQ. This is only one of many resources available to help us address this ongoing problem.

Hospice, introduced to this country in the 1970's, alerted our medical community to the need for sensible pain control in the dying patients and, even in its rudimentary protocols, opened our eyes and minds to the unmet needs of our patients. Palliative care programs will take us another important step in the right direction through its comprehensive approach.

But, as noted above, we are still not doing a good enough job in overall pain management. We can't lay the blame for our shortcomings in this area entirely on the medical community. Patients have every right to refuse adequate pain control even if that refusal is based upon faulty beliefs or assumptions. Many patients see themselves as weak or certainly non-heroic if they "give in" and use medication to control their pain. Others fear that using any kind of pain reliever will identify them as an "addict" to the public and to family members. Others fear that pain relievers have such mysterious power that they will automatically be addicted by the first dose. For patients who think and feel this way, the medical community needs to put more effort into assuaging their fears and improving their understanding of the proper and appropriate use of these medications.

> *"...substance abuse in this country has little or nothing to do with the proper practice of pain management in palliative and end-of-life care. Studies indicate that only approximately one to four percent of patients are addicted iatrogenically."*

Unfortunately, patients are not the only ones either misinformed or under educated about this issue. Too many, but thankfully not a majority, of physicians hold outdated and or prejudicial views about the use of pain relievers. Many of those views mirror those held by patients. As younger physicians who

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have more current and focused training in pain management become the majority care givers in our communities, this problem should continue to ameliorate.

Physician pain specialists and formal, structured pain treatment centers have afforded our patients up-to-date, comprehensive approaches to pain management. These highly trained specialists and their treatment teams tend, by necessity, to deal with outpatients who experience a full range of acute and chronic pain symptoms. All modalities of treatment are considered and applied with the goal of adequate pain relief for the patient in the safest and least noxious manner.

However, it is my observation that pain-treatment centers have to be preoccupied with the specific population mentioned above and do not routinely become involved with the dying patient. I mention this not to be critical, but to suggest that those who are taking care of the dying patient not overlook these valuable specialty programs and consultations when appropriate. This, too, in my opinion, should be part of a comprehensive palliative care program for our patients.

If it is true that some of our medical community, specifically physicians, either are improperly trained or inordinately under informed or incomprehensibly prejudiced with regard to appropriate pain management, then what, if anything, can or should be done about the problem? Please note that I said "some" of our physicians, not a majority, fall into this category. Also note that this minority of physicians have charge of the treatment of a significant number of dying patients and thereby influence decisions about their palliative care.

> *"Facilitating a 'good death' is what any humane and civilized society must demand for its citizens."*

What can be done to help these physicians practice pain management according to more currently acceptable guidelines? In the mid-1990s, the North Carolina Medical Board, while trying to deal with "over-prescribing" of pain medication by some physicians, observed that these same medications were being "under-prescribed" by other physicians. There was a heightened awareness of the inadequacy of pain treatment prevalent in the country at that time and the Board examined the findings of several studies of this issue. It discovered that many physicians were afraid to prescribe adequate pain relief, especially opioids, for fear of being sanctioned by the Board. This was the state of affairs at that time, not only in North Carolina but throughout the nation, which led to national debate among licensing and disciplinary boards about what position boards should take in the matter.

The North Carolina Medical Board elected to write and publish a "position statement" on the topic for the purpose of letting physicians know about the problem, to educate physicians about the kind of protocol to follow in using these medications, and hopefully to help alleviate fears of being sanctioned by the Board for prescribing these medications appropriately. Reassurance to physicians was provided in the following paragraph taken from the position statement:

> *"No physician need fear reprisals from the North Carolina Medical Board for appropriately prescribing as described above, even large amounts of controlled substances indefinitely for chronic non-malignant pain."*

The last paragraph of the statement is as follows:

> *"Nothing in this statement should be construed as advocating the imprudent use of controlled substances."*

The entire position statement by the North Carolina Medical Board is meant to address what we felt might be an impediment to proper pain management by North Carolina physicians and is especially applicable to formal palliative care programs and caregivers.

It is generally accepted that we have a drug problem in this country, and that citizens hold strong and varied opinions about what should be done about the problem. These strong and diverse opinions can and, in some instances do, have an impact upon pain management decisions made by caregivers.

In my opinion, substance abuse in this country has little or nothing to do with the proper practice of pain management in palliative and end-of-life care. Studies indicate that only approximately one to four percent of patients are addicted iatrogenically.[1] If caregivers have any role to play in the "drug problem" it is likely to be in the area of diversion of prescription drugs for illicit sale and use by recreational drug users and hardcore addicts. The latter group will find their supply by whatever means possible, and their addictive behavior should not be allowed to compromise quality of care for any of our patients, especially those in a palliative care program.

End-of-life issues have rightfully captured our attention and demand continued study by our profession. We are miles from where we were just a few decades ago and articles such as Dr. Hanson's will help point the way to the future of this important life event. A good life is what we all wish for our loved ones. Facilitating a "good death" is what any humane and civilized society must demand for its citizens. **NCMJ**

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North Carolina Medical Board Position Statement on
MANAGEMENT OF CHRONIC NON-MALIGNANT PAIN

It has become increasingly apparent to physicians and their patients that the use of effective pain management has not kept pace with other advances in medical practice. There are several factors that have contributed to this. These include a history of relatively low priority given to pain management in our healthcare system, the incomplete integration of current knowledge in medical education and clinical practice, a scarcity of practitioners specifically trained in pain management, and the fear of legal consequences when controlled substances are used—fear shared by physician and patient. There are three general categories of pain.

Acute Pain is associated with surgery, trauma, and acute illness. It has received its share of attention by physicians. Its treatment by various means is widely accepted by patients, and it has been addressed in guidelines issued by the Agency for Health Care Policy and Research (AHCPR) [now the Agency for Healthcare Research and Quality (AHRQ)] of the United States Department of Health and Human Services.

Cancer Pain has been receiving greater attention and more enlightened treatment by physicians and patients, particularly since development of the hospice movement. It has also been addressed in AHCPR/AHRQ guidelines.

Chronic Non-Malignant Pain is often difficult to diagnose, often intractable, and often under-treated. It is the management of chronic non-malignant pain on which the North Carolina Medical Board wishes to focus attention in this position statement.

The North Carolina Medical Board recognizes that many strategies exist for treating chronic non-malignant pain. Because such pain may have many causes and perpetuating factors, treatment will vary from behavioral and rehabilitation approaches to the use of a number of medications, including opioids. Specialty groups in the field point out that most chronic non-malignant pain is best managed in a coordinated way, using a number of strategies in concert. Inadequate management of such pain is not uncommon, however, despite the availability of safe and effective treatments.

The Board is aware that some physicians avoid prescribing controlled substances such as opioids in treating chronic non-malignant pain. While it does not suggest those physicians abandon their reservations or professional judgment about using opioids in such situations, neither does the Board wish to be an obstacle to proper and effective management of chronic pain by physicians. It should be understood that the Board recognizes opioids can be an appropriate treatment for chronic pain.

It is the position of the North Carolina Medical Board that effective management of chronic pain should include:

- thorough documentation of all aspects of the patient's assessment and care;
- a thorough history and physical examination, including a drug and pain history;
- appropriate studies;
- a working diagnosis and treatment plan;
- a rationale for the treatment selected;
- education of the patient;
- clear understanding by the patient and physician of methods and goals of treatment;
- a specific follow-up protocol, which must be adhered to;
- regular assessment of treatment efficacy;
- consultation with specialists in pain medicine, when warranted; and
- use of a multidisciplinary approach, when indicated.

The Board expects physicians using controlled substances in the management of chronic pain to be familiar with conditions such as:

- physical dependence;
- respiratory depression and other side effects;
- tolerance;
- addiction; and
- pseudo addiction.

There is an abundance of literature available on these topics and on the effective management of pain. The physician's knowledge should be regularly updated in these areas.

No physician need fear reprisals from the Board for appropriately prescribing, as described above, even large amounts of controlled substances indefinitely for chronic non-malignant pain.

Nothing in this statement should be construed as advocating the imprudent use of controlled substances.

(Adopted 9/13/96)

North Carolina Medical Board Position Statement on
END-OF-LIFE RESPONSIBILITIES AND PALLIATIVE CARE

Assuring Patients

Death is part of life. When appropriate processes have determined that the use of life-sustaining or invasive interventions will only prolong the dying process, it is incumbent on physicians to accept death "not as a failure, but the natural culmination of our lives."*

It is the position of the North Carolina Medical Board that patients and their families should be assured of competent, comprehensive palliative care at the end of their lives. Physicians should be knowledgeable regarding effective and compassionate pain relief, and patients and their families should be assured such relief will be provided.

Palliative Care

There is no one definition of palliative care, but the Board accepts that found in the *Oxford Textbook of Palliative Medicine*: "The study and management of patients with active, progressive, far advanced disease for whom the prognosis is limited and the focus of care is the quality of life." This is not intended to exclude remissions and requires that the management of patients be comprehensive, embracing the efforts of medical clinicians and of those who provide psychosocial services, spiritual support, and hospice care.

A physician who provides palliative care, encompassing the full range of comfort care, should assess his or her patient's physical, psychological, and spiritual conditions. Because of the overwhelming concern of patients about pain relief, special attention should be given to the effective assessment of pain. It is particularly important that the physician frankly, but sensitively, discuss with the patient and the family their concerns and choices at the end of life. As part of this discussion, the physician should make clear that, in some cases, there are inherent risks associated with effective pain relief in such situations.

Opioid Use

The Board will assume opioid use in such patients is appropriate if the responsible physician is familiar with and abides by acceptable medical guidelines regarding such use, is knowledgeable about effective and compassionate pain relief, and maintains an appropriate medical record that details a pain management plan. (See the Board's position statement on the Management of Chronic Non-Malignant Pain for an outline of what the Board expects of physicians in the management of pain.) Because the Board is aware of the inherent risks associated with effective pain relief in such situations, it will not interpret their occurrence as subject to discipline by the Board.

Selected Guides

To assist physicians in meeting these responsibilities, the Board recommends *Cancer Pain Relief: With a Guide to Opioid Availability, 2nd ed* (1996), *Cancer Pain Relief and Palliative Care* (1990), *Cancer Pain Relief and Palliative Care in Children* (1999), and *Symptom Relief in Terminal Illness* (1998), (World Health Organization, Geneva); *Management of Cancer Pain* (1994), (Agency for Health Care Policy and Research, Rockville, MD); *Principles of Analgesic Use in the Treatment of Acute Pain and Cancer Pain*, 4th Edition (1999)(American Pain Society, Glenview, IL); *Hospice Care: A Physician's Guide* (1998) (Hospice for the Carolinas, Raleigh); and the *Oxford Textbook of Palliative Medicine* (1993) (Oxford Medical, Oxford).

(Adopted 10/1999)

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*Steven A. Schroeder, MD, President, Robert Wood Johnson Foundation.

RELATED STATEMENT

Joint Statement on Pain Management in End-of-Life Care

(Adopted by the North Carolina Medical, Nursing, and Pharmacy Boards)

Through dialogue with members of the healthcare community and consumers, a number of perceived regulatory barriers to adequate pain management in end-of-life care have been expressed to the Boards of Medicine, Nursing, and Pharmacy. The following statement attempts to address these misperceptions by outlining practice expectations for physicians and other healthcare professionals authorized to prescribe medications, as well as nurses and pharmacists involved in this aspect of end-of-life care. The statement is based on:

- the legal scope of practice for each of these licensed health professionals;
- professional collaboration and communication among health professionals providing palliative care; and
- a standard of care that assures on-going pain assessment, a therapeutic plan for pain management interventions; and evidence of adequate symptom management for the dying patient.

It is the position of all three Boards that patients and their families should be assured of competent, comprehensive palliative care at the end of their lives. Physicians, nurses, and pharmacists should be knowledgeable regarding effective and compassionate pain relief, and patients and their families should be assured such relief will be provided.

Because of the overwhelming concern of patients about pain relief, the physician needs to give special attention to the effective assessment of pain. It is particularly important that the physician frankly, but sensitively, discuss with the patient and the family their concerns and choices at the end of life. As part of this discussion, the physician should make clear that, in some end-of-life care situations, there are inherent risks associated with effective pain relief. The Medical Board will assume opioid use in such patients is appropriate if the responsible physician is familiar with, and abides by, acceptable medical guidelines regarding such use, is knowledgeable about effective and compassionate pain relief, and maintains an appropriate medical record that details a pain management plan. Because the Board is aware of the inherent risks associated with effective pain relief in such situations, it will not interpret their occurrence as subject to discipline by the Board.

With regard to pharmacy practice, North Carolina has no quantity restrictions on dispensing controlled substances including those in Schedule II. This is significant when utilizing the federal rule that allows the partial filling of Schedule II prescriptions for up to 60 days. In these situations it would minimize expenses and unnecessary waste of drugs if the prescriber would note on the prescription that the patient is terminally ill and specify the largest anticipated quantity that could be needed for the next two months. The pharmacist could then dispense smaller quantities of the prescription to meet the patient's needs up to the total quantity authorized. Government-approved labeling for dosage level and frequency can be useful as guidance for patient care. Health professionals may, on occasion, determine that higher levels are justified in specific cases. However, these occasions would be exceptions to general practice and would need to be properly documented to establish informed consent of the patient and family.

Federal and state rules also allow the fax transmittal of an original prescription for Schedule II drugs for hospice patients. If the prescriber notes the hospice status of the patient on the faxed document, it serves as the original. Pharmacy rules also allow the emergency refilling of prescriptions in Schedules III, IV, and V. While this does not apply to Schedule II drugs, it can be useful in situations where the patient is using drugs such as Vicodin for pain or Xanax for anxiety.

The nurse is often the health professional most involved in on-going pain assessment, implementing the prescribed pain management plan, evaluating the patient's response to such interventions, and adjusting medication levels based on patient status. In order to achieve adequate pain management, the prescription must provide dosage ranges and frequency parameters within which the nurse may adjust (titrate) medication in order to achieve adequate pain control. Consistent with the licensee's scope of practice, the RN or LPN is accountable for implementing the pain management plan utilizing his/her knowledge base and documented assessment of the patient's needs. The nurse has the authority to adjust medication levels within the dosage and frequency

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ranges stipulated by the prescriber and according to the agency's established protocols. However, the nurse does not have the authority to change the medical pain management plan. When adequate pain management is not achieved under the currently prescribed treatment plan, the nurse is responsible for reporting such findings to the prescriber and documenting this communication. Only the physician or other health professional with authority to prescribe may change the medical pain management plan.

Communication and collaboration between members of the healthcare team, and the patient and family are essential in achieving adequate pain management in end-of-life care. Within this interdisciplinary framework for end-of-life care, effective pain management should include:

- thorough documentation of all aspects of the patient's assessment and care;
- a working diagnosis and therapeutic treatment plan including pharmacologic and non-pharmacologic interventions;
- regular and documented evaluation of response to the interventions and, as appropriate, revisions to the treatment plan;
- evidence of communication among care providers;
- education of the patient and family; and
- a clear understanding by the patient, the family, and healthcare team of the treatment goals.

It is important to remind health professionals that licensing boards hold each licensee accountable for providing safe, effective care. Exercising this standard of care requires the application of knowledge and skills, as well as ethical principles, focused on optimum patient care while taking all appropriate measures to relieve suffering. The healthcare team should give primary importance to the expressed desires of the patient tempered by the judgment and legal responsibilities of each licensed health professional as to what is in the patient's best interest.

(10/1999)

Both of these statements can be found on the North Carolina Medical Board web site at http://www.ncmedboard.org/pos2.htm.

Guiding the Decisions of Physicians and Families in End-of-Life Care:

The Case of Long-Term Feeding Tube Placement

Ethical and Judicial Affairs Committee, North Carolina Medical Society

The issue of long-term feeding tube placement for patients near the end of life who are unable to make decisions with regard to their own care is a complex issue for physicians and families. There is controversy about how appropriate the placement of percutaneous endoscopy gastrostomy (PEG) tubes might be in specific cases, and physicians have felt a need for clearer guidelines for their use. Consequently, the North Carolina Academy of Family Physicians asked that the 2001 House of Delegates of the North Carolina Medical Society (NCMS) undertake efforts to educate policymakers about the inappropriate use of long-term feeding tubes and to seek and support legislative and/or administrative actions supporting the adoption of the following language into law:

"Before placement of any long-term feeding tube, in a mentally incompetent patient, the hospital or nursing home ethics committee (whichever is appropriate) would have to review the case and render a non-binding written opinion. This opinion would have to be presented to the responsible parties. The rationale for this non-binding opinion would have to be explained to the responsible parties in easily understood layman's terms."

Resolution 1-2001 was referred for study to the Ethical and Judicial Affairs Committee of the NCMS, whose members undertook to develop an educational statement for physicians about the efficacy of long-term feeding tubes and then to convene a larger task force that would include representatives from external interest groups to develop a consensus on the statement.

> *"Tube feeding does not necessarily provide medical benefit to the dying patient by enhancing quality of life nor by reducing suffering."*

A subcommittee was appointed and charged with developing a set of guidelines for physicians. The committee members were: Janelle Rhyne, MD, Chair; Darlyne Menscer, MD; Glenn Pickard, MD; Douglas Nelson, MD; Richard Stephenson, MD; and Lance Stell, PhD. The subcommittee met a number of times and produced a draft statement in the summer of 2003.

Given the sensitivity of the subject matter and the central role of patients and their families or loved ones in deciding whether a long-term feeding tube should be placed, the subcommittee also decided to promote the importance of patient and family education.

A task force, which included the subcommittee as well as representatives from nursing homes, hospitals, hospice, home health, elder law, speech pathology, the Medical Directors Association, was convened in September 2003. Members of the task force agreed that educational information was definitely needed on this issue for providers and patients alike. After significant discussion, the task force approved the following draft with some modifications. The task force also agreed that educational pieces for patients and their families should be promoted. The statement was subsequently approved by the House of Delegates of the North Carolina Medical Society in November 2003 and is presented here with the hope that it will be of value to physicians and families struggling with these issues in the care of patients and family members in these complex situations. **NCMJ**

Long-Term Feeding Tubes: Ethical Issues in Physicians' Decision Making

Statement Adopted by the North Carolina Medical Society House of Delegates, November 2001

When a decisionally incapable patient who suffers from a chronic, progressive illness develops swallowing difficulty, physicians, families, nurses, and other care providers have, with increasing frequency, elected non-oral nutritional support. However, recently accumulated outcome data make dubious a reflexive decision in favor of tube feeding in this setting.

- Feeding tube placement is associated with an in-hospital mortality of 15-25%, and a one-year mortality of 60%.
- Co-factors associated with increased risk of mortality include: advanced age, CNS pathology (CVA, advanced dementia), cancer (except early stage head/neck cancer), disorientation, and low albumin.
- Aspiration occurs in up to 50% of patients being tube fed.
- For patients with advanced dementia, feeding tubes have not proven effective in prolonging life, in preventing aspiration, or even in providing adequate nourishment.[1]

David Weissman, MD, has outlined the *tube feeding death spiral*:[2]

1. Hospital admission for complications secondary to brain failure or other predictable end organ failure due to primary illnesses (e.g. Urosepsis in the setting of advanced dementia)
2. Inability to swallow documented and/or direct evidence of aspiration and/or weight loss associated with low or no p-o (by mouth) intake
3. Swallowing evaluation followed by a recommendation for nonoral feeding.
4. Feeding tube placed followed by increasing patient agitation, resulting in feeding tube dislodgement.
5. Re-insertion of feeding tube; restraints placed.
6. Aspiration pneumonia
7. Intravenous antibiotics and pulse oximetry.
8. Repeat steps 4-6 two or more times.
9. Family conference.
10. Death

- The specter of aggressive, over-treatment was a major factor motivating the patients' rights movement.
- Legal and ethical standards have been developed to support an informed decision to withhold or withdraw any medical intervention, including tube feeding.[3]
- North Carolina does not prejudice with unique restrictions the medical decision of whether or not to place a feeding tube.
- There is no ethical or legal warrant for the physician to evaluate differently a decision to withdraw tube feeding from a decision to withhold tube feeding.[4]
- Advance care directives, such as living wills, healthcare powers of attorney, etc., enable decisionally capable patients to anticipate and plan for the contingency of losing their ability to communicate healthcare decisions, including a decision whether to withhold or withdraw tube feeding.
- Persons authorized to give informed consent to feeding tube placement on a patient's behalf may also make an ***informed refusal*** of tube placement.
- In the absence of advance care directives, a surrogate's decisions regarding feeding tube placement or removal should be based, whenever possible, on what the patient would choose in the circumstances. Otherwise, the surrogate's decisions should be guided by considering the patient's best interests.

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The physician should not bias a discussion of the pros and cons of tube feeding with an implicit assumption that nursing home residents would prefer tube feeding in the event they cannot swallow. On the contrary:

- A study of 421 randomly selected, competent persons living in 49 nursing homes found that only one-third would favor feeding tube placement if they were unable to eat because of permanent brain damage. Sixty-one percent opposed tube feeding. Of those who initially favored tube placement, 25% changed their preference when they learned that physical restraints might be necessary to facilitate feeding tube use.[5]
- The desire for tube feeding decreases as the hypothetical degree of cognitive impairment increases.[6]

Tube feeding does not necessarily provide medical benefit to the dying patient by enhancing quality of life nor by reducing suffering.

- Tube feeding is associated with increased agitation and may reduce quality of life and dignity because it increases the need for physical restraints;[7]
- Typically, dying patients do not experience hunger or thirst;
- Malnutrition, a concomitant of the natural dying process, should not be confused with "starvation";
- While dry mouth commonly occurs in dying patients, tube feeding does not relieve it;
- Complete relief from symptoms associated with dry mouth may be achieved with ice chips, moist sponge, sips of liquid, lip moisteners, hard candy, and mouth care."[8]

Recommendations:

- Prior to feeding tube placement in a decisionally incapable patient, it is the physician's ethical responsibility to determine whether the patient has executed an advance directive whose provisions may apply to the placement decision. Otherwise, the physician should take the lead in discussing with the patient's surrogate decision maker the pros and cons of long-term tube feeding.
- The physician should be prepared to address the common tendency to confuse "malnutrition" (a concomitant of the natural dying process) and "starvation."
- The physician should relate decisions about tube feeding +/- to achievable goals of care. A summary of discussions regarding tube feeding should be documented in the medical record.
- The goals of care should be reviewed regularly to determine whether, or to what degree, tube feeding promotes or contradicts them.
- Consultation with hospice or with a palliative care service facilitates setting realistic goals of care.
- Since tube feeding has not proven beneficial in patients with advanced dementia, but on the contrary, is associated with significant increased morbidity, mortality, and indignity, physicians may, in good conscience, recommend that it be withheld or withdrawn in these circumstances.
- In the event a valid decision is made to forego tube feeding, the physician should enter in the patient's medical record an order "Do Not Tube Feed."
- Patients who are genuinely hungry should be allowed to eat anything they please.

This document was written with adult patients in mind; issues facing pediatric patients were not discussed by the authors and are not addressed herein.

FEEDING TUBES—continued on page 245

FEEDING TUBES—continued from page 244

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Current End-of-life Issues:
A Practicing Physician's View

Phillip A. Sellers, MD

As a third-year internal medicine resident in the 1960s, I visited the small North Carolina Cancer Hospital in Lumberton, NC. To my amazement patients received no blood transfusions or nutritional supplementation; the only medication provided was morphine for pain. With my newly developed and up-to-date scientific knowledge about how to prolong life, I was disturbed by the predominant treatment philosophy in this facility. This was not the standard of care accepted by the medical community at that time, or now. Over the last 40 years, however, a new set of concepts has gradually been accepted by the healthcare delivery system and, more importantly, by most of the public.

End-of-life health policies have been slow to evolve. Living wills, healthcare power of attorney documents, Do-Not-Resuscitate (DNR) orders, as well as the so-called "yellow sheet" DNRs have all been made legal by the North Carolina General Assembly. The use of feeding tubes increased rapidly, but has now receded after studies have shown that feeding tubes used in the chronically ill are not as beneficial as we originally thought.[1] It is now clearly recognized that IV fluids and "hydration" are not indicated at the end of life. Dehydration and malnutrition do not cause symptoms or discomfort. The passing is easy. As the old-time practitioner always knew, pneumonia and infection frequently can be "the dying person's friend." Antibiotics may be contraindicated at the end.

The above changes include both good and bad concepts of care. Hospice care and the rapidly emerging new medical specialty of palliative care have better defined the concepts and how they should be applied. I would like to explore some of these from the perspective of the practicing physician.

Comfort Care

The concept of comfort care has developed over the last several years. The primary goal of comfort care treatment is to make the patient comfortable, which includes relieving the patient's pain and other symptoms. No other treatment is provided to sustain life. Medication such as sleeping pills, tranquilizers, and narcotics, as well as food and fluid by mouth, are appropriate to assure comfort. This is an excellent option for the chronically ill, severely demented, immobile nursing home patient, as well as for the less debilitated terminally ill cancer patient. In addition, for the competent patient who has verbally and unequivocally let it be known—and who has signed the appropriate legal papers such as a living will and a DNR order—comfort care is appropriate. For the incompetent patient who has a healthcare power of attorney who knows the patient's desire for comfort care only, it is also appropriate, especially if the appropriate papers were signed earlier.

"A trusting relationship between a terminally ill patient and her or his physician is the most important basis for realistic and good decision making."

Many have interpreted a living will or a DNR to mean comfort care only. This is not true. The living will is effective only when the patient has lost his or her competency to make her or his own decisions. The same is true for the Health Care Power of Attorney. Competency of the individual is the critical factor. A DNR order is only effective if the patient is not breathing or does not have a heart beat and therefore is not responsive. If there is a heart beat and the patient is breathing, the healthcare providers (emergency medical technicians, hospital and nursing home nurses, emergency room physicians, etc.) are obligated to treat unless the patient is competent and refuses treatment. This policy has resulted in many individuals receiving treatment they did not desire in hospitals, emergency rooms, nursing homes, and at home. An available, effective, and legal comfort care physician's order

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would have averted the unwanted treatment. The patient could stay in the nursing home or at home and receive comfort care treatment without having their wishes exceeded.

Problems

Today some healthcare givers assume the presence of a living will or a DNR order is also a comfort care only order. It clearly is not. Many healthcare providers—including doctors, nurses, patients, and families—are unclear about the difference. At times there is a tendency for the care-giving medical staff to assume it is okay for the patient to die if there is a living will and/or a DNR order. The staff may not be as attentive to that patient's needs and complaints as they would be to patients having no living will or DNR order. Indicated and beneficial treatment may be delayed or not instituted.

Under comfort care orders, the decision not to treat with antibiotics frequently poses a dilemma. Do you treat reversible and easily curable urinary infections or skin infections? Some would argue treatment of an easily curable infection is a component of comfort care. But not all agree. There is no clear-cut answer to this question. A competent patient can make the decision at the time, but the incompetent need better-defined advanced directives.

The care of the patients with ultimately fatal medical illnesses, such as congestive heart failure or chronic obstructive pulmonary disease, is much more difficult to address from a comfort care or palliative care approach. To be comfortable, these patients will continue to need medication for treatment of their disease. Decision making and medication management are much more complicated and require more than the usual palliative or comfort measures. Prognosis is much more difficult to predict and instead of living for months the patient may live for years. I am concerned that the hospice principles will be applied too soon to some now receiving palliative care for chronic, slowly progressive medical illnesses. It may be detrimental to some patients.

Some in our community feel we make dying too easy and, subsequently, resist hospice care. Others believe that earlier application of hospice care services and principles give families of these patients much needed respite and enable them to better cope with the possibly long trajectory of illness and death.

"Recent efforts to involve team members—nurses, chaplains, social workers and psychologists—in educating both the patient and the family about end-of-life issues are very helpful."

Team Care

The expansion of hospice and palliative care to include multiple other caregivers—such as physician's assistants, nurse practitioners, chaplains, nurses, social workers, and counselors—has been necessary and good. The personal doctor or specialist cannot do it all. The team is able to give the patient more comprehensive care.

Problems

My concern is that the personal or primary care physician is frequently left out of the loop. I would argue that the care can be just as good if the primary care doctor is involved and head of the team, so long as he or she functions as a "team member." Consistent attention to the needs of the patient is something the primary care physician can provide. The personal physician should know the patient better than any other care giver. The patient's own "doc" should not abandon the patient in his time of greatest need or as he approaches death. I realize my view is in the minority these days. In fact, many primary doctors are happy to turn their patients over to the hospice or palliative care team. Their view is that terminal care takes too much time for too little reimbursement. I think the reason goes deeper than this. Unfortunately, some physicians do not want to deal with the difficult management and emotional issues associated with dying. This is not good for long-term physician-patient-family relationships. I personally find helping a long-term patient die a good death is one of most beneficial things I do.

Family Relationships

Recent efforts to involve team members—nurses, chaplains, social workers and psychologists—in educating both the patient and the family about end-of-life issues are very helpful.

Problems

Frequently a family's understanding of the process of death and its variability is difficult. Much time must be expended in elucidating the diagnosis, deciding between treatment or non-treatment, and expected course. Families are vastly more knowledgeable about medical illnesses than in the past. But they may not fully understand the jargon in an experienced medical sense. A little knowledge may lead to great expectations both realistic and unrealistic. With their increased Internet-derived medical knowledge, families can reasonably challenge the physician's decision making. This more easily happens if family members have not been around the patient recently and have not experienced the patient's recent physical and mental decline.

Trust

A trusting relationship between a terminally ill patient and her or his physician is the most important basis for realistic and good decision making. It is even better if the trusting relationship extends to the family. A long-time physician-patient-family relationship in which all parties are comfortable and are free to express themselves in a trusting environment makes the care for all much easier. Primarily the patient needs to be comfortable and able to clearly communicate her or his wishes whenever the he or she wants. Compassionate caregivers must communicate with honesty, modified by prudence and fidelity to the patient's wishes.

Recommendations to Improve the Possibilities of a "Good Death"

POST - Physicians Orders for Scope of Treatment

The North Carolina General Assembly should approve the use of the POST form (as developed in West Virginia) as a legal upgrade to the currently approved North Carolina DNR Yellow Sheet. The proposed new "pink-sheet" or POST form has been approved by the West Virginia State Legislature for use in that state. The current North Carolina "yellow-sheet" DNR only addresses the patient with no pulse or who is not breathing. The new POST form addresses the patient with no pulse and not breathing plus offering options for comfort care only, not being hospitalized or moved, as well as decisions on whether or not to receive antibiotics or tube feedings. It fully defines the patient's desires and is reinforced by state law. For terminally ill or severely demented patients, it clearly defines for families, nursing homes, emergency medical technicians, and emergency room physicians, what should be done and not done. The POST forms are physician orders that will stay with the patient all the time and can be changed anytime, but only by a physician's order. You can learn more about POST at the West Virginia Center for End-of-Life Care at http://www.hsc.wvu.edu/chel/wvi/ContactUs.asp.

Patient-Physician Relationships

Physicians who know their patients well should continue to follow and be involved in critical decisions at the end of life. They should participate in the team approach to terminal illness and receive reasonable reimbursement for it.

Trust

For multiple reasons, trust in the healthcare system is becoming more difficult to achieve at the end of life. Physicians must see that patient trust is maintained to the end, and they must not abandon their patients.

So, we have indeed learned a lot from the time I visited the North Carolina Cancer Hospital in the 1960s about the appropriate treatment for those of us who are about to die. But we can always make it better. **NCMJ**

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COMMENTARY

Why the Patient Self-Determination Act Has Failed

Dee Leahman

Deciding when and how to cross the bridge from curative to palliative care is both complicated and simple. Complicated by clashes in perspective and values: Opinions differ as to what is best for the patient, how quality of life should be defined, who is best qualified to make these important decisions.

Simple? Sometimes as simple as asking, "What would the patient want?" But what if they can't express themselves?

Over a decade ago the Patient Self-Determination Act (PSDA) was passed. If designed to give patients the right to refuse unwanted treatments before the fact so that tragedies like the family of Nancy Cruzan and Terri Schiavo faced would disappear, then the PSDA has not worked.

> *"Why are we still dying in places we would not choose, in ways we do not want, surrounded by strangers, our wishes undocumented, unknown and, therefore, often not honored?"*

Today, only about 30% of Americans have advance directives. Living Wills are the simplest, most common and least effective type. Healthcare Powers of Attorney require that you appoint a healthcare agent, tell that agent which treatment options you would choose under what circumstances, document your choices and wishes, make sure all the right people have copies of the document... Whoa!! Talk about complicated. Most people respond: "We'll get around to that later—when we need it." Discussion deferred.

As Dr. Laura Hanson points out in this edition's lead article,[1] "Patients and their families say they prefer terminal care at home, but four of five deaths in the United States take place in hospitals and nursing homes." In other words, about 80% of us would rather die in a home-like setting, but that only happens 20% of the time. What we say we want is NOT what we get. Why are we still dying in places we would not choose, in ways we do not want, surrounded by strangers, our wishes undocumented, unknown and, therefore, often not honored?

A cancer patient who was active in her church taught me the answer. Asked if she had talked with her doctor about her disease, she replied: "Oh, no! He's much too busy." I asked, "What about your minister?" "Lord, no," she replied. "This kind of talk makes him really uncomfortable." Her perceptions may not have been accurate but they kept her from helpful information and support she needed.

I agree with Dr. Hanson when she says "patients generally welcome these conversations, and many are willing to record their wishes in some form." I also believe that most patients, physicians, and family members are reluctant to *initiate* the conversation. Once given permission and some coaching, discussion flows freely. But permission to talk about these care options is often implicitly denied.

Most of us know clearly what kind of treatment we want near life's end. Few of us are comfortable and skilled when approaching the subject. Avoiding discomfort now, we invite confusion, conflict, and permanent damage to relationships later. Documented wishes are often too vague to be of much help once patients cannot speak for themselves. The only fail-safe I know is thorough and early conversations about these tough decisions.

We have failed in implementing the Patient Self-Determination Act because we have allowed documents to speak for us, and paper can't talk. We don't say the right things to the right people at the right time in the right place. We have failed both organizationally and personally.

Organizationally

Organizations receiving Medicare funding are mandated to distribute advance care documents and information about them. *Wrong place!*

Information about living wills and healthcare powers of

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attorney is given to patients upon admission to healthcare facilities along with a mix of other material about the facility. ***Wrong time!***

Healthcare facility admissions personnel seldom have time to facilitate in-depth advance care planning discussions and often don't have answers to questions that should be asked. ***Wrong person!***

Admissions staff ask, "Yes or No: Do you have an advance directive?" Most of the time that is translated to the easier default: "Do you have a Living Will?" Healthcare Powers of Attorney are more complicated and confusing. Time is limited. Seldom is the patient asked to identify their healthcare agent. Most patients don't bring a copy of the document with them. Many medical records that have the "yes" box marked do not contain copies of advance care documents that are easy to access and understand. Even completed documents clearly marked on the medical record do not give physicians much direction. They are often vague and open to interpretation. That is not a good thing in the presence of difference of opinion. ***Wrong mechanism!***

Personally

Focus has been on documents rather than on the all-important conversation. Time, skill, and comfort level are in short supply all around when talking about treatment options and end-of-life care decisions. Parents don't want to upset children; children don't like talking to their parents about life's end. Patients expect the physician to bring it up. Physicians hope the patient will. In short, the conversation doesn't happen, at least not in the way it should.

The Carolinas Center for Hospice and End of Life Care, in collaboration with the North Carolina AARP and the Life's End Institute in Missoula, Montana, conducted a survey of North Carolina AARP members that revealed interesting facts about the way they approached (or did not approach) discussions about end-of-life care.

Ninety-two percent of respondents reported they wanted honest answers from their physician; 88% wanted to understand treatment options; 74% feared dying painfully. Even so, only 11% had spoken to their physician about their concerns.

Eighty-three percent said it is very important to be at peace spiritually (this number was 93% among African American respondents); 62% said it is very important to have comfort from spiritual or religious persons. Still, only six percent had talked with their clergy about these issues.

What an Incredible Disconnect!

Instead of using the documents as a catalyst to promote conversation, they have been used as a shield to protect us from having the conversation. The formal documents leave out the personal touch.

Two of my most memorable conversations about advance directives and end-of-life care, one with an aging relative, the other with my closest friend, taught me a lot about how important the details of the conversation can be and how void of meaning and direction the documents alone are.

Mamie was practically blind and deaf. She knew she didn't have much longer to live. She was bed ridden and dependent on others but mentally alert. As we talked about her future, she said, "I can't hear, I can't see. I can hardly move. But I can still smell. Can we get some flowers and scented candles in here?" I couldn't find that request anywhere in her formal documents.

I asked my friend: "What's on your list of the kind of care you'd like near the end of life?" He said quickly and matter-of-factly, "I want my pain controlled. I'd like to be with people I love. And I want music."

"Fine," I said. "I can help make that happen." We changed the subject. A few days later I realized I had failed to ask something important: What ***kind*** of music did he want? I assumed I knew, knowing what he listened to all the time. I asked, "Classic Rock, right?" He replied, "No, Celtic Harp." Lessons learned: it's in the details; ask the right questions.

You would think that healthcare professionals would have protected themselves and those they love by selecting a healthcare agent and documenting their wishes. They will have expressed to their agent and those in their important "inner circle" details about the setting, care, treatment options, and personal details they'd like someone to handle when they can no longer speak or act for themselves. Knowing that such a conversation makes it more likely that their wishes will be honored, they will have recorded their wishes and made them easily accessible to the right people. Not so. A clear majority of most audiences of physicians, nurses, social workers, clergy, and attorneys I speak to have not adequately dealt with these issues.

I maintain that it is difficult, if not hypocritical, to encourage patients to do advance care planning unless we have done it ourselves. It is appalling that so many of us are willing to subject our patients, our families, and ourselves to "pot luck" when it comes to end-of-life care.

So What Can We Do?

1 Normalize the conversation. Talk about the taboos early, prior to diagnosis or crisis. Ask about the kind of care they want. Take enough time or make a referral to someone who can.

I like the familiar model of the "consult." If my primary care physician discovers I have a cardiac problem, she calls for a cardiac consult. If I'm in respiratory distress, she may ask for a pulmonary consult. Why not call for an advance care planning consult if a patient needs assistance discussing and documenting one's end-of-life care wishes?

2 With terminal diagnoses, help the patient and family redefine hope. Rather than avoiding the truth, creating false hope, and delaying the inevitable, help patients and families focus on hope for comfort and maximizing quality of remaining life. As Dr. Hanson points out, identifying the point in time to transition from curative to palliative care and helping the patient and family manage that transition well is one of the central dilemmas of end-of-life care. I like her mention of compassionate communication. She states, *"Absent this skill, physicians will be unable to help patients decide on appropriate treatments, assess physical symptoms, or address emotional and spiritual suffering. Meaningful and compassionate communication is the core skill in end-of-life care. Patients facing the crisis of their own mortality require time to express fears and to seek reassurance of physician attention to their needs, in addition to medical aspects of their care."*

3. Use the documents as a vehicle to foster discussion about treatment options and preferences rather than viewing them as the desired outcome
4. Encourage policy change by sponsoring consumer and physician-friendly statutes such as Oregon's POLST (Physician Orders for Life-Sustaining Treatment) or West Virginia's POST (Physician Orders for Scope of Treatment). Become a process improvement activist in institutions having difficulty with advance directive documentation, tracking, and education. Help create an organization recognized for patients' wishes being known, documented, and honored wherever possible.
5. Spend time talking with patients' families about the whole person, not just the medical components of the disease. An unsolicited, positive outcome of this kind of trust-building dialogue is risk reduction. Well informed families who feel the physician has been caring, compassionate, and open are less likely to litigate.
6. Help "relocate" advance directives. Move them out of the acute care setting and "upstream" to physicians' offices, ministers' studies, estate planning sessions with attorneys, and kitchen table conversations.
7. Break the barrier of silence by bringing the subject of advance care planning into routine intake and assessment appointments. Add questions related to selection of a healthcare proxy to paperwork completed during the initial visit.

Linda Lewis, former hospice chaplain and currently Project Coordinator for *Faith In Action* End of Life Care Ministries at the Hospice & Palliative CareCenter in Winston-Salem, North Carolina, sums it up well:

> *"What used to be the moment of death when life ended fairly abruptly and quickly, has now become, in many cases, the season of death. Ventilators, feeding tubes, artificial hydration, dialysis, and even antibiotics can prolong the inevitable, meaning that the dying process may take weeks or months, or as in Terri Schiavo's case, even years.*

The dialogue has to be more than, "I don't want to live like a vegetable." What is it that makes life meaningful? What would I want my family and other decision-makers to know about me should I be unable to communicate my wishes? Encouraging people to complete Advance Directives is important, but these documents are of little use unless open and reflective conversation has taken place with those who may be faced with making crucial decisions in a time of crisis.

This is not just about "autonomy," the ethical principle that has guided most of the discussion around these issues in recent years. It is not just about "what I want." Who will be the one to speak for me when I cannot speak for myself? What does that person need to know about my values and my feelings about life? How can I have conversations now that will pave the way for wholeness and community when a crisis occurs? Personal wishes need to be discussed in the context of community, recognizing that others will be involved in carrying out wishes and will be affected by decisions that are made. Meaningful conversations with loved ones before a crisis not only help make medical decisions easier down the road; they can also strengthen relationships and create bonds as life values are shared openly and honestly."

Too many people are dying in ways they would not choose simply because they did not talk about it ahead of time. Physicians can only honor patients' wishes if they know what those wishes are. Encourage the conversation.

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1 Hanson, LC. Palliative Care: Innovation in Care at the End of Life. *North Carolina Medical Journal* 2004:65(4): 202-208.

Running the Numbers

A Periodic Feature to Inform North Carolina Healthcare Professionals
About Current Topics in Health Statistics

From the State Center for Health Statistics, North Carolina Department of Health and Human Services
www.schs.state.nc.us/SCHS

Deaths Among North Carolinians Age 85 and Older

According to the United States Census Bureau, the nation's population age 85 and older is projected to increase from 4.5 million in 2002 to 9.6 million in 2030. North Carolinians also are living longer and dying later in life than in the past. In 2002, there were 17,739 deaths of North Carolina residents age 85 and older. This represented 25% of all 71,780 deaths of North Carolina residents during 2002. By comparison, deaths to persons age 85 and older were 14% of all deaths in 1980.

In 2002, there were 1,938 deaths of persons at exactly age 85, and the number declined steadily at each single year of age, with 238 deaths of persons age 99. There were 461 deaths of persons age 100 and older in 2002, with the oldest reported age at death being 113 (one death).

Of the deaths of persons age 85 and older, 70% were female and 30% were male. Seventy-four percent were widowed and 19% were married at the time of death. Men age 85 and older who died were much more likely to be married than women: 48% compared to 6%. For deaths of North Carolina residents of all ages, 51% were female and 49% were male; 38% were widowed, 40% were married, 11% were never married, and 10% were divorced. Fifty-eight percent of decedents age 85 and older had less than a high school education, compared to 47% of decedents of all ages.

Persons age 85 and older are much more likely to die in a nursing home. Among deaths of those age 85 and older, 42% occurred in a nursing or rest home, 39% in a hospital, and 16% in the home or not in an institution. For deaths of North Carolina residents of all ages in 2002, the comparable percentages are 20%, 50%, and 23%. Cremation occurred for 15% of the deaths of persons age 85 and older, compared to 19% for North Carolina resident deaths of all ages.

Following are the ten leading causes of death in 2002 for persons age 85 and older:

Cause of Death	Number of Deaths	% of Total Deaths
Heart disease	5,616	32%
Stroke	2,005	11%
Cancer	1,987	11%
Alzheimer's disease	1,124	6%
Pneumonia and influenza	863	5%
Chronic lung disease	711	4%
Diabetes	411	2%
Nephritis and nephrosis	394	2%
Non-motor vehicle unintentional injuries	384	2%
Septicemia	305	2%
All other causes	3,939	22%
TOTAL	17,739	100%

For persons age 85 and older, heart disease and stroke accounted for 43% of the total deaths in 2002, compared to 33% for persons of all ages. Cancer deaths were 11% of the total for persons ages 85 and older, compared to 23% for deaths of persons of all ages. Alzheimer's disease accounted for 6% of deaths of persons age 85 and older, compared to 3% of deaths in the total population.

Contributed by Paul A. Buescher, PhD
State Center for Health Statistics, North Carolina Division of Public Health

Infant Mortality in North Carolina

To The Editor:

I have just reviewed the May/June 2004 issue on Infant Mortality. It is very well done. In particular, the article on folic acid by Robert Meyer and Anna Bess Brown was of particular interest. It is nice to know that some of one's efforts pay off. I chaired the Food and Drug Administration (FDA) Food Advisory Committee (FAC) that recommended folic acid fortification of cereal grains. This was a very controversial issue for two reasons. The first concerned the principle of whether the FDA should order the "artificial" modification of "natural" foods. The second was more substantial and was concerned with how much folic acid should be added. The issue was to not increase it so much that Vitamin B12 deficiency was masked in the elderly since the elderly consume more cereal grains than young women. Hence, the final level will not meet the 40mcg. needed in young women. In spite of this final decision, it is clear that folic acid fortification of cereal grains is having an effect.

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(The writer was Assistant Secretary for Health, United States Department of Health and Human Services under President Ronald Reagan.)

To The Editor:

I read with interest the article, "Demand for CME Programs on Cancer Care Among Primary Care Physicians in North Carolina," published in the May/June 2004 issue of the *North Carolina Medical Journal.* As a Continuing Medical Education (CME) provider for one of the North Carolina Area Health Education Centers (AHEC) organizations, we survey physicians in the 16-county western region of the state each year, and our survey results support the findings of Dr. Anderson, Dr. Torti, and their research associates and assistants at Wake Forest University School of Medicine.

In response to our regional survey in the fall of 2003, we began last spring to plan a CME conference to address primary care physicians' concerns and the clear need for updated information. I am pleased to report that the Lineberger Comprehensive Cancer Center at UNC-Chapel Hill responded to our need, and the conference is scheduled October 8 and 9 at Fairfield Mountains, Lake Lure, NC.

Dr. Beverly Mitchell, Associate Director of the Lineberger Comprehensive Center, is serving as the medical course director of Early Detection, Screening, and Detection of Malignancies —A Cancer Update for Primary Care Providers. She will be joined by six of her colleagues, and the topics will include updated information on cancer of the breast, colon, lung, prostate, and skin, as well as discussions on hematological and central nervous system malignancies.

I encourage interested primary care physicians who would benefit from the October conference to visit our website www.mtn.ncahec.org for more information.

I extend my thanks to you for highlighting a pressing educational need in your journal.

Sincerely,
Irene D. Jurczyk,
Co-Director Continuing Medical Education
Mountain Area Health Education Center (MAHEC)
Asheville, NC

"It is nice to know that some of one's efforts pay off... it is clear that folic acid fortification of cereal grains is having an effect."

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In 1983 the North Carolina General Assembly chartered the North Carolina Institute of Medicine as an independent, nonprofit organization to serve as a non-political source of analysis and advice on issues of relevance to the health of North Carolina's population. The Institute is a convenor of persons and organizations with health-relevant expertise, a provider of carefully conducted studies of complex and often controversial health and healthcare issues, and a source of advice regarding available options for problem solution. The principal mode of addressing such issues is through the convening of task forces consisting of some of the state's leading professionals, policy makers and interest group representatives to undertake detailed analyses of the various dimensions of such issues and to identify a range of possible options for addressing them.

Members of the North Carolina Institute of Medicine are appointed for five-year terms by the Governor, and each task force convened by the Institute typically includes at least one-third of its membership from among the appointed members. Topics to be addressed through task force efforts are chosen following requests from the Governor, the General Assembly or agencies of state government. In some cases, topics are selected on the basis of requests from a number of stakeholder organizations across the state where this type of analytical process is considered to have potential value.

The North Carolina Institute of Medicine assumed the role of publisher of the *North Carolina Medical Journal* in January 2002 when the North Carolina Medical Society reached the decision to cease support for its publication. The Institute views the *North Carolina Medical Journal* as an extension of its mission. The Journal provides a forum for stakeholders, healthcare professionals, and policy makers and shapers to study and discuss the most salient health policy issues facing our state. Like many states, North Carolina is grappling with issues such as an increasing number of uninsured, the unmet health needs of the growing Latino population, a critical shortage of nursing personnel, the health risks of tobacco and obesity, rising prescription drugs costs, mental health system reform, the increasing societal burden of chronic illness care, the threat of bioterrorism and the necessity of assuring adequate public health preparedness—all in the midst of an economic downturn. Each of these issues presents unique challenges to healthcare providers and state policy makers. Yet, a fully implemented task force to consider each of these sets of issues is not feasible. The Journal makes it possible to present an organized and balanced overview of some of these issues, six times per year, and allows interested persons the opportunity to engage in the ongoing discussion of these issues throughout the year. The Institute hopes that our readers of the *Journal* will, in this way, become involved in the continuing debate about the most promising avenues for assuring the highest standards of health and healthcare for all North Carolinians.

health policy

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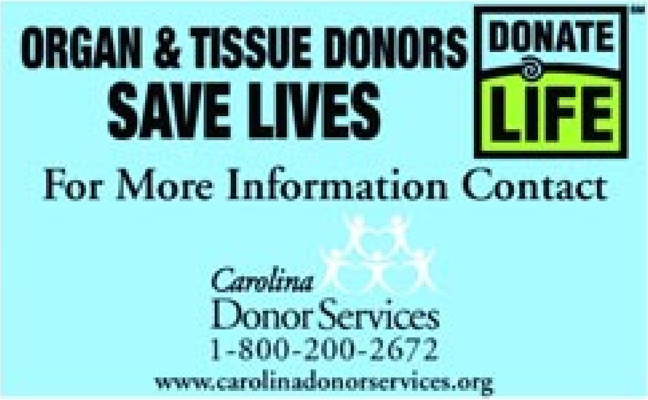

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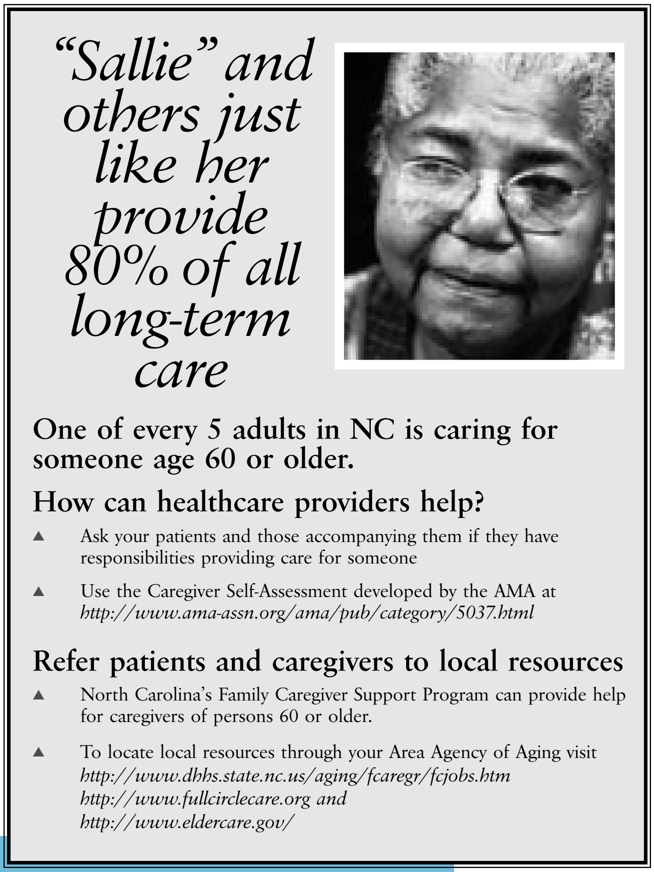

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North Carolina Medical Journal: Call for Papers

Herbert G. Garrison, MD, MPH
Scientific Editor, North Carolina Medical Journal

North Carolina is blessed with some of the finest medical research institutions in the world. The work of the medical scientists that labor in our research facilities becomes complete (in many ways) and public when it is published in peer-reviewed journals.

While medical researchers in North Carolina have many journals to which they can submit their manuscripts, we want them to consider keeping their work here at home. To be more specific, we invite the authors of our state to submit their papers to the *North Carolina Medical Journal*.

The *Journal* seeks papers that convey the results of original research. We are especially interested in publishing research papers that have relevance to the health of the people of our state.

An editor reviews all papers received and those of sufficient quality are peer-reviewed. As with any journal of merit, only papers of high quality will be published. Papers printed in the Journal are indexed in the National Library of Medicine's MEDLINE public database.

The *North Carolina Medical Journal* is published six times a year. It is distributed free of charge to the members of the North Carolina Medical Society, the North Carolina Hospital Association, the North Carolina College of Internal Medicine, the North Carolina Academy of Physician Assistants, the North Carolina Board of Pharmacy, the North Carolina Association of Pharmacists, the North Carolina Division of Public Health, the North Carolina Association of Health Plans, and the Medical Review of North Carolina. The *Journal* is available by subscription to others.

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a journal of health policy analysis and debate

Quality of Care and Performance Improvement

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September/October 2004, 65:5

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A partnership that's working for eastern North Carolina

Bariatric surgery: Team approach wins national acclaim

Bariatric surgery is offered at Pitt County Memorial Hospital in conjunction with the Surgical Obesity Program at the Brody School of Medicine at East Carolina University and in partnership with private practice physicians in Greenville. Last year, the National Institutes of Health designated our program as one of six centers that will work cooperatively on research into the surgical treatment of obesity. More recently, the surgeons who practice bariatric surgery at PCMH have been recognized as a Center of Excellence by Blue Cross / Blue Shield of North Carolina.

The Brody School of Medicine Obesity Program, which has been offered here for 24 years, has developed a nationally recognized protocol that incorporates extensive preliminary screening and lifetime follow up by a multi-specialty team including psychiatrists, nutritionists and medical counselors. Bariatric surgery has proved particularly effective in reducing the effects of diabetes in morbidly obese patients. The Brody School of Medicine and University Health Systems are working together to make things happen — in the community, in the region and in the state.

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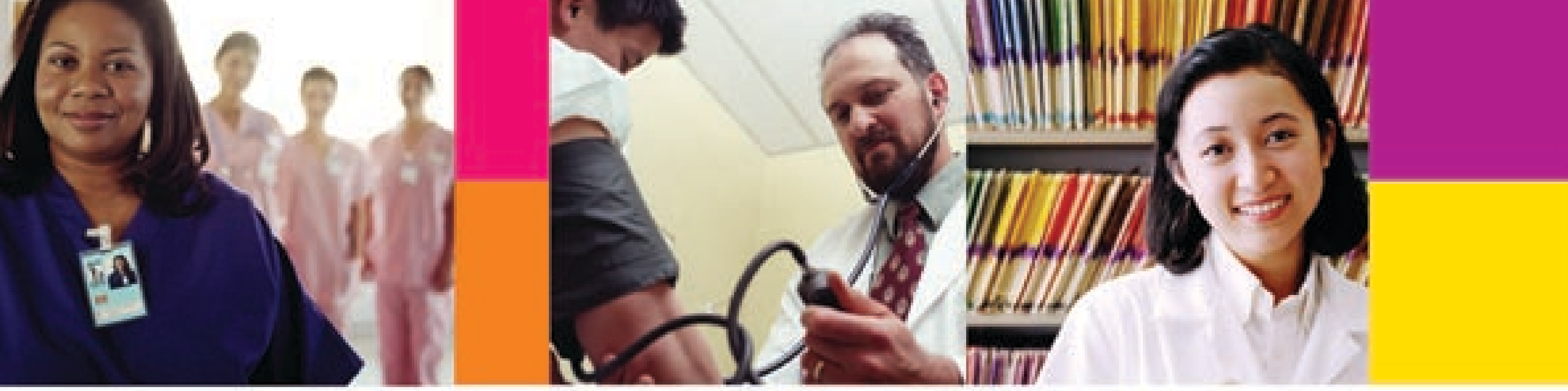

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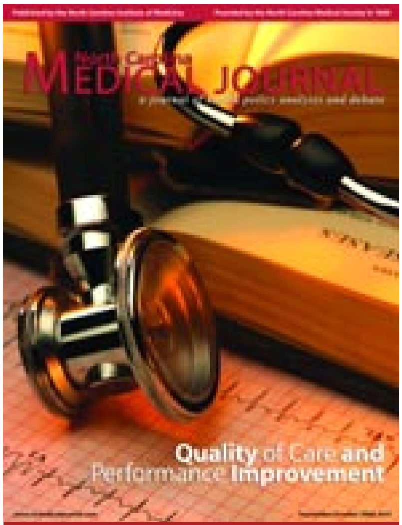

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a journal of health policy analysis and debate

September/October 2004, Volume 65, Number 5 **Published by the North Carolina Institute of Medicine**

POLICY FORUM

Quality of Care and Performance Improvement

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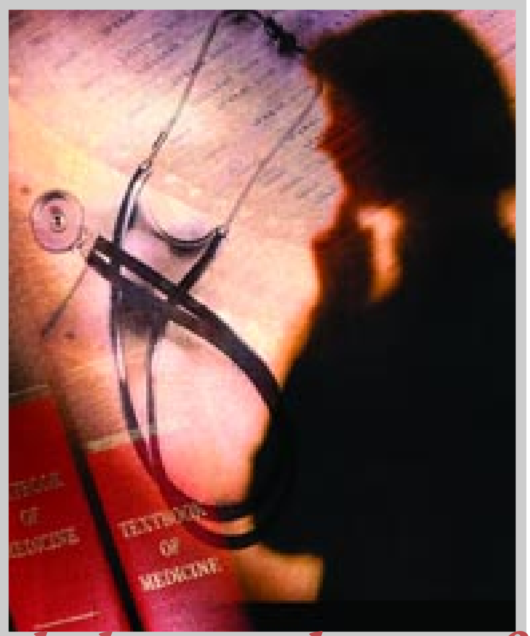

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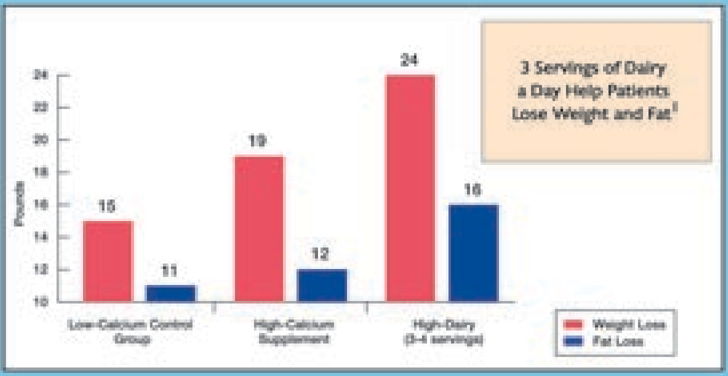
The mix of essential nutrients found in dairy foods, including calcium and protein, appears to improve the body's ability to mobilize and burn fat.[3] A recent study published in *Obesity Research* showed that people on a reduced-calorie diet who consumed 3 servings of milk, cheese, or yogurt each day lost significantly more weight and more body fat than those who consumed calcium supplements or just cut calories while consuming little or no dairy.[1]



Recommend that your patients include 3 servings of dairy foods a day in their weight-loss plans and advocate a healthy lifestyle that includes ample physical activity. The dairy case has a wide variety of reduced-fat, lowfat, and fat-free products to choose from to fit your patients' reduced-calorie eating plans.

For more information about the important role dairy foods play in weight loss, visit www.3aday.org.

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3 servings of dairy a day in a reduced-calorie diet supports weight loss.

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[1] Zemel MB, et al. Dietary calcium and dairy products accelerate weight and fat loss during energy restriction in obese adults. *Obesity Research* 2004; 12(4): 582-590. In the study dairy products that counted as a dairy serving were excellent sources of calcium and good sources of protein.
[2] Zemel MB, et al. Dairy (yogurt) augments fat loss and reduces central adiposity during energy restriction in obese subjects. *The FASEB Journal* 2003; 17, 5: A1088.
[3] Melanson, EL, et al. Relation between calcium intake and fat oxidation in adult humans. *International Journal of Obesity* 2003;27: 196-203.

GUEST EDITORS' INTRODUCTION

Quality of Care and Performance Improvement:

An Important New Emphasis Whose Time Has Come

Lawrence M. Cutchin, MD, and Clyde L. Brooks, Jr., MD

Background

In December of 2003, the North Carolina Medical Society (NCMS) appointed a Task Force on Quality of Care and Performance Improvement. The NCMS Task Force, consisting of 13 members and six consultants, is charged with "recommend[ing] actions the NCMS [could] take to expedite the employment of available resources to address documented problems with care quality and patient safety in North Carolina." The Task Force has met on a number of occasions since its initial appointment and has reviewed the literature on quality of care and perfomance improvement, looking at the national experience as well as experience in our own state. The Task Force has discussed the range of actions that the North Carolina Medical Society could take to create a safer and more effective healthcare delivery system for our patients. The Task Force is submitting a white paper with specific recommendations on the subject to the North Carolina Medical Society this fall.

At the invitation of the Editor of the *North Carolina Medical Journal*, the Task Force summarized some of the principal themes developed during its early work. Members of the Task Force are contributing papers to the *North Carolina Medical Journal*—papers designed to share these ideas and themes with a broad spectrum of healthcare professionals, healthcare organizations, and policy makers in our state. We hope that these writings will serve as a basis for further discussion of how North Carolina physicians can work in partnership with others to elevate the safety and effectiveness of care available to the citizens of North Carolina.

A Philosophical Perspective on Quality of Care and Its Improvement

From the outset, the Task Force was concerned with a few central ideas that are well described in various literature:

(1) Insofar as there exists a body of knowledge from which medical decisions should be made, there is a presently a lack of consistent application of this knowledge in clinical practice. This is known as the knowledge-practice gap. Clearly any action recommended by the Task Force must incorporate ways to address this issue.

(2) The Task Force was concerned with national (and state and local) publicity related to the volume of errors occurring in routine medical care (particularly since the publication of the national Institute of Medicine report, *To Err is Human*, in 2000).[1] This has raised feelings of alarm and distain among the general public. The publicity has also spawned expectations that healthcare professionals and provider organizations will take specific steps to ensure that these systematic errors are minimized or eliminated. Task Force members recognized the effort to reduce the frequency of errors as an essential component of overall system performance and care quality and that Task Force recommendations must address this issue.

(3) The Task Force has taken the view that quality of care is a broader concept than simply the issue of errors or adverse events (safety). The effectiveness of healthcare delivery—the extent to which desired patient outcomes are achieved—is the other side of the quality coin. The Task Force's recommendations will address the extent to which the delivery of healthcare in general, and the practice of medicine by physicians in particular, achieve desired outcomes. To that end, the Task Force will recommend some initiatives aimed at improving the decisions and actions of practicing physicians.

(4) The Task Force is aware of recently documented care quality deficiencies in the United States, as well as disappointing efforts to address these deficiencies through interventions

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targeted to either individual practitioners or care delivery systems. For example, McGlynn, et al.[2] recently presented data to show that United States adults receive only about half of the recommended care for a group of common acute and chronic conditions and preventive services (a *process* indicator of care quality). Comparisons of key quality of care indicators delivered in 12 United States metropolitan communities show that for 439 indicators across 30 conditions and types of preventive care (representing 52% of the reasons adults use ambulatory care services in this country and 46% of the reasons for which they are hospitalized), on average, adults in these communities were receiving 50 to 60% of the recommended care. These studies, which found considerable variation among communities studied, indicate that there are significant quality differentials among communities with regard to these indicators of service "omission" for which there is solid evidence of appropriateness. Our own North Carolina Teachers' and State Employees' Comprehensive Major Medical Plan has recently disseminated data showing that there are substantial numbers of North Carolina state employees, dependents, and retirees with diagnosed chronic diseases for whom standard, evidence-supported healthcare services are not being provided. Medical Review of North Carolina (MRNC) has shown similar findings with respect to patients discharged from North Carolina hospitals following a myocardial infarction. Clearly there are reasons to examine the patterns of such services for defined clinical entities. It is important to ascertain the extent to which explicit services covered by standard health insurance plans are not provided, even though there is substantial evidence of their appropriateness and effectiveness in the care of specific patients.

(5) The Task Force recognized that there are arguments with the current emphasis on evidence-based approaches to medical practice, particularly as this movement has led to the promulgation of so-called "clinical guidelines" pertaining to the care of patients with particular conditions or diagnoses by various professional, third-party, and governmental agencies. Even so, few can deny the merit of disease management strategies. These strategies have attempted to encapsulate clinical guidelines in an organized and cost-effective strategy for managing the care of large numbers of individuals who have similar clinical diagnoses/conditions and for whom it is possible to standardize both the patterns of healthcare encounters, related services, and pharmaceutical usage. Despite these advances, the fact remains that there is a substantial lack of evidence, by any criteria used, to evaluate the effectiveness of many of the treatments and strategies for disease management in use today. Hence, there is a continuing need for the development of the clinical evaluation science base of contemporary medical practice. The fact that randomized, placebo-controlled research evidence does not yet exist (or perhaps cannot ever be developed) to support every clinical procedure or maneuver does not mean that clinical decision making has to sit idly by and remain non-responsive to the needs of patients. But, where such evidence is available, or where it can be amassed, it should be used to shape the clinical decisions of those on the frontlines of medical practice.

(6) The Task Force took heart from recent reports from studies in the United Kingdom and elsewhere indicating that for those clinical procedures *actually performed* or prescription medications *actually ordered*, the majority seem to be procedures and prescriptions for which there is evidence from randomized, controlled trials or convincing non-experimental evidence with high consensus among clinicians that these procedures or treatments are actually "evidence-based." for example, Mulligan, et al., reported in *The Lancet* that a *post hoc* analysis of 100 consecutive patients in a single medical ward in Oxford, England found 82% of the patient management interventions "...were based on high quality scientific evidence."[3]

Similar retrospective findings have been reported from internal medicine departments in Canada,[4] for dermatology outpatients in Denmark,[5] hematology-oncology clinics in the United States,[6] and thoracic surgical practice in Buffalo, New York.[7] The literature is rapidly growing in this regard, and these are only illustrative of the range of clinical situations where evidence-based approaches have been shown to be implemented. The point is: though the conduct of randomized clinical trials of every procedure or maneuver in medicine and surgery is a practical impossibility, there is substantial data available to show that not only is there a growing body of literature offering evidence of effectiveness of common medical and surgical procedures, but there are also data to show that the procedures being performed are ones for which there is supporting evidence of effectiveness.

The Value of Quality Improvement

The Task Force grappled with the question of establishing the *economic value* of quality improvement (the so-called "business case" for quality). This question comes up most often in discussions among purchasers of group health insurance (e.g., large employers) or among insurers themselves who ask whether investments in quality improvement programs or initiatives yield a financial benefit to those who either purchase or insure healthcare for defined beneficiary populations.

The Task Force believes that despite the difficulties of establishing the "business case" for quality improvement, the fact that there are usually clearly demonstrated health and economic benefits to those served constitutes a sound reason for the North Carolina Medical Society to lead the way in promoting the improvement of quality of care and the performance of healthcare systems in our state. We plan to do so in the interest of benefiting the health and healthcare available to all North Carolinians.

This special issue of the Journal begins with a two substantial Issue Briefs. The first is prepared by prepared by two colleagues affiliated with Medical Review of North Carolina, the federally-designated Quality Improvement Organization (QIO) serving

North and South Carolina. Drs. Meera Kelley and Ross Simpson have offered a comprehensive overview of key health policy issues surrounding the problems of quality improvement and assurance. The second is by Drs. Sharon Hull, Leila Kahwati, Elizabeth Kanof, and Ms. Jennifer Proko. It offers a detailed discussion of how considerations of quality may be integrated with mainstream clinical practice in primary care. Their reviews are followed by papers on: data and information systems essential to quality improvement by Mr. Robert Weiser and Dr. Christopher Mansfield; evidence-based medicine by Drs. Charles Willson and Hadley Callaway; disease management approaches to quality improvement by Drs. John Mangum and Conrad Flick; educational programs addressing quality of care by Drs. Stephen Willis, Thomas Pulliam, and Thomas Bacon; efforts to make quality of care efforts "patient-centered" by Drs. Allen Dobson and Michelle Jones; and a summary paper on how quality of care and performance improvement efforts are mutually reinforcing by Drs. Noel McDevitt, William Walker, and Gordon DeFriese.

We are grateful to the authors of the papers appearing in this special issue of the *North Carolina Medical Journal*, most of whom are members of the Task Force on Quality of Care and Performance Improvement appointed a year ago. The preparation of these papers, and the deliberations which have led to their collection in this issue of the Journal, reflect the intensity of interest among these Task Force members, but also provide a template and a roadmap for further quality improvement initiatives taking place in our state. **NCMJ**

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ISSUE BRIEF

Quality of Care and Health System Performance:

Where Are We Now? Where Should We Be Going? Who Can Take Charge and Lead Us There?

Meera A. Kelley, MD, and Ross J. Simpson, Jr., MD, PhD, MPH

Where Are We Now?

We have observed tremendous advances in healthcare during the past century. Between 1900 and 2000, life expectancy in the United States increased from 46.3 to 73.9 years for a man and from 48.3 to 79.4 years for a woman. Significant developments include vaccines, antibiotics, modern surgery, anesthesia, and treatments for chronic conditions such as diabetes and hypertension—just to name a few.

In the face of these dramatic improvements, however, there is considerable concern about the safety and quality of our current healthcare system. The concerns with healthcare quality focus on medical errors, underuse and overuse of diagnostic tests and therapies, and waste of resources. Medical errors reflect unintended actions, such as the wrong drug being given to a patient. Underuse of therapies, which can also be termed "errors of omission" reflect lack of use of recommended care, such as use of beta-blocker medication for patients with a heart attack. Overuse of certain aspects of care is suggested by the significant geographic variability across the United States in resource utilization (e.g., the cost of care for the average patient), and in rates of certain procedures such as hysterectomy. Finally, waste reflects the all-too-common repetition of tests and services such as x-rays or CT scans when patients receive care at different sites.

Errors

"Medical errors" include events in which an unintended action was performed, an intended action was not performed, or an intended action was performed incorrectly. Not all errors result in a negative outcome for the patient—indeed, most do not. Similarly, not all bad outcomes result from medical errors; "adverse events" are occurrences that are deleterious to the health of the patient and may or may not result from an error. A patient with no history of drug allergy, for example, who develops a severe rash when prescribed an appropriate therapy experienced an "adverse event," but not a "medical error." The focus on medical error reduction is to minimize the opportunity for adverse events that result from medical errors—these are termed "preventable adverse events."

The 1999 national Institute of Medicine's *To Err is Human*[1] reported that 44,000-98,000 people die in United States hospitals each year as a result of medical errors. While the precise number has come under considerable scrutiny, certainly the true number is "too many," and the number of people hurt non-lethally is likely to be much, much greater than the number who actually died. Adverse drug events are common in hospitalized patients, with 2-35% of patients having such events, and cause over 7,000 deaths per year. Over two million nosocomial (hospital-acquired) infections occur per year in United States hospitals. As previously suggested, not all adverse drug events or infections acquired in the hospital are preventable.

Variability

Healthcare delivery varies considerably across our country. Among Medicare beneficiaries, for example, spending per enrollee in 1996 in Miami, Florida was $8,414, while in Lynchburg, Virginia it was $2,829. The chance of being hospitalized when a person dies in Newark, New Jersey was 49%, while in Boulder, Colorado it was 19.9%. The likelihood of spending greater than seven days out of the last six months of life in an intensive care unit in Munster, Indiana was 25.5%, while in Eugene, Oregon it was 2.9%. Finally, the chance of getting aspirin upon discharge from the hospital after a myocardial infarction in Mason City, Iowa was 96%, while in San Luis Obispo, California it was 52%.[2] Interestingly, states with higher

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Medicare spending actually seem to receive lower-quality care. States with more general practitioners use more effective care and have lower spending, where states with a higher proportion of specialists have higher costs and lower quality as measured by specific process of care criteria.[3]

Underuse of Standard Treatments

Overall in the United States, the proportion of patients receiving the recommended care for prevention, acute treatment, and chronic care is approximately 55%.[4] Beta blockers following acute myocardial infarction, testing for hemoglobin A1C in patients with diabetes, administration of vaccines for pneumococcus and influenza, anticoagulants for stroke prevention in patients with atrial fibrillation, mammography screening, and smoking cessation counseling are often not used in appropriate patients.

Overuse

There is a growing consensus that certain diagnostic tests, drug therapies, and surgeries are overused. These include hysterectomies, cardiac catheterizations, cardiac bypass surgery, pacemakers, and the use of sedatives and antibiotics. For example, antibiotic prescriptions for sore throats, which are commonly caused by viral infections that are not responsive to antibiotics, are prescribed in over 60% of encounters. By expert panel review, over 40% of hysterectomies, coronary bypass surgeries, and coronary angioplasties are either inappropriate or of questionable utility.[5]

Waste

Our healthcare system is inefficient. Duplicate history taking, complex billing requirements, incomplete or missing patient records, and unnecessary reports all contribute to added costs and decreased patient satisfaction. In addition, patients seeking care from multiple institutions often face duplication of tests due to lack of availability of prior ones.

Comparison of Consumer Perceptions in the United States with Those of Other Industrialized Nations

The goals for healthcare in the 21st century suggested by the 2001 national Institute of Medicine report, *Crossing the Quality Chasm*,[6] are for healthcare to be: (1) safe, (2) effective, (3) patient-centered, (4) timely, (5) efficient, and (6) equitable. The Commonwealth Fund conducted international health policy surveys measuring these six factors.[7,8] The 2001 International Health Policy Survey sponsored by the Commonwealth Fund included 1,400 adults and the 2002 International Health Policy Survey included a sample of 750 from the United States, United Kingdom, New Zealand, Australia, and Canada. Subsequent comparisons among the countries surveyed in these healthcare quality priority dimensions revealed the following:

(1) ***Safety:*** The United States ranked last. The United States had the highest reports of medication errors (receiving the wrong medication or dose over the past two years), and patients who were most likely to say a medical mistake was made in their treatment.
(2) ***Effectiveness:*** The United States tied for last. The United States had more patients not getting a recommended test, treatment, or follow-up due to cost, and was last in patients not filling a prescription due to cost.
(3) ***Patient-Centered:*** The United States ranked second to last. The United States ranked last (tied with the United Kingdom) on physicians spending enough time with patients and last on physicians listening carefully to patients' health concerns.
(4) ***Timeliness:*** The United States ranked third. The United States was the best on hospital admission waiting times, but next to last on waiting five days or more for a physician appointment when patients last needed medical attention.
(5) ***Efficiency:*** The United States ranked last. The United States was last on being sent for duplicate tests by different healthcare professionals, and worst on not having medical records or test results reach a doctor's office in time for appointment.
(6) ***Equity:*** The United States ranked last for lower-income patients. The United States was worst on patients having problems paying medical bills and worst on patients being unable to get care where they live.

How Did We Get Here?

Despite the dramatic scientific advances we have seen over the past century, the way we deliver care for patients has not changed significantly. In other words, we have revolutionized the *products* of healthcare—medications, interventions, etc., but we have not changed the fundamental *process* of providing care. The physician-patient encounter still remains as the hub of American healthcare, with essentially all care orchestrated by the physician.

In our current environment, this method of delivery poses two serious challenges. For one, in order to provide the best, guideline-based evaluations and therapies at the time of the patient encounter, the sheer volume of information that the physician must have is staggering. As of July 2004, the National

> *"Physicians face numerous interruptions, distractions, and required activities that are not critical to the actual care of the patient."*

Guidelines Clearinghouse contained 1,329 individual guideline summaries.[9] Patients today take significantly more medications than even five years ago, with new drugs developed all the time.

Second, providing care itself is much more hazardous than in the past. Physicians face numerous interruptions, distractions, and required activities that are not critical to the actual care of the patient. Just a few examples include documentation for billing that is not essential to the care of the patient, administrative demands from the practice and hospital, health plan programs with redundant and distinct safeguards, such as prior authorizations and post-payment audits, and inconsistent formularies across plans so that the physician cannot, as a routine, simply write for the medication he or she feels is most appropriate and has experience with. Therefore, the resources needed at the time of the patient-physician encounter have increased, while the time actually available for focused, uninterrupted interaction has decreased.

How Do We Build a Better Health System?

Given how complex our healthcare system is, there will be no single easy solution. One key component that will be essential is the consistent availability of information on how we are doing. Without this ongoing information, attempts to determine effective solutions will be unsuccessful and highly inefficient. How do we know where we are now and how will we know if a change has resulted in improvement? We need a practical way to measure quality that results in data that are meaningful; that is, data which are based on sound scientific evidence and are clinically important.

How Do We Measure Quality?

In order to measure quality, several things need to be in place. Easily available and accurate health data are a necessary requirement as standards for care norms and appropriate or achievable outcomes for patients are agreed upon.

There are three types of quality of care measures: structure, process, and outcome measures. Structural measures include capacities, technologies, and infrastructure, such as telecommunications, a management information system, and staffing, which may affect outcomes. Structural measures may also include the credentials (e.g., board certification) of healthcare providers. Outcome measures include adverse events that happen to patients like death and readmission to a hospital. These events are the ones physicians often find easiest to relate to and understand. Process measures include the procedures to assure the appropriate use of diagnostic tests and therapeutics.

Quality of care can be measured through assessment of appropriate outcomes and by the processes of care delivered to patients. Facility licensing and accreditation, for example, usually rely on structural measures of quality. Requirements range from rooms size and sanitation to fire detection and staffing (both numbers and credentials). Facilities and support systems must be physically adequate to uphold the provision of quality care.

Outcome measures are the end results of particular healthcare practices and interventions that patients feel and recognize. Poor outcomes are obviously events like death or serious complications that might lead to hospital readmissions. Studies of outcome measures can lead to decisions about where a patient can be treated. If the patient has pneumonia and can be treated at home, that could reduce treatment costs. Or, if there is not a cure, outcomes research can provide information that may help improve a patient's quality of life.

Process measures reflect actual care provided to a patient. Examples of a process measure include timely administration of beta blocking drugs to appropriate patients recovering from a myocardial infarction, and regular testing of blood lipid levels and hemoglobin A1C levels in patients with diabetes.

Neither structure, process, nor outcome measures are inherently better for measuring quality as each type has its own advantages and disadvantages, and quality of care projects often include all three types of measures. For example, outcome measures are often influenced by factors outside the healthcare system and are often not amenable to direct improvement. Process measures are most likely to be under the control of the healthcare system and amenable to change. However, their link to improved health may not always be obvious. For example, a hospital's rate for administering a beta-blocking drug to patients who do not have contraindications to these drugs is an important process measure of good care, but it may be difficult to show that improving this single process of care results in an improved outcome of lower death rates following discharge. Quality of care requires efforts in the assessment of multiple processes of care and outcomes that are linked to these processes.

Good measures of healthcare quality share several key attributes. They must be accurately measured; there must be consensus that the measure is important for health; and there must be room for improvement and established approaches to improve the measure. Health information might be in the form of administrative data, such as claims data or information that can be obtained or abstracted from medical records. There must be agreement in the medical community on the type of care that is appropriate for patients with the medical condition under study. Typically, information from randomized trials and expert panels are utilized to identify populations and treatments appropriate for the specific disease. Most importantly, there must be accepted interventions available to improve the measure. The key factor offering the promise for improving care is developing and implementing change. Such interventions often include performance reports in which an individual hospital's or physician's ratings of key care indicators are compared to appropriate normative data. Increasingly, more specific interventions (e.g., care maps or plans, standardized discharge orders, or educational material) are developed and disseminated as part of the program.

What Is Happening on a National Level?

Several national organizations have committed to stimulate the necessary changes in healthcare quality. These key organizations include the Centers for Medicaid and Medicare Services (CMS), the National Quality Forum (NQF), the Agency for Healthcare Research and Quality (AHRQ), the Joint

Commission on Accreditation of Healthcare Organizations (JCAHO), the American Health Quality Association (AHQA), and Quality Improvement Organizations (QIOs).

Making quality of care information available to the public has become an increasing priority among these groups. CMS began a national effort to make information on quality of care in nursing homes public in 2002, home health agencies in 2003, hospitals in 2004, and is expected to release physician-level practice quality data in the next few years.[10] Expectations of accountability and openness about the care provided are likely to expand. In addition, Blue Cross Blue Shield and the Centers for Medicaid and Medicare Services are examples of organizations trying models of "pay for performance"—that is, rewarding providers of better care with increased payment.

How Do We Begin to Develop a Healthcare System that Is Safe, Effective, Patient-Centered, Timely, Efficient, and Equitable?

In order to create a better and higher quality healthcare system, information must be readily accessible at the time of the patient encounter. Communication across healthcare settings—hospitals, offices, nursing homes—will have to be efficient and effective. Giving the patient all his or her own basic health history in a concrete format (written or electronic) is one initial step to assist with knowledge transfer. Finally practice complexity must be minimized through the use of standardized, simplified communication—for exchange with health plans, for sharing of information across different healthcare settings and systems, and for improved education and empowerment of patients in their own care. Many of these goals will be more readily achieved through the widespread incorporation of electronic health records.

Physician Culture

The other major shift that will be required is a change in the culture in which we practice—our way of thinking about how care is best delivered, and who is responsible for the results. Traditionally, physicians have been trained to work and think independently, to maintain knowledge through the use of their memory—to avoid the use of crutches, "cookbooks," or checklists; and to appreciate the variation among patients and the necessity of a tailored approach. Instructions of the physician were expected to be followed by other healthcare workers and even patients, without questioning. In order to change our culture, we as physicians must begin to think of ourselves as members of a healthcare team—a team that involves nurses, pharmacists, social workers, therapists, many other healthcare workers, and, importantly, the patient. We must recognize the limitations of our memory and encourage the reliance on readily available, up-to-date clinical information, and check lists to ensure that each patient receives every step of recommended care and so that medication interactions and errors can be better avoided. We must also encourage input from the various members of the team, including the patients, if these goals are to be achieved.

This new culture does not undermine the physician's role. The physician still performs those critical aspects of care that only he or she as a member of the team is trained to do—assess patients, direct major aspects of therapy, perform procedures or interventions, and communicate with the patients. Indeed, by limiting the roles to those things that only the physician can do, the physician-patient interaction once again can become the center, can be strengthened, and distractions, which include concerns about medical errors, will be minimized.

No longer can we afford to rely solely on the physician to ensure all aspects of care. We must set up systems of care that include the various members of the team—each empowered to do that which he or she is trained to do according to protocols, which are often predetermined. While physicians cannot be solely responsible for each aspect of care, given our clinical training and experience, we must lead the changes—the new systems.

Some Examples of Successes

For the past two decades, many national organizations, led by the Health Care Financing Administration, now the Centers for Medicare and Medicaid Services (CMS), have been actively involved in healthcare quality improvement. Such efforts began with the use of implicit criteria for case review of individual medical records by peer physicians and have progressed to explicit review of quality using standardized epidemiological and educational methods. Specific diseases with specific indicators were identified and compared across providers. The improved use of warfarin in the prevention of stroke in patients with atrial fibrillation, decreasing the delay time in administration of antibiotics in patients with pneumonia, and the administration of ACE inhibitors in patients with heart failure occurred as the result of these efforts.

These data-based activities were effective in improving key processes of care in specific diseases. However these projects were limited by the extensive costs and delays inherent in the collection, analysis, and feedback of this information to providers. Most importantly, the interventions used to improve care were limited by the efforts involved in data collection, and these efforts could not encompass the full range of modern interventions. Current efforts focus less on data collection and more on public reporting and specific educational interventions. Future efforts will focus on use and support for electronic health records, increased focus on outpatient care rather than care provided in the hospitals, and active steps to support and encourage widespread culture change to support quality care. Quality Improvement Organizations (QIOs), like Medical Review of North Carolina, are expected to provide active support for these programs.

First steps

Donald Berwick, MD, likely the most prominent leader in the healthcare quality improvement movement, suggests that in order to change the system, three preconditions seem helpful;

to face reality, to seek new designs, and to involve everyone. Facing reality means looking honestly at the weaknesses in our current system. New designs will be essential for success. We must involve everyone on the healthcare team—including patients—to create the new vision and to develop solutions.

As individual physicians we can take one step, now, to look at weaknesses in our practice settings. For the primary care physician, this may include examining a small proportion of charts of patients with diabetes mellitus and assessing the frequency with which the recommended steps of care were met. For a hospital physician, contacting the quality improvement department will readily generate performance data for some common, significant medical conditions. Nursing homes and home health agencies also have extensive data on care for the current national priority conditions.

We can also empower our patients with knowledge of their health conditions and treatments. We can acknowledge to them that the system is far from perfect. We can encourage them to take an active role in their own care, to ask questions, and to bring a friend or family member with them when they are hospitalized to help gather and process the information and care provided.

Some in healthcare assume that we as individuals can wait for the system to be changed, that somehow there will occur sweeping, broad, systematic changes across the United States. This assumption is incorrect. Past experience reveals that models of success have been developed by small groups of people working together, trying something new. Margaret Mead put it best; "Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it is the only thing that ever has." **NCMJ**

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ISSUE BRIEF

The Practice of Quality:
Incorporating High-Yield Strategies into the Daily Reality of Medical Practice

Sharon K. Hull, MD, Leila C. Kahwati, MD, MPH, Elizabeth P. Kanof, MD, and Jennifer P. Proko, RN, CHCQM

Introduction

Today's physician is expected to incorporate clinical guidelines, increasing numbers of preventive services, and patient safety concerns into the realities of the day-to-day practice of medicine, regardless of specialty.[1-4] Fifty years ago, the concepts of "utilization review," "best practices," or "patient safety" were virtually unheard of, and the field of preventive medicine was in its infancy (though great strides in sanitation and other public health issues had been made by the early 1900's). As medicine progressed during the latter half of the 20th century, physicians were increasingly asked to be mindful of the costs and effectiveness of healthcare. With the increased oversight of therapeutic interventions, particularly by the Food and Drug Administration (FDA) in the United States, significant emphasis was given to the safety of particular medications and medical devices. As we enter the 21st century, physicians now must to be aware of patient safety and quality issues at both the individual patient and the systems of care levels. Third party payors are increasingly linking quality of care and safety measures to reimbursement and privileging decisions, holding physicians and corporate healthcare systems accountable for their practice in new ways.

> *"Today's physician is expected to incorporate clinical guidelines, increasing numbers of preventive services, and patient safety concerns into the realities of the day-to-day practice of medicine, regardless of specialty."*

It is challenging to incorporate quality improvement into our primary care delivery system. The value of quality care is obvious, but methods for measuring it and for improving it are not so easily determined, nor is it familiar territory to most practicing physicians. A number of difficulties arise in simply measuring quality in healthcare. These include the balancing of stakeholders' perspectives, developing a framework to enforce accountability, development of clinical criteria, choosing the indicators to be reported publicly, addressing the ethical and other conflicts between reimbursement and quality, and development of information systems to support the collection and analysis of quality data.[5] It is also important that measurement of quality take into account outcomes that matter to patients, such as pain relief, improved functional ability, and relief of emotional distress. Despite the challenges, however, the potential exists for this evolving concern about quality to lead to development of a new paradigm of healthcare. The concept of "prospective healthcare," utilizing personalized health plans to determine individual risk for disease, planning for early detection of disease and delivery of preventive or therapeutic interventions early enough to be effective, has been proposed as a model for the future of the United States healthcare system.[6]

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Moving from our present system to "prospective healthcare" is a lofty goal that will require a major overhaul of our current healthcare system. It will also require changes that extend far beyond any one physician, patient, or medical practice. Such change can only occur through systems-level redesign, taking into account patients, physicians, and the myriad of business entities that comprise our healthcare system. For the practicing physician, success in improving quality of care begins with the actual day-to-day encounters between a patient, a physician, and the medical practice. In this paper we discuss the practicalities of quality improvement (with an emphasis on systems-level considerations) in two commonly targeted areas: clinical preventive services and chronic disease management.

> *"Studies have shown that office organization and staff and provider attitudes are more important than tools such as flow sheets and computerized records."*

Is Quality a Primary Care Issue?

McGlynn, et al., surveyed metropolitan United States residents and found that only 56% receive recommended care for chronic conditions and less than 55% receive recommended preventive care.[7] The increasing burden of chronic illness, time constraints, and practice, as well as healthcare system organization, all contribute to problems delivering high-quality care. Physicians want to "do the right thing," agreeing with the importance of most clinical recommendations,[8,9] but they want the flexibility to form their own opinions about relevant and appropriate guidelines for their patients.[10] Despite their general agreement with such recommendations, physicians may find themselves confronting clinical inertia, defined as "failure of healthcare providers to initiate or intensify therapy when indicated."[10,11] The burden of chronic disease and pressures to increase practice volume and productivity combine to create a "perfect storm" in primary care, making delivery of quality healthcare a significant challenge.

Escalating chronic disease burdens challenge a healthcare delivery system that is already strained by difficulties with access to and payment for care. More than half of patients in primary care clinics have a chronic disease.[12] Over 80% of patients who have cardiovascular disease, stroke, hypertension, diabetes, cancer, chronic obstructive pulmonary disease, asthma or anxiety/depression and who have a physician see a family practitioner, general internist, or general pediatrician on a regular basis.[13] This means that primary care physicians are the front-line providers for people who already have or are at risk to develop one or more chronic illnesses.

Clinical preventive services also lie within the domain of primary care practice and evidence indicates that preventive services recommended by knowledgeable sources are not being delivered. Since the 1980's, the United States Preventive Services Task Force (USPSTF) and other organizations have issued evidence-based recommendations for clinical preventive services.[14] Such recommendations are useful and often form the basis of clinical practice guidelines and performance measures. However, they are often difficult to implement, and uptake rates for many services are low. Among the 15 recommendations from the USPSTF with the greatest likelihood of reducing the burden of disease and the highest degree of cost-effectiveness, eight are being provided to eligible patients less than half the time.[15]

So why is there a gap between the recommendations that work and those that get done in practice? Many barriers have been proposed including lack of time, lack of staff, lack of knowledge, and lack of appropriate levels of reimbursement.[10,16-20] High-volume practices have been shown to deliver preventive services less frequently.[10] Though the average time spent delivering health promotion or health education in a routine family physician's office visit ranges from 0.7 to 1.98 minutes,[10,21] a recent study showed that delivery of the full set of USPSTF recommendations to eligible patients in a typical primary care practice would require 7.4 hours of physician work time per day.[20] Thus, time constraints often force primary care physicians to prioritize between illness care and delivery of preventive services. There is some evidence that physicians and patients do not always make such priority choices in accord with the best evidence available.[19,20,22]

Interventions to Improve Delivery of Quality Care

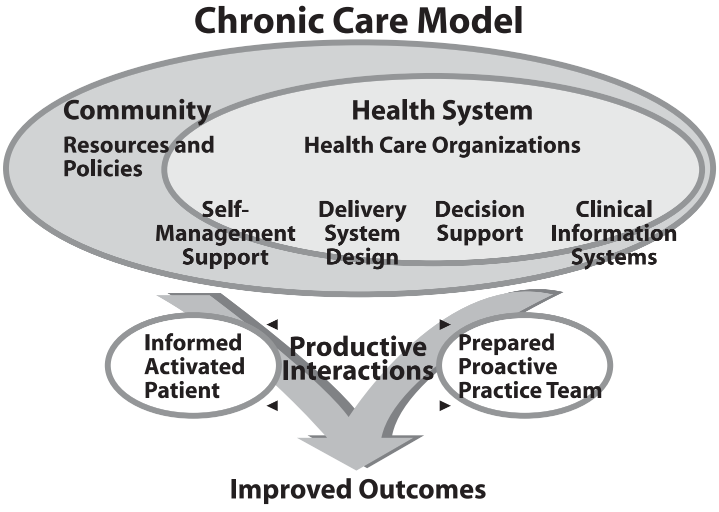
Many strategies have been used to translate research into practice and so we have some ideas about what works and what doesn't work. Passive education about guidelines such as lectures and seminars are not very effective at increasing uptake rates,[16,23] while one-on-one discussions,[16,23,24] reminder systems and other computer information systems[16,23] may be more effective. Multifaceted interventions (i.e., those that combine more than one strategy) appear to be more effective than any one single strategy,[25] and systems that automate or use standing orders fare better than on-demand type systems.

In one of the largest interventions to improve preventive services delivery in community family practice settings (Study to Enhance Prevention by Understanding Practice, or STEP-UP), tailored approaches were developed to increase the delivery of preventive services.[26,27] This program incorporated several systems-level interventions, including a one-day assessment of practice operations by a trained nurse facilitator, analysis of staff relationships and the external environment. Staff and physicians were provided feedback about their rates of preventive service delivery and a toolkit was developed from which practices could choose items most useful to them. Follow-up of this program at 12 and 24 months after the intervention showed that practices participating in the STEP-UP program had a significant and persistent increase in overall preventive service delivery rates, rates of health habit counseling, and screening rates. No significant increase was found in immunization rates.[26,28] It is unclear from the literature how many of the practices that implemented the STEP-UP program were also using electronic medical records.

A study of 44 primary care clinics testing systems-level changes to improve a variety of preventive services cited several barriers to the effectiveness of quality-improvement measures at this level. Some of these barriers included insufficient motivation for change, lack of ability to change on the part of the organizational culture and leadership, lack of evidence for changes that were implemented, processes related to implementation, and lack of sufficient time to make change.[29,30]

In 1994, the United States Department of Health and Human Services began a program called "Put Prevention into Practice" (PPIP) designed to improve delivery rates of preventive services recommended by the USPSTF. The program provides practice workflow and patient education materials for physician practices to use, and is available for purchase through the Agency for Healthcare Research and Quality (AHRQ), with some items available for free download at the PPIP website, http://www.ahrq.gov/clinic/ppipix.htm.[31] These materials appear to be helpful, but implementation without practice-specific assessment and tailored, multifactorial intervention strategies seems to be difficult.[17,18,32-39] Consistent barriers to implementation include clinician issues (time, lack of training, lack of self-efficacy), office systems issues (lack of knowledge, motivation, or support among office staff; inadequate systems to keep and monitor preventive service records), patient issues (lack of knowledge or motivation, anxiety about procedures and results, inconvenience, cost concerns), and systems issues (inadequate reimbursement and excessive time and productivity pressures).[19,20]

Figure 1.
The Chronic Care Model[40]



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Management of chronic disease with appropriate screening, treatment, education, and prevention interventions is also a significant challenge. The Chronic Care Model[40-46] has been developed to address the multi-level considerations that should be incorporated into adequate management of long-term illness. The model considers six dimensions of chronic care (community resources and policies, healthcare organization, self-management support, delivery system design, decision support, and clinical information systems)[40-46] in three settings (the community, the healthcare system, and the provider organization) (see Figure 1).[44] This model is complex, and its implementation requires a practicing physician to become a *systems-level thinker*. Where it has been most successfully utilized, this model has been instrumental in improving disease management, particularly in diabetes, congestive heart failure, and asthma.[46-48]

Electronic medical records (EMR) and computer reminder systems are increasingly common in primary care and other health-related settings and have a significant role to play in improving quality. The Veterans Health Administration recently announced plans to allow its computerized medical record system to be available to other public and private sector healthcare organizations at nominal cost beginning in late 2005.[49] This is consistent with a recently announced initiative by the Department of Health and Human Services to create a health information infrastructure that will incorporate nationally standardized electronic medical records.[50,51] These trends indicate that physicians in the future can likely expect increasing pressure to implement such systems. The cost to implement EMR, privacy issues, standardization of file formats, and implementation of "a minimum but affordable set of variables needed to assess quality and outcomes of care"[52] all can be significant barriers to their use. While only about 5% of United States primary care providers currently (in 2003) use EMR,[53] their use has been shown to improve guideline adherence.[54] It has been noted, however, that computer guideline systems can be difficult to implement.[55] Results of some studies show that use of EMR increases the number of tests ordered, but without significant improvement in clinically relevant patient outcomes.[56,57]

Other uses of information technology include direct physician order entry in hospital and clinic settings[58] and prevention of adverse drug effects by computer warning systems.[59,60] These developing technologies bring with them a distinct set of implementation, privacy, and cost concerns that may delay their widespread acceptance.

There are many external pressures to improve quality in healthcare,[61] and physicians must become familiar with the language and culture of quality improvement (QI). Managed care organizations and healthcare payors have been monitoring quality of care for years, mainly through the use of insurance claims information. Increasingly common are chart audits, which allow the capture of relevant clinical information not always available from claims.

Physician performance report cards have yet to appear, but efforts to improve the methods used to sample and calculate accurate physician-level performance measures are in progress. Recently, the American Board of Medical Specialties (ABMS) developed "Maintenance of Certification" (MOC) requirements for board-certified physicians.[62,63] The MOC program is being adopted by most recognized medical specialty boards and requires four basic components, the last of which mandates that physicians be able to document their ability to "assess the quality of care they provide compared to peers and national benchmarks and then apply the best evidence or consensus recommendations to improve that care using follow-up assessments."[62,63] The specialties of pediatrics, internal medicine and family practice all are offering modules for self-study and assessment relevant to common disease processes.[62-64]

Where to Begin

To improve the quality of care, a practice needs (1) evidence-based clinical recommendations, (2) evidence-based system recommendations, and (3) an improvement strategy.[40] The first spells out the clinical content, the second spells out what system changes can influence the delivery of the clinical content, and the third lays out how to bring items (1) and (2) into routine use. Without all three elements, most attempts to improve quality will not be successful or sustainable.

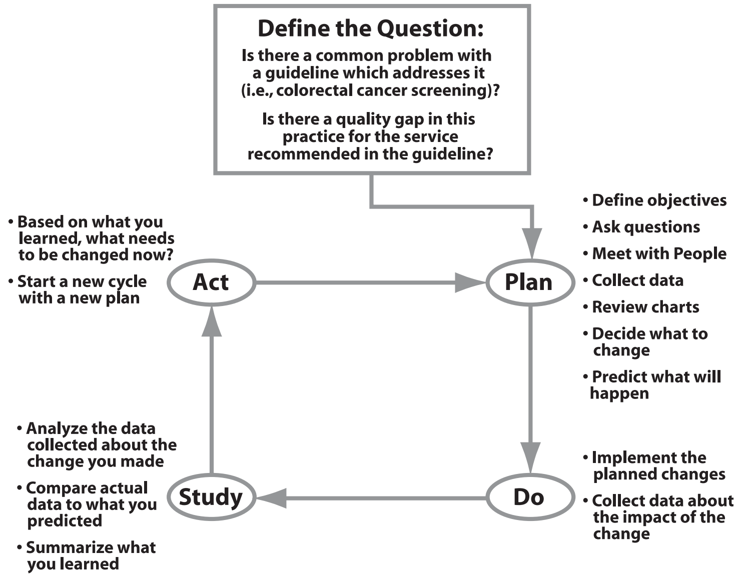
Perhaps the most important suggestion for those who are just starting to introduce quality improvement into their practice is to start with a single medical condition. The selected condition should be prevalent within the practice population and more importantly, it should be one in which current evaluation suggests that patients are not routinely receiving care consistent with clinical practice guidelines and best evidence. To determine whether a quality gap for a particular service exists, a practice can perform a manual chart audit by reviewing ten to 20 charts of patients eligible to receive that service based on age, gender, or risk factors. For offices without EMR, a request to the practice's largest insurance payors can provide a list of patients in the practice with a particular condition such as diabetes or asthma and can provide a raw list from which a manual chart audit can proceed. Chart audits are even easier for offices with EMR. Lastly, the physicians and practice staff should be highly motivated to study the particular condition and act to improve it.

One useful improvement strategy for affecting change is the "Plan-Do-Study-Act" (PDSA) paradigm (Figure 2) used widely by the Institute for Health Care Improvement (IHI)[65,66] and developed by W. Edwards Deming.[66] This systems-oriented approach to problem solving requires that an organization (e.g., a clinical practice) develop an objective and a plan to meet that objective, carry out the plan, study the results within a relatively brief time period, and act on the results of the initial study.[65, 66] We will not attempt to describe this framework in detail here, but those who are interested are encouraged to consult the original references[65,66] or the IHI website.[67] A sample strategy for utilizing the PDSA strategy in a clinical practice setting is provided in the sidebar accompanying this paper.

The process of quality improvement requires the cooperation of everyone who works in the practice, and it requires thinking at the systems and process levels. The importance of systems approaches cannot be overemphasized. Studies have shown that office organization and staff and provider attitudes are more important than tools such as flow sheets and computerized records.[68] It has also been noted that supportive attitudes and high levels of self-efficacy were not sufficient to improve prevention service delivery; over half of medical practices studied were poorly organized to deliver recommended services.[69]

Figure 2.

PDSA Cycle Overview *(Adapted from Deming[66] and Langley[65])*



In summary, the process of quality improvement in private practice can be daunting if one sets out to provide the entire range of best practice recommendations at one time. For the private practitioner who is not part of a larger healthcare system, success is more likely if one improvement process is undertaken at a time. Subsequent efforts will benefit from the experience of earlier improvements, and enthusiasm is more likely if early efforts are successful. The practitioner who begins with one or two small projects is likely to quickly decide that EMR and computer technology would make the task easier.

As more specialties comply with the ABMS guidelines for Maintenance of Certification, and as governmental regulations and reimbursement strategies focus more heavily on quality issues, this process will become more common, and practitioners who start now, even if they start small, will be well-prepared for the future of quality improvement in the real world. **NCMJ**

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Sample PDSA Cycle Strategy for Colorectal Cancer Screening

The following sample strategy illustrates the use of the PDSA model.

I am general internist in a small town solo practice that does not presently use EMR. I know that colon cancer is among the more common of cancers in older men and women and early detection through screening leads to decreased morbidity and mortality.[70] Annual fecal occult blood testing, periodic sigmoidoscopy or colonoscopy, and periodic double contrast barium enema are all acceptable and effective screening strategies.

QUESTION:
Does my practice have a quality gap for this service?
A manual review of 20 charts from patients 50-70 years in age without terminal illness or obvious medical contraindications to screening reveal the following statistics:

- 65% of charts document that colon cancer screening was offered to the patient
- Of those offered screening:
  - 40% received a recommended test
  - 15% received an inadequate or incomplete screening
  - 25% did not follow through with the screening after intially agreeing to it
  - 20% refused screening
- 100% of those with abnormal screening results had appropriate follow-up arranged in a timely fashion

As my practicing partners and I review these results, we realize that our practice has no systematic way to ensure we offer colon cancer screening to every eligible patient. Furthermore, our practice has no systematic way of facilitating patient decision-making about screening, particularly with regard to choosing from among the various recommended strategies. We seem to do well with ensuring the results are reviewed and appropriate follow-up is arranged.

PLAN:
I meet with my staff to review these findings, and to ask for their input about how to improve our practice performance in this area. We agree that our first objective will be to increase the percentage of eligible patients who are offered a screening test, and we set our target at 90%. We will take the following steps:

(1) A preventive services flow sheet, such as the one obtained for free at the PPIP website, will be placed in every patient chart at their next scheduled visit by the front-office clerk who pulls patient charts prior to appointments.

(2) The nursing assistant (NA) who triages the patient at the appointment will ask the patient about his/her last colon cancer screening and also review the chart to determine the current status. The physician will develop a simple one-page flowchart based on USPSTF recommendations for the NA to use in determining whether a patient is due for this service.

(3) Patients who are overdue for screening will have a "sticky note" placed on the chart by the NA to remind the physician to offer screening.

(4) Physicians will strongly recommend screening to patients and answer any questions they may have. Patients who decline screening will have this noted in their progress note. Patients who accept screening will be referred back to the NA for further arrangements. Either way, the physician will note on the flow sheet the date on which screening was offered.

DO:
The office staff implement these policies and agree to review our progress in six weeks. To facilitate implementation, small adjustments to the policies can be made along the way and do not have to wait until the STUDY phase.

STUDY:
After these policies have been in place for six weeks, we select another set of 20 charts of patients age 50-70 who were seen within the prior six weeks and find the following:

- 80% of charts document that colon cancer screening was offered to the patient
- Of those offered screening:
  - 60% received a recommended test
  - 5% received an inadequate or incomplete screening
  - 20% did not follow through with the screening after initially agreeing to it
  - 15% refused screening

The staff note that several patients had to have their procedures rescheduled because they did not follow any preparation instructions, and others did not return the entire set of hemoccult cards to the office. Staff also report that patients have many questions about the differences in the various screening options available. While our office has certainly improved the percentage of patients offered a screening test, it is still short of the practice goal of 90%.

This completes one PDSA cycle, and a new one begins.

In the new PDSA cycle we begin with the following changes or additions to the PLAN based on our last STUDY results and agree to STUDY again in six weeks:

(1) We will place posters in the waiting and exam rooms encouraging patients to ask their physician or nurse about colon cancer screening.

(2) During triage, when the NA determines if the patient is due for screening, the NA will ask the patient if he/she is interested in screening, and, if "yes," will begin to prepare the necessary paperwork for the physician to order the test.

***Sample PDSA**—continued on page 280*

***Sample PDSA**—continued from page 279*

(3) NAs will give patient education materials about colon cancer screening (including a decision aid to help patients choose from the effective alternatives) to the patient waiting in the exam room. Patients can read the material while waiting for the physician.

(4) Standard written patient preparation instructions for each of the four screening strategies are given to patients who have tests scheduled. We arrange necessary referrals and give them to the patient before he/she leaves the office.

This sample strategy may seem archaic to those who have access to computers or EMR, but it is presented to illustrate that care quality improvements can be made even without access to computers. While EMR and computerized databases would improve efficiency in this process, it is possible to improve without them. In our practice, we have agreed to "start somewhere."

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COMMENTARY

Data and Information Requirements for Healthcare Performance Monitoring and Improvement

Robert R. Weiser, and Christopher Mansfield, PhD

Quality improvement requires the ability to measure performance. In healthcare, because of the many variables that can affect outcomes, performance measurement has been difficult. Establishing standardized measures based on valid and reliable clinical data on a state or national scale has proven to be especially challenging. A good deal of effort and resources by several different national groups and many individual physician practice organizations has demonstrated that performance measurement in healthcare is possible, and that, when combined with quality improvement methods, it does produce results.[1,2]

Quality improvement efforts must address two principal objectives. Safety is the first objective of quality, (i.e., "First, do no harm."). And safety, is defined as freedom from accidental injury.[3] Prevention of accidental injury in medical care depends on practicing within rational, evidence-based systems designed to anticipate, avoid, minimize, and learn from error. Such systems rely on algorithms, checklists, and recording and sharing information about the patient's care among the host of health providers likely to be involved. The second objective of quality is that the best care possible is provided within reasonable cost parameters. We can think of "best" care as that which is "safe, effective, patient-centered, timely, efficient, and equitable."[4] If not the best, then at least that which is adequate within conventional standards of care (i.e., "reasonable care"). It is not just that "Healthcare harms too frequently... but that it also...routinely fails to deliver its potential benefits."[4] Things that ought to be done may be left undone.

To achieve these two objectives, there must be commitment, accountability, leadership, systems for review and decision making, performance standards, means to measure performance, and data systems and procedures that allow providers to identify and learn from error. This commentary focuses on the measures, data systems, and procedures (i.e., establishing the information base required for quality improvement) both at a state- or system-wide level and within individual institutions and practice organizations.

> *"The need for better health records and recognition that technology exists to provide them is apparent not just to a few leaders of organized medicine, but to the general public and politicians as well."*

What is the Best Way to Measure Performance?

Performance measurement in healthcare refers to the ability to quantify outcomes, processes, satisfaction, or events in a manner that is objective, valid, and reliable. This means that it must be based on data that are collected accurately and consistently over time and location. The measures should be evidence- or consensus-based and provide a measurement of the care actually being provided against explicit standards. And perhaps most importantly, the measures must be meaningful. This means that the healthcare system has the ability to intervene directly to improve that which is being measured.

While it is not currently possible to measure every nuance of each patient's care, we can measure those parts of care for which there is evidence or wide agreement.[5,6] And this certainly tells us more about the care provided than the limited information in the measures themselves. The fact that only

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64% of Medicare patients admitted to hospitals in North Carolina receive antibiotics within four hours of arrival tells us a great deal beyond the measure. It points to underlying systemic issues. If we can't establish processes that assure that this one well-defined, understood and accepted part of treatment is accomplished, what else is being missed?

The data to drive the measures can be derived from a variety of sources including, payment or claims data, paper or electronic medical records, surveys, and reports such as incident reports. Each of these sources has its pluses and minuses. Claims data are the easiest to obtain, but the accuracy of certain variables, such as diagnoses and comorbidities, is sometimes uncertain. Information abstracted from medical records is the most clinically rich, but is a challenge to abstract reliably when multiple institutions or abstractors are involved. It is also labor-intensive and therefore the most costly means of obtaining data. Widespread adoption of electronic medical records will facilitate access to this information.

While the ultimate aim of quality improvement is to improve *outcomes*, outcome measures are the most difficult to develop. This is because most outcome measures must be risk-adjusted to account for the variations in the patients' condition or severity of illness. Fortunately *process* measures generally do not require risk adjustment and can be far more useful in quality improvement. Process measures address those aspects of treatment for which there is evidence linking them to improved outcomes for a specific diagnosis. Improvement in process measures for the specified population of patients should result in better outcomes. An example of a process measure currently in use is the percentage of eligible acute myocardial infarction (AMI) patients discharged from the hospital on a beta blocker.

Satisfaction measures attempt to quantify the consumers' degree of satisfaction with their encounter with the healthcare system. This is an aspect of quality that has been addressed through commercial surveys that are widely used by hospitals.

Event measures are most commonly associated with patient safety, such as the capture of medication or treatment errors.

Who Is Measuring Performance?

The importance of *performance* measurement is reflected by the number and type of organizations and agencies that have dedicated a significant amount of time and resources to their development. The Joint Commission on Accreditation of Health Care Organizations (JCAHO), the American Medical Association (AMA), the National Committee on Quality Assurance (NCQA), and the National Quality Forum (NQF) have all been deeply involved in the development of quality measures. The JCAHO now requires hospitals to abstract, validate, and submit a set of quality measures covering four clinical topics on a quarterly basis. The AMA in conjunction with several specialty medical societies has published nine sets of physician performance measures. The NCQA developed measures for managed care organizations. The NQF is a non-profit organization that operates a consensus-based process to endorse quality measures. It functions as a standards-setting organization for the healthcare industry. The federal government is obligated to utilize NQF-endorsed measures or must justify why they are utilizing something different.

At the federal level the Agency for Healthcare Research and Quality (AHRQ) and the Centers for Medicare and Medicaid Services (CMS) have worked for several years to develop quality measures. AHRQ has established the National Quality Measures Clearinghouse (www.qualitymeasures.ahrq.gov) that contains more than 400 sets of quality measures. CMS has developed, and now makes public, performance measures for nursing homes and home health agencies. CMS has also indicated it will make hospital performance measures public by the end of this year. All of these measures, plus a set of claims-based quality measures for the outpatient setting, are currently utilized by Medicare Quality Improvement Organizations (QIOs) in their work. Medical Review of North Carolina (MRNC), a private non-profit physician organization, is the QIO for this state.

Using Performance Measures to Improve Care and Ensure Patient Safety

Performance measurement and data collection is difficult, but if it is used constructively it is worth the effort. To utilize it constructively means incorporating it into quality improvement activities rather than using it in a punitive manner. And there are several constructive uses. *Benchmarking* with these measures allows us to determine what an achievable performance level is right now. Benchmarks should represent a demonstrably attainable level of excellence.[7]

For example, if we know that 10% of hospitals in North Carolina can get the proper antibiotic started within four hours of admission for 95% of their pneumonia patients, then we have determined that this is an achievable level. Utilizing systems analysis, we can examine how this was accomplished and construct models of best practice that can be shared with and implemented by other hospitals. Comparisons of performance levels can be done among similar types of institutions and practices.

Utilizing performance data, MRNC has worked with hospitals, nursing homes, and physicians in North Carolina and has seen improvement in several areas. Nursing homes have substantially improved the management of pain in their residents. Physicians have dramatically improved rates of testing for lipids and hemoglobin A1C in patients with diabetes. And hospitals have substantially improved on the number of eligible AMI patients discharged on beta blockers.

Individual physician practices have begun to utilize performance measures and comparative data to improve the care provided their patients. Patient registries, electronic medical records, and manual systems are being used to collect data and assess practice performance. The results are sometimes surprising to physicians who frequently believe that they are performing at a much higher rate. In some instances the ability to identify all of their patients with diabetes and measure practice performance has led to systemic change in the practice.

For individual practice organizations, safety remains the first concern, and systems must be in place to prevent errors of commission. But to provide the best care possible, the systems must also prevent errors of omission. We must make sure that we do the things we ought to do (e.g., not just the proper sequence of steps in a procedure, but acquiring, recording, considering, and sharing information required to prevent, diagnose, prescribe, and treat). For primary care practitioners, patient information systems must be designed to facilitate prevention and management of the most common infectious and chronic diseases. Clinical priority in structuring the patient information system should be preventing the leading diseases associated with mortality (heart, cancer, and stroke) and making sure the leading "actual" causes of death are addressed, (i.e., smoking, diet, and physical activity).[8,9] Does the record system remind, facilitate, perhaps even force, the clinician to consider patient behaviors and discuss them with the patient if appropriate or necessary?

A patient information system should provide a list of the patient's principal problems for the physician at each encounter. A physician, being reminded that Mrs. Jones is a diabetic, should be cued by the system to consider whether her visit should include: an eye exam, hemagolbin A1C test, urine test, foot exam, lipid profile, nutritional assessment, diabetes education, and assessment of blood pressure, weight/body mass index (BMI), and physical activity. For female patients, regardless of the problem list, it should cue to remind about smoking, and, by age standards, for mammograms, cancer screenings, and flu vaccine. The data system should be designed for sharing information with the patient and other providers. If Mrs. Jones is educated and engaged in her care, she should know her "numbers" and encouraged to set goals for those within her control. Sharing data with her may itself reduce the chance of error. Educated and engaged patients may spot potential errors themselves. Sometimes, breakdowns in the clinical-patient relationship are responsible for errors.[10] Breakdowns in communication with other providers are a very common source of error and most error incidents are not single acts, but a chain of events or a cascade.[11,12] An electronic health record, can become a shared communication tool among her providers. The pharmacist can easily know what other medications she is taking and essential information can accompany referrals to other providers.

Error is a condition of being human. The more humans involved, the more error is possible. Indeed, without proper systems the potential for increase in error is exponentially related to the number of people involved a patient's care. Good systems not only allow us to minimize error but to learn from error. Lewis Thomas said "We get along in life this way. We are built to make mistakes, coded for error. We learn, as we say, by 'trial and error.'...Why not 'trial and rightness' or 'trial and triumph'"[13]

Conclusion

"If we want safer, higher-quality care, we will need to have redesigned systems of care, including the use of information technology to support clinical and administrative processes."[4] The need for better health records and recognition that technology exists to provide them is apparent not just to a few leaders of organized medicine, but to the general public and politicians as well. President Bush recently announced an initiative with the goal of an electronic health record (EHR) for most Americans within a decade, proposed doubling federal spending for EHR to $100 million, and challenged the healthcare industry to invest in health information systems.[14] Ultimately that is what performance measurement is about: changing systems to provide better care. Without collecting the data and measuring the system's performance, we don't know what we need to change or the urgency with which we need to change it. **NCMJ**

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COMMENTARY

Evidence-Based Medicine:
Ready for Prime Time?

Charles F. Willson, MD, and G. Hadley Callaway, MD

The authors elected to take separate viewpoints

New and Better
Charles F. Willson, MD

"Evidence-based medicine is most recently defined as the integration of the best research evidence with clinical experience and patient values."[1] As a busy clinician for the past 25 years, I've become accustomed to the science of uncertainty and to making timely decisions based on incomplete evidence. But I've yearned for a way to know that my diagnostic and therapeutic approaches reflected state-of-the-art pediatric care at that moment in time. Most textbooks when published are already two years behind current knowledge. Continuing Medical Education (CME) courses certainly helped to update my knowledge base, but often left gaps in how to implement the best approach being described. Hospital or phone consultations with pediatric subspecialists were helpful, but the specialist I needed at that moment may not be available for hours or days. The movement toward a systemized analysis of the research evidence and development of practical care guidelines for common or more rare clinical problems (i.e., evidence-based medicine) has the potential to meet this significant need of busy primary care clinicians.

Under the old medical care paradigm, when an infant presented acutely to my office with a serious, but uncommon, diagnosis such as septic arthritis, I'd arrange admission to the hospital. Hectically trying to remember the teachings on septic arthritis of our pediatric infectious disease experts during my residency years, 1974 through 1980, I'd quickly consult a general textbook of pediatrics published about ten years earlier. I'd hurriedly write orders that included diagnostic studies prior to antibiotics, intravenous antibiotics, orthopedic consultation, and pediatric infectious disease consultation. If I were really uncertain about what to do, such as whether to have the orthopedist tap the joint or have a radiologist tap it under ultrasound guidance, I'd call the consultant for a recommendation. This process might take 20-40 minutes. All the while patients continue to arrive for care at the rate of four to six per hour. As I entered the next exam room, I'd fret about the serious decisions I'd just launched and wondered if I had met "best-practice" standards.

But things are changing. Spurred by the national Institute of Medicine report, *To Err is Human*,[2] reporting that 98,000 deaths occur yearly in our hospitals due to preventable medical errors, our profession has been called to action. We must improve our systems of care. These mortality statistics don't even address how many hospitalized patients might have received substandard care. In the companion report, *Crossing the Quality Chasm*,[3] the Institute of Medicine Recommendation Number 8 calls for the Secretary of the United States Department of Health and Human Services to be given "the responsibility and necessary resources to establish and maintain a comprehensive program aimed at making scientific evidence more useful and accessible to clinicians and patients." Fortunately, the evolution of computer technology and the Internet will make such a massive effort feasible. Our medical school students and residents have also changed. They are computer literate and savvy. We medical school faculty are encouraging them to search the Internet for evidence-based articles relevant to their patients, and many now turn to the computer for help instead of the aging textbooks on the clinic shelf.

> *"The practice of medicine is an art, based on science. Medicine is a science of uncertainty and an art of probability"*
>
> —Sir William Osler

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Not only will the computer software allow us to access the latest information about a particular clinical problem, I hope the Institute of Medicine will link these sites to a data warehouse that will allow the patient's admission data and eventual outcome to be recorded. That way, we would have an on-going study of the clinical effectiveness on all the patients we treat with a particular diagnosis. Although time-consuming, this feedback on outcomes could be the price we physicians pay for having evidence-based medicine at our fingertips. Of course, in all these activities, patient confidentiality must be maintained. Physician-specific information would be protected under peer-review laws.

Now, when I admit a patient to the hospital, I ask the resident on the pediatric ward to do a quick diagnosis-specific search to see what recent articles may answer our clinically relevant questions. Medication dosages are easily accessed on a personal digital assistant (PDA) linked to the ePocrates®[4] web site. Evidence-based medicine is becoming a reality. I'm left with a few extra, precious minutes to practice the art of medicine, sitting with the parent, holding her hand, and answering her tearful questions.

But, there are bumps in the road. Dr. Onady who authored the chapter on evidence-based medicine in our textbook, *Pediatric Hospital Medicine*,[1] has testified in a malpractice trial where the defendant physician used an evidence-based approach to treat a patient who subsequently suffered a poor outcome. The plaintiff alleged that the physician's care deviated from the community standard and won. Progress is rarely painless.

The future for our physicians in training is truly exciting. Instead of trying to remember what Dr. Willson taught her about managing a 15-month old with fever and a swollen joint, the new physician will turn to her laptop computer. In seconds a pediatric web site will appear that outlines a recently updated algorithm for diagnostic work-up and management of septic arthritis in a child. Perhaps the data will even be age, sex, and ethnically specific. A comprehensive differential diagnosis list may provide much of the value of a specialty consultation. Within seconds, the pediatrician will have ordered a hospital admission, ultrasound-guided arthrocentesis, blood culture, complete blood count (CBC), and pathogen-specific antibiotics. OOPS! The computer screen flashes that the child is allergic to penicillin, and a substitute antibiotic is suggested. The physician then has time to answer the mother's questions and allay fears. The mother knows that her baby's doctor has used the latest medical information in developing the care plan. As the mother carries her child to the hospital, she'll stop first at the radiology suite for the joint tap and the orthopedist consulting will have the fluid analysis when he arrives on the ward to see her. The pediatrician goes into the next exam room with a mind uncluttered by doubts and questions about the crucial decisions she has just made.

Osler would be relieved and proud.

Approach with Caution

G. Hadley Callaway, MD

The new "evidence-based medicine" has a somewhat arrogant name, as though the rest of healthcare is "opinion-based." I would be careful not to throw out the baby with the bathwater.

I hesitate to throw out the "opinions" I was taught in medical school and orthopedic training. My teachers taught from all the evidence that was available, supplemented by their clinical experience. During training we used Medline and critically reviewed the literature. We had lots of evidence, but not randomized controlled studies for every treatment.

In my specialty of orthopedics, the "evidence-based medicine" is surprisingly limited. Very few surgical treatments have been evaluated in randomized controlled studies with comparison to sham surgery or to each other. As an example, consider the difficulty in randomizing a humpback child to scoliosis surgery or not.

If I only used "evidence-based medicine," my scope of practice would be tiny. My standard treatment for back or joint pain might be: "There is evidence that acetaminophen will reduce your pain score, but nothing else to offer." I have ePocrates®, but that is no help in this situation.

I am also wary of sudden changes in the medical "evidence." Witness the Atkins® diet craze. Should my mom have been taking Premarin®? Within orthopedics there are a hundred "scientifically" supported fads that come and go. Many published and unpublished studies are controlled by industry. This is why most doctors do not change their practice based on the newest journal reports.

Finally, most of my life is guided by firmly held opinions based on limited evidence. What to study, whom to marry, which religion, how to raise the children—all are determined by opinion. Why should medicine be so different?

So How Should We Deal with "Evidence-Based Medicine?"

First, tell the public that evidence-based medicine is not new. Physicians have always relied on scientific evaluation of treatment alternatives, but the quality of studies is constantly improving. We have been using computerized literature searches of Medline since the 1980s. We were taught in medical school to critically analyze the literature. Statistics were part of the pre-med and first year curriculum. Most of us update our practice according to monthly journal reports.

Second, let's change the name to "medicine with a constantly updated computer reference." The whole movement owes its existence to the Internet. Either the reference will pop up when I enter orders at the hospital, or I will need to carry it in my pocket. You cannot practice according to the voluminous and changing evidence-based guidelines without an Internet device.

Third, recognize that evidence-based medicine is just the

X-generation reviewing and rewriting the information base. Remember how crude and mistaken the medical evidence was before the baby boom rewrote it last generation? The term "evidence-based medicine" is inflammatory and misleading; it should be abandoned. I would suggest "medicine based on randomized trials," which acknowledges that the rest of medicine has a good foundation in evidence also.

Fourth, tell everyone that updating our information will take a long time. During the transition we must work with a blend of old and new information. Don't let Medicare or insurance companies deny or limit coverage for valuable treatments because they are not yet supported by randomized controlled studies which constitute the best "evidence." Misuse of guidelines by third-party payers may harm more patients than the guidelines help.

Fifth, get familiar with the guidelines. Before they are accepted as dogma, they deserve scrutiny by practicing physicians. Guidelines that conflict with common sense should be reviewed. Areas that need study should be identified. As journal articles are published, their effect on guidelines should be considered. Over time, the guidelines will increasingly restrict our treatment options, so they had better be good. Whoever controls the guidelines will control medical practice.

Finally, use the guidelines as a crutch. I have a hard time keeping up with journal reading. The Cochrane guidelines are like Cliff's (or Spark) Notes, although chapters covering most of my practice are still missing! **NCMJ**

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Evidence-Based Medicine: A Clinical Case Scenerio

Charles F. Willson, MD

The first patient of the morning

The young mother is clearly worried as she relates that her nine-month-old daughter, Kaylee, started running a fever last night. She gave an appropriate dose of Tylenol and checked on her throughout the night. The fever waned initially, but is now back with a vengeance: 104.4F. When she changed the diaper this morning, the child cried in pain as she moved the left leg. The left knee was swollen and warm. The Tylenol dose this morning did little to relieve the pain and fever.

As a pediatrician, I know the diagnosis of septic arthritis is fairly certain. But, it has been several years since I initiated care for a child with septic arthritis, and, over a practice lifetime (25 years), I'd probably made the initial diagnosis only a dozen or so times. Thinking back to my resident days, I try to recall the teachings of my honored mentors. ("What would Floyd Denny have done?") Clearly, I'll admit the child to the hospital, get someone to tap the joint for cell count and culture, and begin intravenous antibiotics. But questions begin crowding my thoughts. ***Should I ask the orthopedist to tap the joint or should I have a radiologist tap it under ultrasound guidance?*** In this era of immunization against Hemophilus influenza group B, ***what antibiotics should I start, and at what doses?*** I remember seeing an article from the Centers for Disease Control and Prevention in the *Journal of the American Medical Association* last month that talked about Kingella kingae as an emerging cause of septic arthritis in children. I'd never heard of Kingella kingae and meant to look it up. ***Is it a new pathogen or one of the old ones now renamed?*** I don't even know if it is a gram positive or gram negative bug. ***What antibiotic would cover it? What are the chances that the baby will have a damaged hip, or make a full recovery?*** As the questions come, so do the patients. I need to call the hospital and have the patient admitted. Fortunately, we have pediatric residents who can take over and call radiology, orthopedics, and pediatrics infectious disease. (My colleagues in more rural practices don't have these resources.) I'd like to sound knowledgeable as I instruct the resident, but I don't know the current literature, and the next patient is waiting.

I take the mother's hand, explaining that her daughter has an infection of the knee that can be quite dangerous. Hospitalization, study of the joint fluid, and intravenous antibiotics for many days will be necessary. Tears begin rolling down her face. "We have wonderful specialists who will help us with Kaylee's care," I tried to reassure her, but I was certain that the worry on my face spoke louder. Her questions start to come. ***How long will Kaylee need to stay in the hospital? Will her knee be ok? Is it dangerous to stick a needle in a baby's knee? Do the antibiotics have side effects? How did she get this infection?*** I reassure her that I'll be over to the hospital at lunch time to answer all these good questions, but we needed to get Kaylee over to the hospital now to start treatment. As I enter the next exam room, I hope that I'll be finished with my morning patients in time to get over to the hospital to check on Kaylee.

I feel an irony that the vast fund of medical knowledge is inaccessible when a busy clinician needs it the most. When a baby presents with a septic arthritis or any other major infection, the clock is ticking. The opportunity for an optimal outcome is hanging in the balance. Evidence-based medicine with its guidelines, decision trees, and clinical care paths will bring the state-of-the-art, up-to-date information to the finger tips of the front-line practitioner, even in the remotest of setting.

Not only must we embrace evidence-based medicine, we must go the extra mile and ask that all physicians who use these tools report the outcomes of their patients. Precious information that would strengthen our knowledge base is being lost every day. Am I concerned about losing some autonomy as a practitioner? It's a small price to pay to benefit Kaylee.

COMMENTARY

Disease Management Approaches to Quality Improvement

John R. Mangum, MD, and Conrad L. Flick, MD

Physicians and other healthcare professionals correctly view good medical decision-making as the cornerstone of quality care for our patients. However, no matter how well-constructed a plan of treatment for an individual patient may be, optimal management of that disease may still not be achieved unless other, less obvious factors fall appropriately into place. Unfortunately, the pitfalls are numerous and commonplace. The cost of medication may lead a patient to not fill a prescription. The patient may take the medication less often than prescribed due to real or perceived side effects. The patient may not understand that a chronic asymptomatic disease requires ongoing therapy and periodic medical re-evaluation. These and numerous other cultural, financial, and social factors may strongly impact the management of a patient's disease and that patient's overall health status.

> *"Disease management is a many-faceted process...usually designed for high-cost and/or high-volume diseases, such as diabetes, hypertension, asthma, HIV, and congestive heart failure."*

The number of Americans living with chronic disease is increasing dramatically. It is estimated that the number will reach 120 million in 2010, constituting 40% of the United States population.[1] Within the Medicare program, as much as two-thirds of the expenditures are estimated to go for the care of participants with five or more longstanding medical conditions.[2] Among younger populations, estimates of lost workplace productivity due to chronic disease are remarkably high.[1]

The federal government, groups of employers, and providers of healthcare are all searching for innovative solutions that can improve health outcomes, reduce hospitalization rates, provide cost savings, and reduce workplace absenteeism. More and more frequently they are looking to "disease management" as a key strategy in achieving these goals.

Disease management is a many-faceted process of organizing care with the intention of improving health outcomes for certain disease states and, when possible, lowering overall healthcare costs. Most of the cost reductions are achieved through methods to prevent errors, limit long-term complications of diseases that are not being maximally managed and prevent duplication or overuse of services. It is usually designed for high-cost and/or high-volume diseases, such as diabetes, hypertension, asthma, HIV, and congestive heart failure.

Disease management can be as simple as a patient education handout explaining the disease or as complex as a multidisciplinary team working together to establish a comprehensive plan of care for an individual with multiple chronic conditions.

Medical conditions that seem to be the best candidates for disease management approaches have some or all of the following characteristics:

- High volume or high cost (or both)
- Evidence that wide variations in care approaches exist among practitioners
- Evidence that particular defined care approaches lead to improvements in clinical outcomes

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Disease Management in Practice

Joe Taylor is a moderately overweight 58-year-old male who has been hypertensive for seven years. His hypertension is controlled with two medications. He presents to his family physician, Dr. Williams, complaining of increased urinary frequency and low energy. He is diagnosed with new-onset type II diabetes mellitus. Dr. Williams discusses with Mr. Taylor many aspects of diabetes—how it is treated, the importance of exercise and weight loss, the vital role diet plays, the potential complications that may arise. She provides written patient education materials. She asks Mr. Taylor to begin home glucose monitoring. Dr. Williams follows appropriate clinical practice guidelines in choosing an oral hypoglycemic agent and re-evaluates his hypertensive regimen in light of the newly diagnosed diabetes.

Through the disease management program already in place, Mr. Taylor is referred to a dietitian and to a local patient education program for diabetics that brings them in for a series of group sessions. A nurse with the disease management program contacts Mr. Taylor by phone two weeks after his diagnosis to ask how he is doing, answer questions he may have about diabetes, see if he is doing the home glucose monitoring, encourage adherence to diet and exercise recommendations, and to reinforce the reasons that long-term control of the diabetes is so important to his health.

A few days before his follow-up appointment with Dr. Williams, Mr. Taylor is contacted by phone reminding him of the day and time of the appointment. At that first follow-up appointment, Dr. Williams has triggered her diabetes software program in the electronic medical record for Mr. Taylor. The program provides for easy tracking over time of blood pressure, weight, hemoglobin A1Cs, annual dilated eye exams, and last flu and pneumococcal immunizations. It provides reminders to Dr. Williams for periodic checking of urine micro-albumin, foot/skin integrity and sensation, and other important aspects of diabetic care. Over the next several months, the pharmaceutical benefit manager monitors medication refill records to see if the patient appears to be taking his medication as prescribed.

Through the combined efforts of the patient and all those involved in his care, Mr. Taylor is given the best possible chance to control his diabetes and reduce the likelihood that he will develop vascular, renal, neurologic or other complications.

- Care by multiple physicians of different medical specialties
- Purchaser interest in reducing treatment variation/cost[3]

Disease management is in its early stages and, thus far, there is little firm evidence regarding outcomes.[1] Over 150 companies in the United States currently offer some form of disease management services or products.[1] Many of these are independent companies, but some have been developed by managed care organizations, e-Health technology companies and pharmacy benefit managers.

Future purchasers of disease management services will require detailed information on the effectiveness of these programs. This is especially important as the medical community strives for a more evidence-based approach to its medical decision-making. The disease management industry has the challenge of providing measurable and accurate data showing improved health outcomes and reduced healthcare costs.

Well-structured disease management programs should incorporate the following characteristics and goals.

- Improve outcomes by promoting the provision of timely and appropriate services.
- Utilize clinical information systems to help identify and track defined patient populations.
- Develop clinical practice guidelines by physicians and other healthcare personnel knowledgeable in treating chronic disease, utilizing evidence-based medicine, where available.
- Promote cooperation between primary care and specialty care physicians, including free flow of clinical information.
- Emphasize educating and empowering patients to successfully manage their own health, use self-monitoring techniques, and intelligently use care resources.
- Allow the choice of pharmaceuticals to be based on clinical judgment and validated outcomes studies rather than forcing strict adherence to program formularies.
- Allow informed and voluntary patient participation in the program.
- Incorporate ancillary medical services to support the physician's treatment plan.
- Allow physicians to deviate from disease management practice guidelines when appropriate, without incurring sanctions or jeopardizing coverage for services.
- Collect, evaluate, and disseminate information on outcomes to physicians and other providers of care.
- Support the primary care physician's authority for decisions to use or not use specialized care and ancillary services for patients.

Physicians have many opportunities within their own offices to establish disease management approaches to the care of their patients with chronic illnesses. Any disease management initiative should make the physician an integral part of the planning and implementation of that system. Without physician involvement and cooperation, the program is far less likely to be effective. A system without physician involvement may, in fact, be counterproductive, since it is the physician who is ultimately responsible for the care plan and health of that patient.

The growing use of electronic medical records should facilitate more and more physicians in utilizing disease management strategies in their offices. Many primary care organizations and, more recently, the Centers for Medicare and Medicaid Services are encouraging the increased use of electronic medical records.[2] They rightly recognize the potential for decreasing errors, making periodic health maintenance (e.g., mammograms, immunizations) easier to track, and improving health outcomes. Current limitations for physician offices include its cost and the difficulties of getting such systems to allow for easy flow of information between all providers of care (primary care physicians, specialty care physicians, hospitals, pharmacies, and others).

Disease management is an evolving concept. Whether it will be successful is highly dependent on a collaborative effort among all members of the healthcare team (patients, physicians, allied health professionals, health insurers, and employers) to bring improved health outcomes. The need for such approaches will only grow with time, as our population ages and as the unfortunate trend of adult and childhood obesity leads to more Americans living with chronic disease states. The potential burden on society and on the healthcare system is great, and the need for innovative and meaningful new approaches is equally great. With a disease management system that is well-constructed, relatively easy to implement, and efficient in its consumption of time and resources, we have a tremendous opportunity to positively impact our patients' health. **NCMJ**

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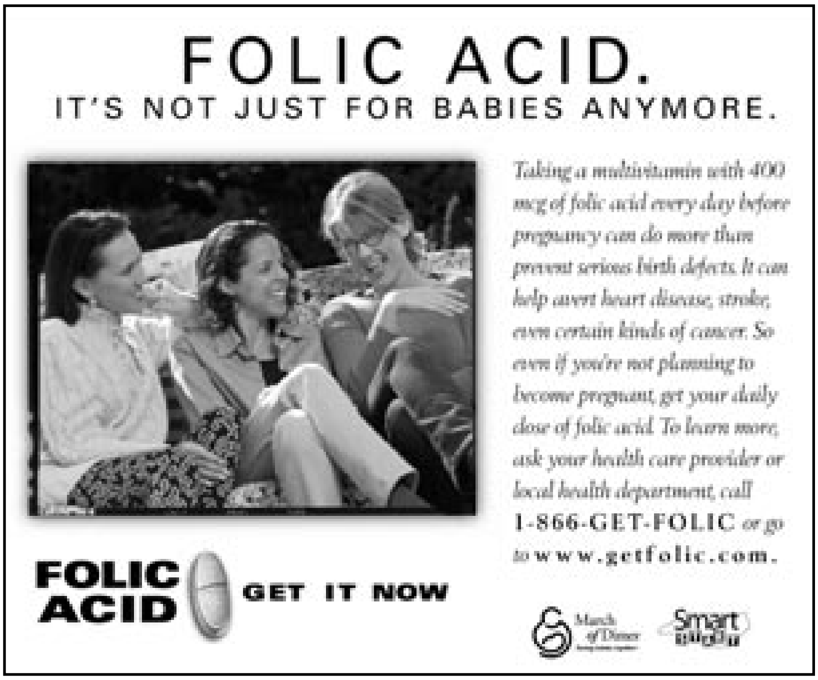

Educating a New Generation of Healthcare Professionals with a Lifelong Commitment to Quality of Care

Stephen E. Willis, MD, Thomas J. Pulliam, MD, and Thomas J. Bacon, DrPH

This is a time of evolution and some turmoil within continuing medical education. Physician continuing professional development is coming under increasing scrutiny by a number of regulatory authorities both within the profession and external to it. A number of areas are receiving especially focused attention. These include the need for continuing professional development to be based on demonstrated needs of the physician and to result in demonstrable positive outcomes. The increased empowerment of the consumer and heightened expectations about quality care and evidence-based practices are also an influencing factor.

> *"...new entrants into the healthcare professions are being trained in paradigms that differ somewhat from the training received by those currently in practice."*

Increased physician accountability is expected to ensure positive outcomes. The influence of commercial entities on continuing professional development is closely monitored and scrutinized. Physicians and educators are challenged to successfully incorporate technology and electronic resources into healthcare and continuing education. Educators throughout the continuum of medical education are challenged to include training designed to augment the skills of learners in interacting effectively with patients.

Furthermore, new entrants into healthcare professions are being trained in paradigms that differ somewhat from the training received by those currently in practice. These new methods emphasize the use of interdisciplinary teams in healthcare, evidence-based practice and best practices, quality improvement initiatives, and the use of medical informatics as a tool for healthcare performance improvement. These are recent developments that will substantially impact the care rendered by new providers entering practice. They may bring a set of skills that may not be entirely congruous with traditions of practice developed by more seasoned and experienced clinicians. One of the challenges for educators involved in continuing professional development will be the need to incorporate training in these newer methods into their offerings. Continuous learning and development are important, first and foremost, to improve the healthcare rendered to, and the health of, those patients we serve.

We must embrace a system of practice-based continuing professional development that encourages physicians to: extract data from their practice, understand how these data relate to evidence-based best practices, design a system for conscious evolution of medical practice that is relevant to the community of patients served, incorporate technology and interdisciplinary healthcare teams into the provision of patient care, and finally, to assess the outcome of appropriate interventions and changes in patient care. Physicians must be both supported in and rewarded for such practice-based, patient-centered, and community-focused educational and practice initiatives. In the near future, it seems likely that physicians will be responsible for accounting for more than just "seat time" at continuing medical education (CME) events as they demonstrate their commitment to the ongoing maintenance of certification and continued competence.

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We are fortunate in North Carolina to have a number of organizations committed to the education of our healthcare professionals. These include, but are certainly not limited to, the North Carolina Medical Society, various specialty and sub-specialty associations and societies, regulatory authorities, third-party payors, the academic health centers, and the North Carolina Area Health Education Centers (AHEC) Program. There are a large number of important initiatives, frequently involving collaborative efforts among these various organizations, currently underway. Many of these initiatives could impact medical practice in very fundamental ways. All of these initiatives require that physicians be skilled in the precepts of lifelong learning and committed to making changes in practice. Lifelong learning and continuing professional development must start with the physician being focused on enhancing the health of those we serve, and never end.

When Does Lifelong Learning Begin?

All clinical professionals evolve in their depth of understanding and knowledge in their areas of expertise. Ideally, the evolution of a professional's learning would begin while a student and continue throughout his or her professional life. Medical educators at the four medical schools in North Carolina continue to modify and refocus programs in the areas of interdisciplinary practice, computer-based learning, and evidence-based standards of care.

As examples:

- The Wake Forest University School of Medicine (WFUSM) provides a problem-based medical education. The medical curriculum is called the "Prescription for Excellence: A Physician's Pathway to Lifelong Learning." The curriculum initiates the learning process of the medical student by integrating the basic and clinical knowledge of medicine with current technology while building upon a foundation of ethical professional behaviors. The curriculum is organized to meet the five specific goals: (1) proficiency in self-directed learning and lifelong learning skills; (2) appropriate core biomedical science knowledge, clinical problem solving, and reasoning skills; (3) interviewing and communication skills; (4) information management skills; and (5) professional attitudes and behaviors. Across the five phases of their four-year curriculum WFUSM students study the basics of clinical sciences in an integrated fashion utilizing a variety of educational methods including small groups and problem-based learning. Community-based clinical experiences begin in the first year and focus on general population health. Issues of professionalism and humanism in medicine are addressed longitudinally throughout the four years. Information technology is integrated with a laptop computer issued early on and a Personal Digital Assistant (PDA) provided during their clinical rotations.

  Students are held accountable for embracing lifelong learning. The emphasis is upon the student gathering information and learning to think rather than simply memorizing factual information. The testing process also enhances the learning process with a focus on critical thinking skills rather than simply recalling factual knowledge. Thus far, the product of the Prescription for Excellence curriculum has been a well-rounded, generalist clinician who is prepared to embrace the evolving changes in medical practice with a focus on learning and self-assessment.

"Physicians must be both supported in and rewarded for such practice-based, patient-centered, and community-focused educational and practice initiatives."

- The East Carolina University Division of Health Sciences, collaborating with Eastern AHEC, has a nationally renowned program for training new entrants into healthcare professions in the nuances of effective interdisciplinary practice. Students are challenged to develop and demonstrate the ability to work together as members of teams aimed at providing comprehensive, cost-effective, efficient, and compassionate care for patients with chronic medical conditions. They utilize the unique skills and knowledge of providers from a large variety of disciplines while simultaneously minimizing repetition, enhancing communication, and capitalizing on the synergy inherent in truly interdisciplinary care. Learners who participate in these programs have skills heretofore not taught in the educational programs in medicine.

- Medical and other health profession students at most, or all, of our universities in North Carolina are now required to utilize computers and electronic resources as an integral mechanism for learning. Real-time and "point-of-care" resources are being utilized by an increasing number of health professionals. It will not be long before physicians emerging from residency will be dependent upon electronic resources in the day-to-day provision of patient care. Many of these practitioners will also use electronic media as a primary learning tool. In our opinion, electronic media will never entirely supplant, nor should they, traditional face-to-face professional development. These events provide critical networking and socialization functions in addition to serving as many practitioners' preferred mechanism of learning. At the same time, these events need to be much more data-driven and tied to changes in practice by the participating physicians.

A project funded by The Duke Endowment is currently getting underway in Charlotte and Southern Regional AHECs, in collaboration with the North Carolina Child Health Improvement Initiative at the University of North Carolina at Chapel Hill, to improve asthma care among all pediatric and family medicine practices in those two regions. Ultimately, some 330 practices will be involved in the project. Participating practices will receive data on their practices, take part in learning collaboratives, and implement evidence-based practices to achieve better outcomes of care.

- The United States Medical Licensing Examination (USMLE) has recently incorporated a clinical skills test utilizing standardized patients. As of June 2005, all potential licensees within the United States will be required to take, as a part of the USMLE Step 2, an examination that challenges them to demonstrate an ability to interact effectively with a patient in the context of an authentic, realistic clinical encounter.

As evidenced by the American Board of Medical Specialties (ABMS) maintenance of certification initiative, certifying boards are likely to expect practicing healthcare providers to demonstrate proficiency in some of these evolving skills to maintain their certification. It will take a sustained commitment among the many entities committed to improving patient health to effectively integrate new initiatives in continuing professional development. These organizations must work effectively and efficiently with physicians and other healthcare professionals to maximize the rational utilization of these new initiatives.

Equally important is the need for academic health centers, the North Carolina AHEC Program, Medical Review of North Carolina, third-party payers, and individual healthcare providers to accumulate and analyze data that will inform decision-making regarding the appropriate and effective utilization of emerging initiatives in healthcare and continuing professional development. While these critically important challenges are great, they are not insoluble. By capitalizing on the synergy of effective collaboration, we can meet these challenges and insure that the evolution in healthcare and continuing professional development results in improved health for those we serve. **NCMJ**

RESOURCES

1. Association of American Medical Colleges www.aamc.org
2. Accreditation Council for Continuing Medical Education www.accme.org
3. American Board of Medical Specialties www.abms.org
4. Accreditation Council for Graduate Medical Education www.acgme.org
5. Institute of Medicine, National Academies, Washington, DC. www.iom.edu

Making Healthcare 'Patient-Centered':
The Centerpiece of Quality Improvement

L. Allen Dobson, Jr., MD, FAAFP, and Michelle F. Jones, MD

In a time when the bottom line drives healthcare delivery, including access to care, diagnostic interventions, and therapeutic plans, we are left with a system that is in need of fundamental change. The system is inefficient, redundant, confusing for patients and providers. It is increasingly fragmented and is not meeting the needs of its recipients. Instead of treating patients, caregivers treat the threat of malpractice law suits as well as concerns of evoking the wrath of payers over the costs of tests ordered and medications prescribed. Despite the best efforts of those involved in caring for patients, our systems have failed both the patients and the caregiver.

The current attention to the need for quality improvement identified in the 2001 national Institute of Medicine report[1] and the subject of this Journal has sparked significant discussion in the medical, government, and business communities. Future models of healthcare must focus on patients' needs and preferences, quality of services, and a reduction in variability of care. Care coordination and integration, the transfer of information, and communication with the patient must be addressed in any emerging system that adequately meets patients' expectations.

> *"...all patients in the healthcare system deserve a medical home."*

Patient-Centered Care

Patient-centered care has been identified as a key attribute of a new system. It has the needs and preferences of each patient as its central focus. The cornerstone of this care is a patient-physician relationship that is satisfying to the patient and humanizing to both the patient and physician.[2] The interaction should be sensitive to the patient's physical and emotional needs and wants and should be culturally competent. These needs are likely to change over time and with different disease states; therefore, an established relationship will augment decisions and help ensure patient satisfaction. This should ideally be a long-term relationship and should be a partnership for the good of the patient. To-date, there is limited research to identify the most important aspects of patient-centered care or how to best deliver such care. The Cochrane Collaborative[3] performed a systematic review of the literature to determine whether patient-centered communication improves patient health outcomes and patient satisfaction. Although there was evidence of positive impact on patient satisfaction, the evidence was insufficient to draw conclusions about the impact on the patient's health status. Yet, intuitively, care that is patient-centered is what we all want for our own families and represents an obvious system goal in the move toward quality improvement. Clearly more research is required.

Unfortunately the quality of care and evidenced-based decision making provided alone may do little to make up for the shortcomings in the quality of service patients receive, and therefore their perception regarding the quality of our healthcare system. A study by the Picker/Commonwealth Program for Patient-Centered Care[4] suggests that patients often define quality care in terms of "service." Among the measures of quality patients identified in the study were: (1) respect for patient's preferences and values, (2) timely access to care, (3) information and education, and (4) continuity. Similarly, a recent study found that medical errors reported by patients are more likely to directly involve the breakdowns in the physician-patient relationship and the access to clinicians than the technical errors that are the focus of the most current patient safety initiatives.[5]

A Medical Home for All Patients

There is clearly a need for the healthcare system to refocus on better coordination and integration of patient care. This coordination and integration of care should focus on better

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service and begin with a personal physician and a personal medical home. The recommendation of a medical home was initially adopted by the American Academy of Pediatrics for children, but all patients in the healthcare system deserve a medical home. A medical home would serve as a point though which all individuals regardless of age, sex, race, or socioeconomic status enter into the healthcare system. It would ensure access to comprehensive and integrated care through physicians, nurses, therapists, and educators. Information and educational materials for patients could be easily accessed by patients. Barriers to access can be minimized with flexible office hours, open-access scheduling, and asynchronous communication such as voice mail and e-mail. Consultation and referral services would be coordinated through this model and would be smooth with a timely and reliable exchange of information to and from the consultant. The electronic medical record has great potential for improving this vital communication exchange. Many patients depend on those who provide care to coordinate seamless transitions from one setting to another and from a healthcare to a self-care setting.[6]

Patient Inclusion Improves Care

In the current system, timely access to information belongs only to the caregivers. Patients may only obtain information after permission is obtained, the appropriate paperwork is completed, and the two-week waiting period during which the charts are copied by contracting agencies has passed. Donald Berwick has introduced a concept of nurturing “transparency” in the healthcare system. By this he means that all information should be available to anyone involved in the system and in the care of the patient, including, and most importantly, the patient. Healthcare should certainly be confidential, but the healthcare industry is not entitled to secrecy.[7]

A quote from Diane Plamping, a public health researcher from the United Kingdom. says, “Nothing about me, without me.”[8] Transparency in the system will allow patients to make informed choices and allow access to facts that may be relevant to the patient’s decision making. Naturally, there is a concern about increased liability risk, and tort reform would be a desirable change, but improvement in the system cannot wait for such change. Healthcare systems with transparency will be more patient-centered and safer because patients may recognize information that is outdated or incorrect, which may affect their care.

Information on disease states may be obtained through many peer-reviewed and non-peer reviewed sources with varying degrees of accuracy. No longer is the physician the major source of medical information for patients. In a 1998 survey of Internet users, 42% said they accessed medical information weekly or daily on the Internet.[9] It is becoming well known through growing scientific literature that informed patients participating actively in their care have better outcomes, lower costs, and higher functional status than those held to more passive roles. Guadagnoli and Ward have found in a recent review of the literature that most patients want to be involved in the treatment decisions and to know about available alternatives.[10] Patients should not be forced to share decision making, but should be able to exercise the degree of control they wish. Arora and McHorney found that the majority of patients with chronic diseases, such as hypertension, diabetes, congestive heart failure and depression, preferred to delegate their medical decisions to their physicians.[11] Currently, two-thirds of United States healthcare expenditures are related to such chronic illnesses. Providing systems that support a continuous ongoing relationship between patient and physician, collaborative multi-provider models that support patient needs, and reliable information exchange with patients and clinical decision support systems for physicians are critical in adjusting the healthcare system from an acute care model to one capable of handling the burden of chronic illness.

> *“Healthcare systems with transparency will be more patient-centered and safer because patients may recognize information that is outdated or incorrect, which may affect their care.”*

The Internet Extends Care Beyond the Office

Traditionally, the doctor-patient interaction is only reimbursed with a face-to-face meeting. Often times this interaction is needed for evaluation of a patient’s condition, but for many this meeting is neither needed by the provider nor wanted by the patient. Twenty-first century technology through the Internet and e-mail communication allows for care in the comfort of a patient’s own home. The Internet may offer providers a way to interact more frequently with patients, to monitor progress, and provide education and reminders.

The Internet will likely be able to support a substantial portion of healthcare services, which will require new payment policies to compensate providers as the face-to-face patient visits cease to be the single method of patient care. In the past, payers have resisted paying for these services, citing this was part of the coordination of care and difficulties in adequately documenting time and effort spent on such services. However, primary care practice involves much more time spent in answering calls and messages and in coordinating care. A new healthcare system must keep the patient and the patient-physician relationship as its central focus and must also compensate providers adequately for such services. As pointed out in a recent commentary by Paul Ginsburg, “mechanisms of payment for primary care services can be a substantial impediment to achieving the vision of the primary care of the future. Fee-for service payment is not evolving in the same way that the practice of medicine is."[12]

Conclusion

Major reform in the system clearly is needed, including new payment methods to support needed changes. However providers should not wait until the system is reformed, tort reform is enacted, or new payment methods are aligned to begin the work at-hand. We must begin the discussions necessary between specialties to re-establish a degree of coordination in care. We must make sure all patients have a medical home. We must innovate and share successes in better service delivery for patients. Insurers must be willing to be flexible in looking at funding innovation. We all must engage our patients in this discussion—becoming patient-centered begins there. **NCMJ**

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COMMENTARY

Quality of Care and Performance Improvement:
Two Ideas that Go Hand-in-Hand

Noel B. McDevitt, MD, William A. Walker, MD, FACS, FASCRS, and Gordon H. DeFriese, PhD

Americans have become accustomed to hearing the statement that "the United States has the highest quality healthcare in the world!" There is little doubt that the best and most advanced medical care exists in this country. But, the term "quality of care" encompasses both *qualitative* and *quantitative* aspects of care. As Shuster, et al.,[1] have pointed out, "poor quality" can refer to too much, too little, or the wrong care. Assuring access to appropriate and needed basic healthcare services is an integral part of what we mean by quality care. We also recognize that some receive far more care and services than is really necessary, effective, or safe. Moreover, receiving the appropriate procedure or therapeutic intervention does not mean that such services were provided correctly, or in a timely manner. Hence, quality of care, as an implied standard or goal of the healthcare industry or of healthcare professionals, is a multifaceted and complex concept. Achieving this goal or standard of care requires concerted action on the part of all who provide, organize, regulate, pay for, and receive healthcare services.

The Paradox of Quality Improvement

Physicians are confronted by a number of seemingly paradoxical dimensions of the increasing emphasis on quality of care. On one hand, there is the claim that we have the best medical care on the planet, but, on the other, there is the crescendo of claims that American healthcare suffers from serious problems of overuse, omissions, and lack of access and errors that have led to serious compromises in patient safety. Physicians and other healthcare providers are admonished to provide *all* appropriate clinical and preventive services appropriate to the age and gender of their patients, while at the same time healthcare insurers, purchasers, and policy makers seem to impose ever more stringent criteria for both performance and payment as part of so-called "utilization-management" programs. Quality of care, as defined by scientific evidence of benefit and considerations of accessibility and equity among all population subgroups, can seem to be an elusive goal.

Systems of Care: The Focal Point for Performance Improvement

So, what does (or should) an increased emphasis on quality of healthcare mean for the individual healthcare professional? There is no question that any attempt to improve the overall quality of care within any defined population will depend on the day-to-day attention to standards of care, clinical guidelines, and available scientific evidence on the part of individual practitioners. However, nearly all physicians and other healthcare professionals practice in some relationship to organized "systems" of care—most of which have specified (and often legal) responsibility for the provision of medical services to defined populations. Hence, quality of care improvement efforts are conventionally defined and developed within these systems of care and in consideration of patterns of health conditions and healthcare needs within the target populations being served. Insurance and managed care companies often consider even unaffiliated physicians to be participants in qualified "panels" of providers approved to participate in the care of patients who share a common employer or insurance carrier. It is within these formal and informal "systems of care" that organized efforts toward the improvement of care quality have received most attention in recent years, and it is within such systems of care that the potential for the greatest overall public benefit may lie.

Within defined populations served by care systems, patterns and categories of health conditions that represent the predominant burden of illness in a given population may be identified, and therefore the greatest proportion of overall healthcare costs.

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Although simultaneously addressing quality of care across the full spectrum of health and illness conditions encountered in a conventional practice situation may be daunting, it is important to agree to "start somewhere." That "somewhere" should be with a focus on health conditions or diseases demanding the most time and resources.

> *"Quality of care, as defined by scientific evidence of benefit and considerations of accessibility and equity among all population subgroups, can seem to be an elusive goal in the imperfect world of mainstream healthcare practice."*

As an illustration of this incremental approach, assume that every fifth patient seen in a primary care practice is a person of middle-age or older with hypertension. In such a practice, systematic steps to assure that all clinical screening and monitoring of this condition—as well as a consideration of recommended pharmaceutical interventions to control blood pressure and counseling for smoking cessation, diet, and physical activity, take place *as a matter of routine* with every hypertensive patient encounter—is a starting point. Data and information from the practice summarizing the extent to which the blood pressures of *all* diagnosed hypertensive patients are being monitored regularly and under control is an essential element of any approach to internal practice (or system) evaluation of care quality. Similar approaches are appropriate for other categories of patients representing significant proportions of overall practice volume (e.g., numbers and proportion of diabetic patients needing hemoglobin A1C testing, having regular ocular and foot examinations, etc.).

This approach, which is increasingly a matter of routine in physician practices of all sizes and complexity, is an integral part of healthcare system *performance improvement*. Having clinical epidemiological information from one's practice can be a source of lifelong intellectual interest in one's major career activities, and serve as a means of self-evaluation.

Utilization Management Should Encompass Quality of Care

Physicians and other healthcare professionals for a number of years have complained bitterly with justification about the increasing burden of bureaucratic procedures associated with patient care. As utilization management systems have been promulgated by third parties (insurance carriers, health plans, employers, and managed care organizations) to reduce costs and rationalize clinical care, the reporting requirements of nearly every aspect of care have increased. Yet, it is time that these utilization management approaches be integrated with efforts to improve the overall quality of care.[2] Instead of a complete focus on cost-containment and the prevention of the overuse of care, utilization management efforts should be enlarged to include a consideration of "...the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge."[3]

Moreover, Wickizer and Lessler[2] have argued that utilization management efforts should give emphasis to areas of care where there is strong evidence of both appropriateness and clinical need in addition to identifying those categories of care where services and procedures are underused and under-prescribed. The emphasis should be on monitoring defined categories of patients, not total populations of the insured, to ensure that those in these defined categories (e.g., all diabetics) receive all appropriate preventive services and acute medical care.

The special Task Force of the North Carolina Medical Society on Quality of Care and Performance Improvement has recommended that the Society identify evidence-based protocols for managing patients diagnosed with diabetes, asthma, and heart failure. Clinical screening and preventive interventions are appropriate and recommended for obesity, smoking cessation, immunizations, alcohol and substance abuse counseling or other intervention, mammography, colorectal cancer screening, and elevated blood pressure. To ensure these services are provided once protocols are identified, the North Carolina Medical Society should provide physicians with tools that are applicable to office-based practice. The North Carolina Medical Society hopes this will help the general public to understand these conditions and the need for clinical screening and other preventive services.

What about Medical Errors and Patient Safety?

All segments of the healthcare industry are placing greater emphasis on reducing medical errors and assuring patient safety. Since the publication of the 1999 landmark report of the national Institute of Medicine, *To Err is Human: Building a Safer Health System*,[4] there has been widespread concern among the general public, the news media, and policy makers over both the enormity of these problems and over the apparent reluctance of professional and healthcare industry groups to address these issues.[5]

As an important part of the overall movement to improve quality and performance in American healthcare, efforts to stem the tide of medical errors and assure the safety of patient care are often too little and too late. As Millenson[5] argues, healthcare professionals have always maintained that, by virtue of their commitment and training, they are motivated to "do the right thing." Yet, professionalism alone often is not enough to address some of the systemic problems in healthcare that require concerted and forceful action. When the common routines of practice allow the possibility of inadvertent error (such as in surgically amputating the wrong limb, or hanging the wrong bottle of fluid on an IV pole, or dispensing the wrong medication), and when these errors occur repeatedly, everyone should be incensed. Such errors are both preventable (through proper labeling and computerized ordering) and also unacceptable. Patient safety should be an integral part of any quality of care or safety improvement initiative.

> *"...it is important to agree to start somewhere."*

As with quality concerns over the provision of clinical preventive services, errors of omission and commission can result in significant harm to patients. If patients recovering from myocardial ischemic events are allowed to leave a hospital without receiving beta-blockers, despite compelling evidence of beneficial effect and mortality reduction, a serious problem of quality with important implications for patient safety exists. Efforts to improve the quality of care and system performance must include steps that assure that all healthcare professionals are aware of life-saving interventions and are provided reminders that ensure that they will not be overlooked.

What about the Incentives for Quality Improvement?

The United States healthcare system does not recognize the quality of care provided at any level and reward those providers who diligently assure the highest standards of care for their patients. Moreover, there is very little easily accessible data by which patients or the purchasers of healthcare insurance can evaluate the quality of care routinely provided by either individual professionals or by healthcare organizations. As methods for the systematic measurement of care quality (and evidence-based strategies for it's provision) are developed, it will be important that healthcare insurers and policy makers find ways to compensate those who consistently provide the highest quality care for their patients. The so-called "pay-for-performance" movement is controversial largely because of past experience with record-based approaches to physician reimbursement by insurance agencies and by governmental regulatory bodies. But, without such systems, there will remain only the incentive of professionalism as a primary motivator of change toward these higher standards of quality and system performance. Much more can and should be done to reward healthcare professionals who uphold the highest quality of care for their patients. **NCMJ**

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SPECIAL ARTICLE

Remembering Cecil*

Donald L. Madison, MD

An accounting of what Cecil Sheps managed to accomplish during his working life might be possible, but it would be less interesting—for the accountant at least—than attempting to understand how and why he did what he did. And so, alongside an admittedly superficial chronicling of his career, I have made that attempt, relying both on the historical record and my own observations.

I begin with the question: Who was Cecil Sheps, MD, MPH, professionally? It is a question that naturally incorporates two others—Where did he come from? And, as importantly, When did he arrive on the scene?

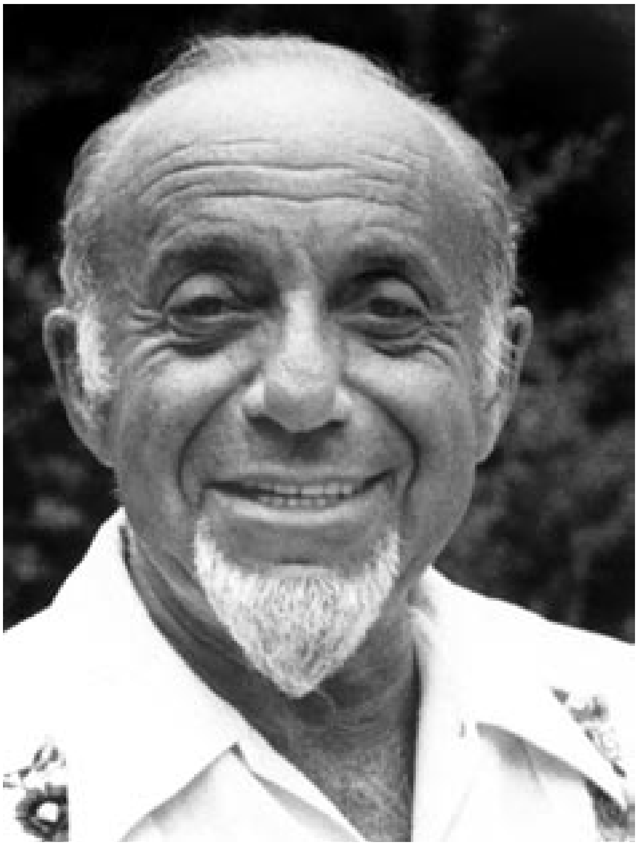
Cecil was one of a small group of "medical careniks" who became active at the end of World War II. They called themselves medical careniks partly in jest; yet one would suppose that the Russian genesis of the word also matched their favorable view of socialist health systems, as well as their view of themselves as young revolutionaries in public health.

The suffix, *nik*, is both Russian and Yiddish. It means something "associated with or characterized by," as in the Russian *Sputnik* (meaning associated with or, literally, traveling with the earth), and two familiar nikwords of American slanguage—beatnik and peacenik, or the Yiddish word *nudnik:* a bothersome boor or pest, which is how some of the old-line public health officers in the late 1940s must have viewed the medical careniks who were urging change on the public health establishment.[1]

What set the medical careniks apart, besides their youth (young for the most part, although the leaders were veterans of earlier campaigns), was their wish to turn both the American Public Health Association and the United States Public Health Service in a direction that would enlarge public health's concern to include medical care.

They called it "medical care," not "healthcare"—which, so far as I can tell, is a recent singleword invention of "publicrelations" consultants to the hospital industry, a term generated out of concern that "medical care" might point too narrowly to the medical profession and thereby exclude the new hospital CEOs and their various underling Os, along with their corporate bosses. Certainly, the medical careniks did not envision, much less embrace, the corporate genesis of so much of today's health services sector. In their day the term "medical care" stood for medical programs for populations—starting with the practice of medicine to be sure, but moving from there in a public health rather than a private practice direction—and certainly never toward a corporate destination.

Almost all in the group of whom I speak were physicians. Virtually all were male. Most were veterans of World War II. Most were Jews. In intellect they ranged from superior to brilliant. And they shared the same commitment to public health and social justice. They were also of about the same age; those I



*Based on remarks by the author at the Memorial Service for Cecil G. Sheps, MD, MPH (1913-2004), Chapel Hill, NC, May 21, 2004.

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knew best (the group mentioned below) were all born between 1912 and 1917.

I should name some names here. Nearly all of these people are gone now. The oldest—Sy Axelrod, and the youngest—Dick Weinerman, plus Milt Roemer and Les Falk had become close friends while working together in the Farm Labor Health Program (the original migrant health program) just after World War II. Others included Milton Terris, Leonard Rosenfeld, Paul Cornely, and my two mentors, George Silver and Cecil Sheps. Those were probably the core, although there were several others. They all seemed to know each other, either through the Public Health Service or the American Public Health Association (APHA), from earlier association as medical students, or through their common mentor—because all would have considered themselves disciples of the medical historian, internationalist, and public gadfly (where medical care was concerned), Dr. Henry Sigerist of Johns Hopkins.

In the years before email and cheap long-distance telephone service they also wrote to each other. That correspondence probably exists in several places, but a good deal of it can be found in the Richard Weinerman papers at Yale. (Weinerman was a faculty member at Yale at the time of his premature death, so his papers were catalogued before those of the others, most of whom, by the way, also gave their papers to the Contemporary Medical Care and Health Policy Collection at the Yale University Library.[2])

Their letters to each other between 1945 and about 1949 voice concerns that were common among veterans: finding a job, entering graduate school, fathering children. These young men, however, also wrote about politics, especially their hopes for the next Wagner-Murray-Dingell Bill, and, often, of the prospect of seeing each other, and of visits to or lectures by or letters from Henry Sigerist.

In the Weinerman correspondence from those years, there are only one or two exchanges between Dick Weinerman and Cecil, but in letters from the others to Dick, Cecil is mentioned several times in ways that make it clear that he is a member of the group, even though in one respect he was an outsider.

Cecil was a Canadian. But not just *any* Canadian; because he had been a "carpetbagger" to Saskatchewan. That was what they called themselves—those who came from outside that mainly rural Canadian Province to help plant the first North American instance of social insurance for hospital care. Mindel Sheps, Cecil's wife and medical school classmate at the University of Manitoba, was also a carpetbagger; and so, later, was Len Rosenfeld. The carpetbaggers would have been automatically welcomed into the group of medical careniks because the Saskatchewan development was so profoundly important to them. Besides, the most famous carpetbagger of all had been Henry Sigerist, who came to Regina at Cecil and Mindel's invitation to direct the preliminary survey for the Provincial health plan.[3] And more than anyone else, it was Sigerist who united the younger medical careniks and articulated their cause.

All the members of this group would distinguish themselves later. By another 20 years, in the mid- to late-1960s, they had become the mentors for a new generation of medical careniks. Sy Axelrod, Milt Roemer, and Milton Terris became teachers—primarily (although they were researchers, too). Len Rosenfeld and Les Falk became administrators, but were teachers and researchers, as well. Paul Cornely, Dick Weinerman, George Silver, and Cecil Sheps did it all.[4]

I met George Silver in September 1964. I was a fourth-year medical student from California and had come east to do a two-month elective with him in Social Medicine at Montefiore Hospital in the Bronx. The American Public Health Association just happened to be meeting in New York City that fall, and so I heard, and even met, some of the medical careniks—those who spoke at the meeting or chaired sessions. But although I'm quite sure he was on the program someplace, I didn't lay eyes on Cecil. I knew his name, though.

A little over a year later—after Silver had become Phil Lee's[5] Deputy in charge of stirring things up in Washington, DC, after he helped me find a job in the Public Health Service, and after my new bosses had accepted my suggestion that I be assigned to Cecil Sheps at Beth Israel Medical Center in New York—after all that had been arranged, I made an appointment to meet him, finally. (I started to write, "to finally meet him," but splitting an infinitive when writing about Cecil is something you can't do—not if he once corrected your prose.)

The night before our scheduled meeting, my wife and I were driving from Staten Island, where we lived, to see a movie in Manhattan. Somewhere in Brooklyn I turned the radio on and, quite by chance, heard two people engaged in a polite but vigorous debate about Medicare, which Congress had enacted nearly a year earlier and which was just about to be implemented, as a matter of fact, by my division of the Public Health Service. In essence, their argument was over whether Medicare had been a bad idea all along and was therefore doomed to fail—as organized medicine was still predicting in the spring of 1966—or whether it was necessary and would succeed. Both debaters were in command of the points they wanted to make, but I had no idea who they were. We were coming off the Brooklyn Bridge when the host identified his guests. One was president of one of the borough medical societies; the other was the General Director of Beth Israel Medical Center, Dr. Cecil Sheps.

The next morning I showed up at Beth Israel and was ushered into the inner sanctum of the office of the General Director. I had already heard him speak, and now, there he was, puffing his cigar in a holder, attired in a bow tie, shorter than I'd imagined. He didn't have the goatee yet, and I remember thinking that he looked like Jacob Javits, who was then the senior Senator from New York. Dr. Sheps accepted my congratulations on his previous night's radio performance and then quickly got to the business at hand. He had only been at Beth Israel a few months, yet he was full of ideas about what projects I might work on—virtually every project, it sounded like, and there were a lot of them.

The Public Health Service's idea (and mine) was that I was there to learn how to be a medical care administrator so that I might be of some use to my unit, which was called, by the way, the Division of Medical Care Administration. Cecil would be my teacher. I was enthusiastic, not having realized yet that my aptitudes, whatever they may have been, did not include administration. But I was still ignorant of that and eager to learn.

Cecil was presiding over at least ten—possibly twice that many—community medical care programs or related projects from Beth Israel: the Gouverneur Ambulatory Care Program, the "I Spy" Children and Youth Project, the Methadone Maintenance Demonstration at Manhattan General, the community medicine curriculum at Mt. Sinai Medical School, the Judson Memorial Church project, nursing home affiliations, the national neighborhood health centers evaluation project for the War on Poverty, the *Guide to Medical Care Administration* project for the APHA. Those are the ones I can remember him mentioning that I might work on.

In 1966 he was 53 years old and at the peak of his professional career. In the office he was a dynamo. Three secretaries stationed just outside the door worked on his dictation. He wrote letters constantly (he followed up on everything). After editing each dictated draft quickly, he gave it back for typing, then read the final version carefully before signing it; and always, in those pre-Xerox days, he initialed every carbon copy. He once told me the reason he did that. I've forgotten what it was, but since he did it, I did it, too, for as long as there were carbon copies. Then the phone calls, one after another, placed by one of those secretaries. And the small blue slips that he habitually attached—perhaps at home the night before, or on an airplane the previous day—to documents that he had already perused and wanted one or several of his colleagues to know about. The notes on the blue slips were sometimes dictated, too, but were more often scribed in his illegible scrawl. At the bottom of each blue slip was a check mark either on the "please return" line or the "need not be returned" line. To an impressionable and wholly inexperienced young person like me, watching him work was an indelible adventure. If I were casting a film about Cecil in New York, I would look for a young Edward G. Robinson.

He had many interests and talents. First, of course, he was interested in—and knowledgeable of—all developments in medical care. That's a lot right there. Beyond that he was keenly interested in politics and history, theatre and art—and travel. Also in all jokes that started with the line, "Two old Jews were talking." He collected those.

But he was no Renaissance man; there were things he didn't know, and things he couldn't do so well. He could barely drive a car. And despite his love of travel, his sense of direction lacked a great deal. As a writer and editor he was a stickler more than a stylist. And he didn't understand sports at all; this would turn out to be a disadvantage later, when he became Vice Chancellor of a major state university and was obliged to sit in the Chancellor's box at football games, and converse at halftime with other, more observant fans who also happened to be trustees and important alumni.

Cecil's first listed publication, in *Canadian Advance*, was on a medical care topic: it was titled "The Municipal Doctor System." The article appeared in 1939, three years after his graduation from medical school, perhaps when he was working in general practice in Manitoba, which he did for a time. I say "perhaps" because he omitted those early experiences from his *curriculum vitae*, including only this entry: "Health Administration, Health Professions Education, Health Policy, Preventive Medicine and Public Health, 48 years." Presumably that would cover everything. World War II also began in 1939, and Cecil entered the Canadian Army—although his military service doesn't appear on his vita either. However, from the end of the war forward, one can follow his major professional interests pretty well from reading the titles of his 154 publications.

The first thing I notice is an impressive series of articles on the subject of venereal disease control, beginning in Saskatchewan. The venereal disease papers are interrupted by a second publication on a medical care topic, "Health Regions—(the) Essential First Step in (the) Saskatchewan Health Program," and one on general public health, "Mortality in Socio-Economic Districts of New Haven" (written while he was getting his master's degree in public health at Yale). The venereal desease papers then continue, but now from the School of Public Health at the University of North Carolina at Chapel Hill (UNC-CH).

To explain this odd trajectory—Winnipeg to Regina to New Haven to Chapel Hill—I should amplify something I mentioned earlier. Near the end of the war, the people of the Province of Saskatchewan elected a socialist government headed by Premier Tommy Douglas, leader of a political party called the Cooperative Commonwealth Federation (CCF). The CCF was the first socialist government in North America—if one discounts municipal governments. In Great Britain, at nearly the same time, the socialists (Clement Atlee's Labor Party) defeated Winston Churchill's Conservatives, and a few years later Britain put in place the National Health Service. How heady a time those immediate post-war years must have been for young socialists like Cecil and Mindel!

In Saskatchewan Cecil held the title of Acting Chairman of the Health Services Planning Commission and the political title of Assistant Deputy Minister. He was 31 years old then. By some accounts—but not his—he aggravated the medical profession of the province, and the government acceded to the doctors' wish that he be relieved.

Enter the Rockefeller Foundation. In the immediate post-war years, Alan Gregg, who ran the medical sciences program at Rockefeller, made a few small grants in medical care. He had been doing this for a number of years, but strictly on the side, so to speak, because the Rockefeller Foundation had no formal program in medical care; it was merely one of Dr. Gregg's hobbies. At the end of the war he proposed that the Foundation launch such a program, which it did, bringing in John Grant, who had been a long-time field officer—in China primarily, but also in India and elsewhere—to head it up.

During the 1940s, first Gregg and then Grant invested in a few young men (I'm reasonably certain they were all men) by giving them stipends and sending them off for a year to a school of public health—either Hopkins, Harvard, Yale, or Michigan—to study medical care and get a degree. Several of those I named earlier received such Rockefeller stipends; and that is how Cecil was able to attend Yale during the 1946-47 school year. His medical care teacher was Franz Goldmann, who authored one of the first American texts on the topic.[6]

At the end of his year at Yale, Cecil needed a job and found a temporary one—in North Carolina. The School of Public Health at Chapel Hill needed someone to teach biostatistics in summer school. On his way south he stopped in New York to see Dr. Grant, who made an entry in his diary (all Rockefeller Foundation officers kept diaries): "Sheps is certainly bright, and one judges (he) will make an excellent and enthusiastic teacher."

Later on, Cecil and Dr. Grant would come to know each other well. Cecil used to say that of all the people he knew professionally—and he seemed to know everyone—the two he most admired, whom he considered his mentors, were Henry Sigerist and John Grant.


Assistant Professor of Public Health, 1947

At the end of that summer session, someone—it was probably John Wright, who was then the chair of the Department of Public Health Administration and the co-author on several of those early articles on venereal disease control—asked Cecil to stay on at the School of Public Health.

After a couple of years, Cecil's interest in venereal disease gave way to an altogether different theme—planning. Rockefeller awarded a major grant to UNC-CH to plan to become a statewide medical center. John Grant considered the UNC-CH grant one of the most significant investments of his burgeoning medical care program. A teaching hospital was due to open in Chapel Hill in 1952, and with it what Abraham Flexner had called a "half medical school" (in his 1910 report, *Medical Education in the United States and Canada*) would expand at last to a full four years. Further, the University promised its constituents that the new hospital's mission would be "to serve the people of North Carolina." These events were the stimuli for the Rockefeller grant. Cecil was put in charge—John Grant more or less insisted on this—and given the title, Director of Program Planning in the Division of Health Affairs.

But soon his publications began to shift again, to the subject of the hospital. In fact, Cecil ended his six-year sojourn in Chapel Hill in 1953 to become General Director of the Beth Israel Hospital in Boston.

I notice that during the early and middle 1950s, some of his titles began to sound less like scholarship and research and more like mild exhortations or at least wise musings, which suggests that they were probably speeches edited for publication —for example, "Community Hospital: The Future Health Center" and "We Must Use Hospitals More Effectively."

During both of Cecil's two main administrative jobs—as head of two major urban medical centers—he published articles, not just occasionally but regularly. In fact, when I worked with him in New York, he reported in print, promptly, on whatever it was that he was doing or thinking. From his example I assumed that writing for publication must be part of a medical care administrator's job. It never occurred to me until years later, after I had met many important administrators, some of whom could hardly draft a press release, that Cecil's example was not the standard; that the *sine qua non* quality for an institutional administrator was not an eagerness to lead by communicating ideas—to one's staff, professional peers, and the public—so much as good conduct in the board room.

At the Beth Israel in Boston Cecil also began medical care research. (We now call it health services research.) He received a grant from the Public Health Service, found two outstanding colleagues, Jerry Solon and Sidney Lee, and they began their pioneering investigations—intellectually and methodologically important studies of hospital-based ambulatory care. For the first time, an important teaching hospital, used by thousands of people as their major source of medical care, was actually tracking its community of patients, finding out who they were, understanding the reasons why they used the outpatient department as their primary source of care, and learning what finally happened to them. This was research focused on the modern teaching hospital, where by the mid-1950s, biomedical research and house staff training ruled. Furthermore, it was non-biomedical patient care research designed to uncover information that any administrator would want to know, should want to know, and Cecil did want to know.

Most of his publications during the Boston years reflect or report on these studies of outpatient care. But he was also interested in the larger environment of the teaching hospital, for example, on how it related to the medical school. With a group of colleagues that included Dean Clark, the General Director of the Massachusetts General Hospital (who would later join Cecil at the University of Pittsburgh), he undertook a national survey of teaching hospitals, concentrating on the nature of their affiliations with medical schools. He wrote about the hospital's responsibility for home care and community health education. And along with his old professor Franz Goldmann and a couple of fellow medical careniks, Sy Axelrod and Milton Terris, he co-edited a book for teaching medical and public health students, titled *Readings in Medical Care*.

In 1960, Cecil became a full-time academic for the second time when he moved to the University of Pittsburgh to chair the Department of Health and Hospital Administration in the School of Public Health. During his five years at Pittsburgh, the topics of his publications broadened further. Much of his writing was still about the hospital, but now he was writing also about medical schools, schools of public health, expenditures for health and medical care, and on the general topic of research in medical care and community health. One notices, too, that some of his publications reported the results of some outside committee and consulting assignments, for example, emergency medical care in Allegheny County, and the adequacy of health resources in Idaho, Montana, Nevada, and Wyoming. In addition, he was engaged in community medical care research, with articles about families and their regular doctors, how the citizens of an industrial town that the authors called "Aluminum City" made use of medical specialists, and the office practices of 500 internists in New York State.

I had always assumed that Cecil's move to New York City in 1965 was explained by the lure of Beth Israel Medical Center, which to my mind was already becoming the Montefiore of Manhattan in terms of its strong social medicine orientation. I assumed that the general directorship of this institution was simply too attractive an offer to turn down. I assumed wrong. Much later, Cecil told me that the reason he had moved to Chapel Hill (the first time) and then to Boston, and to Pittsburgh, had been because of the professional opportunity each of those positions offered. Mindel had gone along, had followed him, so to speak, as the "less-qualified" member of the couple. But while they were in Boston, she had earned her graduate degree in biostatistics, and in Pittsburgh she became a member of the faculty of the Graduate School of Public Health. After a time, however, she found herself in a fundamental disagreement with her superior over some basic matters of academic behavior. The disagreement was important enough so that Cecil told her that they would leave Pittsburgh, and that it was now her turn to take the lead; she should find her best opportunity, and wherever it was he would follow. She picked Columbia University, and he then applied at Beth Israel. He would have found some other job in New York had the position at Beth Israel not been open.

In New York several of Cecil's publications began to reflect some of the federal health legislation that was part of President Johnson's Great Society, and the general theme of "serving the community." His pieces of that period had titles like "The Medical School—Community Expectations" and "The Role of the Teaching Hospital in Community Service" and "Evaluation of Neighborhood Health Centers" and "Relating a Neighborhood Health Center to a General Hospital."

The return to Chapel Hill in 1969 seems to have been a perfect fit for both Cecil and the University. The ideal candidate to head a new federally funded health services research center, he had, after all, been a pioneer in that field—well-recognized for his own work and highly regarded as an advisor to the Washington, DC, funding agencies.

But for Cecil the opportunity must have seemed fortuitous for personal reasons. One day in New York, I think it was in the spring of 1967, he told me that he and Mindel were going to Chapel Hill the following day to close on the purchase of a lot on which they intended to build their retirement home. I asked him when that would be. "Probably a long time from now," he said. The opportunity to move to Chapel Hill earlier—for Cecil to launch a new research center, for Mindel, who was just then emerging as a world-class demographer, to join Bernie Greenberg's department of Biostatistics, for the couple to go where they intended to move eventually—must have been something both were enthusiastic about.

Many of Cecil's Chapel Hill writings—numbers 90 through 154 on his publications list—were becoming even more hortatory. The titles suggest this, but since he sent most of them to me, I can also bear witness. Once he asked me whether I thought one of his offerings, I believe it was a commencement address, was "too opinionated" for publication, not well enough supported by "data." I said that at his age and career standing he was entitled to speak his mind in print. "That's what I was thinking," he said, "but I'm glad to hear you say it." By this time he was being invited frequently to comment, for publication, on topics that concerned him; and by this time those topics were many. Again, he was writing about medical schools, schools of public health, hospitals and academic medical centers, consumer sponsorship of medical services, and regionalization, plus four new topics—the Health Maintenance Organization (HMO), the Area Health Education Center (AHEC), the family nurse practitioner, and something called "primary care." And as he had done in Pittsburgh, he was accepting consulting assignments when they suited his interests, which were now turning increasingly international. There were papers on Puerto Rico and Beer Sheva, Israel, and an edited volume, *Primary Health Care in Industrialized Nations*.

Early in the history of the UNC-CH Health Services Research Center—it might have appeared in the first annual report—Cecil announced a motto for the Center: "turning services into programs." I knew what it meant, but I wasn't sure exactly how or where research fit into that phrase. Cecil *was* sure. "Turning services into programs" had been the theme of his entire career. And it was what the Health Services Research Center was going to do. Sometimes research would come first—as it had at Beth Israel Hospital in Boston. But just as often, the meaning of that phrase would be realized through direct action, by organizing programs, with only an implied promise that research would, might, someday follow. The promise was enough for Cecil. As a result, some of his research associates organized health centers, others worked on plans for a local HMO, some worked at developing an AHEC program, and a few actually did research.

It is clear to me that Cecil wielded considerable influence. He was responsible for a few policies and many programs. In some cases he was directly responsible, in more, indirectly responsible—through a remark he made to someone, through someone he appointed or suggested for an assignment or job, or by his continuous coaxing, and because he always followed up.

I started to draw up a list of programs and institutions that Cecil might have been responsible for, at least where one can fairly ask the question: Would this have existed if it hadn't been for Cecil? Often, of course, we don't know. But even that element of doubt is a measure of his influence. I began my list locally, but soon realized that I just don't know enough to go very far with it. Beyond the health services research center that now bears his name, I thought first of the Orange-Chatham Comprehensive Health Service Program (now Piedmont Health Services), probably because it was the first thing he suggested I work on when I arrived in Chapel Hill. Then there was the Lincoln Community Health Center in Durham; HealthCo in Warren County; the North Carolina Office of Rural Health (and by extension all of the many local initiatives throughout the state that this office has been responsible for, as well as similar rural health offices in other states that so admired the one in Raleigh that they copied it); UNC-CH's family nurse practitioner program (and by extension, because it was one of the earliest and most influential, other such programs throughout the nation); the distinctive community orientation of the medical school at Ben Gurion University of the Negev in Beer Sheva, Israel; and countless other programs—federal, state, and local, on which he "gave advice."

During his time in New York, Cecil was often in Washington, DC, for a day. During those years, the federal government was launching a host of new medical care programs. When Cecil would return from one of his day trips to Washington, DC, and someone asked what he had been doing there, he would usually say, "I was giving advice." His advice was frequently sought and often followed.

Vice Chancellor, mid-1970s

I could never quite understand exactly why he was so influential, but I acknowledge that he was. Sometimes when I heard him pressing some point in a group, I would think that what he was saying could not possibly make a difference because it was too familiar; I'd heard it many times, even said it myself, and I imagined his other listeners were responding in the same way. But he *was* effective. I remember, for example, hearing him speak at a retreat to the group of idealistic young physicians and administrators who were organizing their own community health centers through the Rural Practice Project.[7] He was talking with them as colleagues, informally, but he seemed again to be repeating the obvious, and I thought his words would be of little value to this group. That wasn't their reaction. They listened closely, and several of them came up to me afterward, or the next day, or in some cases months later, to say how much they'd learned from Cecil, how clear he had made everything, and how much his words meant to them. They were stimulated—intellectually and, I think now, even emotionally—by what he had to say. I'm not sure why, but I think it wasn't as much the content of what he said as the conviction with which he said it; he was telling them what he stood for. They must have realized that all of that experience, passion, and commitment were authentic, and that they were hearing The Word from a genuine medical carenik. **NCMJ**

NOTES & REFERENCES

1 The story of this battle is told by Arthur Viseltear in Emergence of the Medical Care Section of the American Public Health Association, 1926-1948: A Chapter in the History of Medical Care in the United States. Washington, DC: American Public Health Association, 1972.

2 The exceptions are Axelrod and Cornely. The Solomon J. Axelrod papers are at the University of Michigan, the Paul B. Cornely papers at the National Library of Medicine.

3 There are several published accounts of Sigerist's mission to Regina. Probably the best is: Duffin J, Falk LA. Sigerist in Saskatchewan: The Quest for Balance in Social and Technical Medicine, Bulletin of the History of Medicine 1996;70(4)658-693. See also various chapters in: Fee E, Brown T (Editors). Making Medical History: The Life and Times of Henry E. Sigerist. Baltimore: Johns Hopkins University Press, 1997.

4 Axelrod spent most of his career at the University of Michigan; Roemer was at Cornell and then UCLA; and Terris at the New York College of Medicine. Rosenfeld held several administrative positions—in Nicaragua, Saskatchewan, Rochester, Detroit, and New York—before he finished his career at UNC-Chapel Hill. Falk worked for the United Mine Workers in Pittsburgh and then as a professor at Meharry Medical College in Nashville. Cornely was at Freedman's Hospital in Washington, but spent most of his career at Howard University; Weinerman was at the University of California at Berkeley, Kaiser-Permanente in Oakland, and at Yale; Silver was at Johns Hopkins, Montefiore Hospital in the Bronx, and then Washington, DC; he finished his career at Yale.

5 Lee was twice Assistant Secretary for Health and Scientific Affairs: first in the Johnson Administration (under Secretary of Health, Education, and Welfare Wilbur Cohen) and again in the Clinton Administration (under Health and Human Services Secretary Donna Shalala).

6 Franz G. Public Medical Care: Principles and Problems. New York: Columbia University Press, 1945.

7 Madison DL. Starting Out in Rural Practice. Chapel Hill, NC: Department of Social and Administrative Medicine, University of North Carolina at Chapel Hill, 1980.

Running the Numbers

A Periodic Feature to Inform North Carolina Healthcare Professionals
About Current Topics in Health Statistics

From the State Center for Health Statistics, North Carolina Department of Health and Human Services
www.schs.state.nc.us/SCHS

Potentially Avoidable Hospitalizations in North Carolina

While many inpatient hospitalizations are for trauma emergencies or elective procedures, some hospitalizations might be avoided if satisfactory primary care were used or if the conditions were diagnosed earlier. Research suggests that certain hospital diagnoses in particular are often associated with problems in access to or use of primary care. Using diagnostic criteria established in previous research,[1,2] we examine potentially avoidable inpatient hospital discharges in North Carolina (sometimes called ambulatory sensitive conditions) based on selected principal or first-listed diagnoses.

We used the principal ICD-9-CM (International Classification of Diseases, 9th Revision, Clinical Modification) diagnosis codes from the 2002 North Carolina hospital discharge data base to identify potentially avoidable hospitalizations. Discharges for newborns and deliveries were excluded from the analysis, as were records for residents of other states. North Carolina residents discharged from out-of-state hospitals are not included in the North Carolina hospital discharge data base.

The following table presents potentially avoidable hospitalizations in 2002 by diagnostic category, showing the total number of discharges, the average length of stay, total hospital charges, and average charges per hospital stay.

Potentially Avoidable Hospitalizations in North Carolina, 2002

Primary Diagnosis	Total Discharges	Avg. Length of Stay (days)	Total Hospital Charges	Average Charges Per Stay
Pneumonia	32,900	6.0	$423,612,729	$12,876
Congestive heart failure	29,193	5.4	$395,333,009	$13,542
Asthma	11,280	3.4	$74,265,930	$6,584
Cellulitis	8,186	5.1	$71,943,189	$8,789
Diabetes with ketoacidosis or coma	4,560	3.8	$39,720,703	$8,711
Pyelonephritis	3,652	3.9	$27,182,354	$7,443
Perforated or bleeding ulcer	3,584	5.1	$51,015,899	$14,234
Ruptured appendix	1,874	5.9	$33,267,109	$17,752
Malignant hypertension	1,458	4.2	$16,442,232	$11,277
Hypokalemia	743	4.3	$6,357,782	$8,557
Gangrene	163	7.2	$2,608,125	$16,001
Immunizable conditions	39	6.6	$423,887	$10,869
Total	**97,632**	**5.2**	**$1,142,172,948**	**$11,699**

These 97,632 discharges represent 11% of the total of 855,268 hospital discharges in North Carolina in 2002 (with the exclusions mentioned above). These hospitalizations accounted for $1.14 billion in hospital charges. Charges indicate the amount billed by the hospital to the patient or the patient's insurance company, not what was actually paid to the hospital. Pneumonia and congestive heart failure were the most common primary diagnoses, accounting for 64% of all potentially avoidable hospitalizations. The rate of potentially avoidable hospitalization was 1172.6 per 100,000 North Carolina resident population, which is only a slight decline from the 1997 rate of 1182.5.

RUNNING THE NUMBERS—continued on page 310

RUNNING THE NUMBERS—continued from page 309

Persons on Medicare accounted for 57% of all potentially avoidable hospitalizations (data not shown in table). Rural counties and counties with the lowest per capita income levels have potentially avoidable hospitalization rates (per 100,000 population) substantially higher than the state average.

There could be some debate about exactly which diagnoses are used to indicate "potentially avoidable" hospitalizations, and certainly not all hospitalizations for conditions such as pneumonia and congestive heart failure can be prevented, especially among older persons. Nevertheless, the results here indicate that many hospitalizations in North Carolina could be prevented if the seriousness of the diseases were reduced through better primary care services.

An earlier report of the State Center for Health Statistics on this topic by Kathleen Jones-Vessey can be accessed at http://www.schs.state.nc.us/SCHS/pdf/schs118.pdf.

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1 Weissman J, Gatsonis C, Epstein A. Rates of avoidable hospitalization by insurance status in Massachusetts and Maryland. JAMA 1992; 268: 2388-2394.
2 Pappas G, Hadden W, Kozak Z, Fisher G. Potentially avoidable hospitalizations: inequalities in rates between US socioeconomic groups. American Journal of Public Health 1997; 87:811-816.

Contributed by Paul A. Buescher, PhD
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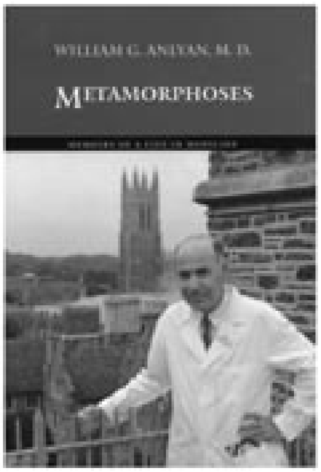
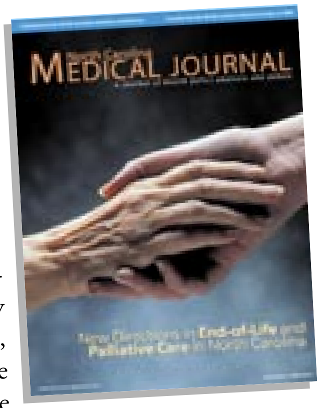


Letters to the Editor

New Directions in End-of-Life and Palliative Care in North Carolina



To The Editor:

I just finished reading Dr. Keith Meador's article on Spirituality and I for one want to sound out an enthusiastic Hurrah! Finally, an article from a physician that seems to understand the complexities of contextual and content issues in spirituality and medicine.

Calling a chaplain early in the process of end-of-life care is absolutely essential. He is absolutely correct that not all institutions have chaplains, but some medical professionals out there are working very hard to get institutions to see the value of paid professional chaplains. And he is also correct when he says that standards for spiritual care have not been developed. However, some chaplains are writing about the need for standards, the Association of Professional Chaplains (www.professionalchaplains.org) and the Association of Clinical Pastoral Education (www.acpe.edu) have study documents on their web sites that would offer a first set of universal standards for spirituality. Unfortunately, they are conceived of by professional chaplains for professional chaplains, and as of yet we have not seen any secular accreditation organization take the risk to affirm or deny the importance of such standards.

I applaud Dr. Meador's insight. I hope that articles such as his and others written by informed and committed physicians and chaplains will be used as stepping stones for opportunities to sit down together and discuss context and content of spirituality and medicine.

Larry J. Austin, D.Min
ACPE Supervisor, BCC
Director of Pastoral Services
Pitt County Memorial Hospital
Greenville, NC

North Carolina Medical Journal: Call for Papers

Herbert G. Garrison, MD, MPH
Scientific Editor, *North Carolina Medical Journal*

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The North Carolina Institute of Medicine

Since January 2002, Publisher of The *North Carolina Medical Journal*

In 1983 the North Carolina General Assembly chartered the North Carolina Institute of Medicine as an independent, nonprofit organization to serve as a non-political source of analysis and advice on issues of relevance to the health of North Carolina's population. The Institute is a convenor of persons and organizations with health-relevant expertise, a provider of carefully conducted studies of complex and often controversial health and healthcare issues, and a source of advice regarding available options for problem solution. The principal mode of addressing such issues is through the convening of task forces consisting of some of the state's leading professionals, policy makers and interest group representatives to undertake detailed analyses of the various dimensions of such issues and to identify a range of possible options for addressing them.

Members of the North Carolina Institute of Medicine are appointed for five-year terms by the Governor, and each task force convened by the Institute typically includes at least one-third of its membership from among the appointed members. Topics to be addressed through task force efforts are chosen following requests from the Governor, the General Assembly or agencies of state government. In some cases, topics are selected on the basis of requests from a number of stakeholder organizations across the state where this type of analytical process is considered to have potential value.

The North Carolina Institute of Medicine assumed the role of publisher of the *North Carolina Medical Journal* in January 2002 through an agreement with the North Carolina Medical Society, which founded the Journal in 1845. The Institute views the *North Carolina Medical Journal* as an extension of its mission. The Journal provides a forum for stakeholders, healthcare professionals, and policy makers and shapers to study and discuss the most salient health policy issues facing our state. Like many states, North Carolina is grappling with issues such as an increasing number of uninsured, the unmet health needs of the growing Latino population, a critical shortage of nursing personnel, the health risks of tobacco and obesity, rising prescription drugs costs, mental health system reform, the increasing societal burden of chronic illness care, the threat of bioterrorism and the necessity of assuring adequate public health preparedness—all in the midst of an economic downturn. Each of these issues presents unique challenges to healthcare providers and state policy makers. Yet, a fully implemented task force to consider each of these sets of issues is not feasible. The Journal makes it possible to present an organized and balanced overview of some of these issues, six times per year, and allows interested persons the opportunity to engage in the ongoing discussion of these issues throughout the year. The Institute hopes that our readers of the *Journal* will, in this way, become involved in the continuing debate about the most promising avenues for assuring the highest standards of health and healthcare for all North Carolinians.

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Eliminating Racial and Ethnic Health Disparities

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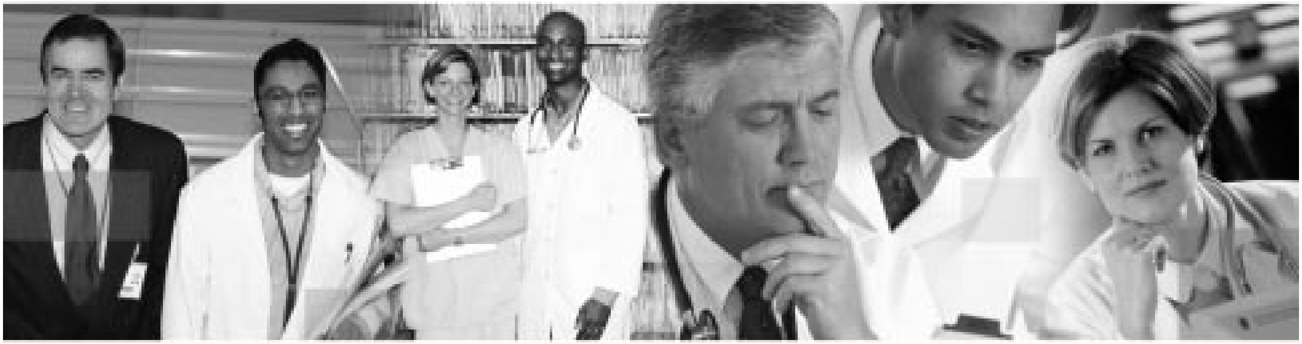

North Carolina MEDICAL JOURNAL

a journal of health policy analysis and debate

November/December 2004, Volume 65, Number 6 **Published by the North Carolina Institute of Medicine**

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ARTICLE

Influenza Vaccination of Healthcare Workers:

Institutional Strategies for Improving Rates

Kristina Simeonsson, MD, MSPH, Chris Summers-Bean, MS, RN, and Allison Connolly, MA, MPH

Abstract

The nosocomial transmission of influenza has been well documented since the 1970s with both direct and indirect effects of outbreaks in healthcare settings. Outbreaks can directly increase morbidity among patients and residents of long-term care facilities. Indirect effects include disruption of normal operations of healthcare institutions, shortages of healthcare workers (HCWs), fewer elective admissions, and income loss due to absenteeism. Influenza vaccination of United States HCWs remains below 40% despite the availability of a safe, effective vaccine and a long-standing recommendation for vaccination of HCWs. New strategies to improve the rate of influenza vaccination among HCWs are needed as the percentage of those receiving yearly vaccination has changed little in the past 20 years. Increasing HCW influenza vaccination coverage calls for a paradigm shift; institutions should view vaccination of HCWs as a crucial part of a comprehensive infection control program designed to protect patients and staff. Administrators of hospitals, long-term care facilities, and other health agencies should respond to this challenge by developing programs to improve yearly influenza vaccination of their staff. Such efforts would put these employees into compliance with national recommendations and also benefit the institution by reducing absenteeism, nosocomial influenza transmission, and the associated economic losses and disruption of routine operations.

Introduction

Influenza epidemics occur each year in the United States; however, the impact of the disease on morbidity, mortality, and the economy is underestimated both by healthcare workers (HCWs) and the general public. An average of 200,000 people are hospitalized and 36,000 die due to influenza or its complications each year in the United States.[1,2] The healthcare costs related to these episodes as well as the time lost from work and school have a significant economic impact. In the United States, it is estimated that the economic cost associated with influenza epidemics exceeds $12 billion annually.[3]

Influenza is easily spread from person-to-person by respiratory droplets, particularly in enclosed areas. Infected adults can transmit influenza virus even in the absence of symptoms.[4] Therefore, infected HCWs can unknowingly serve as vectors of the virus even if they avoid contact with patients after the onset of illness.

Vaccination is the most effective means of preventing influenza illness. HCWs are among the target groups to receive influenza vaccine each year, yet their compliance with vaccination remains low. Institutions should promote influenza vaccination of HCWs as a necessary step to ensure the health of employees and patients.

Nosocomial Transmission of Influenza

Nosocomial transmission of influenza has been well documented since the 1970s. Outbreaks have been identified even during times when influenza activity was not documented in the surrounding community.[5,6] The effects of these outbreaks can be far reaching. They can increase morbidity among hospitalized patients and residents of long-term care facilities, who are at risk for complications from influenza illness. Outbreaks of influenza can also have the indirect effects of disrupting the normal operations of healthcare settings (if there are shortages of staff), decreasing elective admissions, and loss of worker income due to absenteeism.

Numerous outbreaks of nosocomial influenza, with effects

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on staff, institutions, and patients, have been documented in the infection control literature. A descriptive example by Sartor of an outbreak on an internal medicine ward is illustrative: Five of the 22 staff members became ill with influenza.[7] These five cases resulted in 14 person-days of sick leave during the two-week outbreak. Because of the staff shortage, eight scheduled admissions to this ward were postponed, and all admissions to the ward from the emergency department were suspended for 11 days. In this same study, nine of the 22 susceptible patients developed influenza illness, and three of the nine had prolonged hospitalizations.[7]

Outbreaks of influenza in high-risk settings like neonatal intensive care units, transplant units, and specialty care units, have resulted in increased morbidity or mortality for patients.[5,6,8-10] For example, Munoz and colleagues describe an outbreak of influenza A in a 20-bed neonatal intensive care unit (NICU).[8] This outbreak resulted in four infants developing influenza-like illness. Laboratory results confirmed influenza A in three of these infants. One of the infants subsequently died. Although no definite source for this outbreak was identified, four NICU staff members had been sick with influenza-like illness when the first infant manifested symptoms.

Cunney and colleagues describe an outbreak of influenza in a 34-bed NICU in which 19 infants became infected with influenza virus, six showed symptoms, and one died.[9] In both of the outbreaks described (by Munoz and Cunney), a very low percentage of NICU staff had been vaccinated for influenza. In the first instance, 45% of NICU physicians and 5% of NICU nurses had been vaccinated; in the second instance, only 15% of the NICU staff were vaccinated.[8,9]

The Effect of Vaccination

Research demonstrates that vaccination is effective in reducing morbidity and mortality due to influenza. In healthy persons under 65 years of age, the efficacy of influenza vaccination exceeds 80% when there is a good match between the vaccine strain and the circulating strain of influenza virus.[11,12] While the vaccine is not as effective in preventing illness in those over 65, it has been shown to significantly reduce severe complications and deaths in this age group.[13,14]

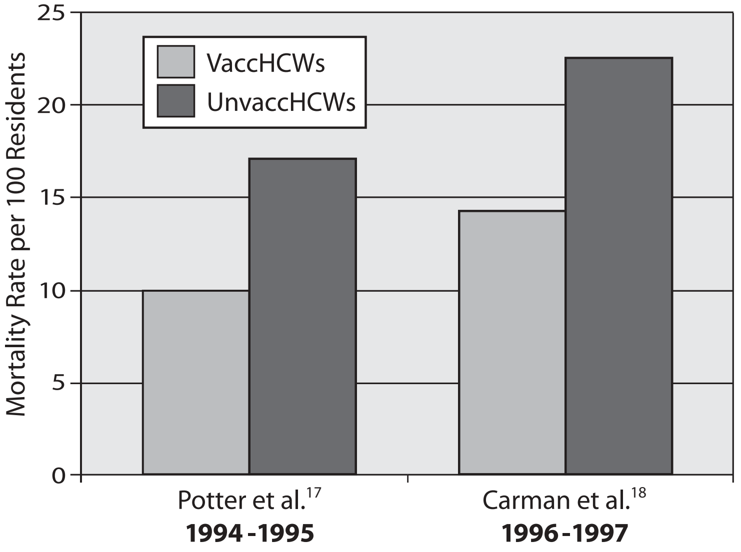
Further, vaccination has been shown to be effective in reducing absenteeism among healthy working adults.[11,12,15] In the largest study of healthy working adults (randomized and placebo-controlled), influenza vaccination reduced absenteeism due to upper respiratory infections from any cause by 43%.[15] In a study looking specifically at healthcare workers, influenza vaccination resulted in a 28% reduction of absenteeism due to respiratory infections during the influenza season.[16]

Vaccination of HCWs against influenza has also been associated with a reduction in patient mortality, as shown by two studies that examined the effect of vaccination of HCWs on patient mortality rates in long-term care facilities.[17,18] The first study, by Potter and colleagues, was conducted during the 1994-1995 influenza season in 12 long-term care facilities (LTCFs) in Scotland.[17] The investigators stratified the LTCFs according to their policy regarding vaccination of patients for influenza. The study then randomized the LTCFs into two groups—those in which HCWs were routinely offered influenza vaccination and those in which HCWs were not offered vaccination. In the LTCFs in which influenza vaccination was routinely offered to the workers, 61% of HCWs received the vaccine. Although the authors did not determine how many HCWs may have received vaccine at the LTCFs that did not offer the vaccine, they believed that the percentage of vaccinated HCWs in these facilities would be negligible.

A follow-up study was conducted by Carman and colleagues during the 1996-1997 influenza season in 20 LTCFs in Scotland.[18] LTCFs were again stratified according to their policy on influenza vaccination of patients and also by size of the facility. As in the study by Potter et al., the sites were then randomized into two groups. In one group, HCWs were routinely offered influenza vaccine, while in the other group of sites they were not. In those facilities where influenza vaccine was routinely offered to HCWs, 51% received the vaccine; in facilities where vaccine was not routinely offered, only 5% were vaccinated.

Both of these studies showed an association between vaccination of HCWs and decreased patient mortality (See Figure 1). In the study by Potter et al., patient mortality in facilities where HCWs were not routinely offered influenza vaccine was 17%, and in facilities where HCWs were offered the vaccine, patient mortality was 10%.[17] (The difference in patient mortality remained statistically significant after controlling for patient characteristics such as age, sex, influenza vaccination status, and

Figure 1.
Association of Long-term Care Resident Mortality and Healthcare Worker (HCW) Vaccination



degree of disability). The study by Carman et al. showed an unadjusted rate of mortality of 14% for residents in facilities where vaccine was offered to HCWs, compared to 22% in the facilities where vaccine had not been offered. A significant difference was still observed after adjusting for patient characteristics.[18]

Influenza Immunization of Healthcare Workers

Every year the Advisory Committee for Immunization Practices (ACIP) issues recommendations regarding which population subgroups should be targeted to receive influenza vaccination; the most recent recommendations are summarized in Box 1.[4] Although the ACIP has recommended for over 20 years that HCWs receive annual influenza vaccination, only 36% of HCWs (estimated) actually receive the vaccine each year.[19] The HCWs who receive influenza vaccine tend to be older, more likely in their work to be caring for children or the elderly, more likely to have received influenza vaccine in the past, and more likely to be physicians.[20,21]

Reasons for Acceptance

Compared to HCWs who are not vaccinated, those who are vaccinated are more likely to acknowledge the seriousness of influenza illness and its complications, recognize the efficacy of the vaccine, and understand their increased risk of contracting influenza.[20] In a study by Martinello et al., HCWs who responded correctly to a set of five basic knowledge questions pertaining to influenza vaccine were more likely to have been vaccinated compared to those who responded incorrectly to any one of the questions. [22]

Self-protection and personal health are the most common reasons that HCWs give for why they accept the influenza vaccine.[20,21,23-25] Beyond the wish to avoid illness, HCWs may accept vaccination in order to decrease the chance that they might miss work because of illness. In one survey of house staff physicians, one-third of the respondents said they got the vaccine to help avoid absenteeism.[26]

The desire to protect patients from influenza is another reason why HCWs decide to receive influenza vaccine. In some studies over half of vaccinated HCWs listed protection of patients as a major reason to receive the vaccine.[21,25]

Finally, the wish to serve as a role model may factor into a HCW's decision to receive influenza vaccine. Setting an example to other HCWs and patients was mentioned by 46% of hospital physicians surveyed in one study.[24] Twenty-four percent gave this as their most important reason for being vaccinated.

Reasons for Nonacceptance

Why are the majority of healthcare workers not receiving influenza vaccine? Surprisingly, the reasons are the same ones given by the general public. For instance, unvaccinated HCWs share the public's perceptions about the vaccine's side effects and its efficacy. The literature suggests that 20-44% of unvaccinated HCWs decline the influenza vaccine because they are concerned about side effects.[20-25] The most frequently mentioned side effect is the possibility of getting influenza or an influenza-like illness from the vaccine itself.[21,23,24,27] HCWs also fear allergic reactions or contracting Guillain-Barré syndrome following

Box 1: 2004 ACIP Recommendations: Target Groups for Annual Influenza Vaccination[4]

Persons at risk for complications

- persons aged ≥65 years;
- residents of nursing homes and other chronic-care facilities that house persons of any age who have chronic medical conditions;
- adults and children who have chronic disorders of the pulmonary or cardiovascular systems, including asthma;
- adults and children who have required regular medical follow-up or hospitalization during the preceding year because of chronic metabolic diseases (including diabetes mellitus), renal dysfunction, hemoglobinopathies, or immunosuppression (including immunosuppression caused by medications or by human immunodeficiency virus [HIV]);
- children and adolescents (aged six months-18 years) who are receiving long-term aspirin therapy and, therefore, might be at risk for experiencing Reye syndrome after influenza infection;
- women who will be pregnant during the influenza season; and
- children aged six-23 months.

Persons Aged 50-64 Years

- recommended because this age group has an increased prevalence of persons with high-risk medical conditions

Persons Who Can Transmit Influenza to Those at High Risk

- physicians, nurses, and other personnel in both hospital and outpatient-care settings, including medical emergency response workers (e.g., paramedics and emergency medical technicians);
- employees of nursing homes and chronic-care facilities who have contact with patients or residents;
- employees of assisted living and other residences for persons in groups at high risk;
- persons who provide home care to persons in groups at high risk; and
- household contacts (including children) of persons in groups at high risk.

influenza vaccination, although these side effects are mentioned less often.[20,25] Unvaccinated HCWs may also have doubts about the efficacy of the influenza vaccine.[23,24,28] A study of pediatricians in a Swiss hospital revealed that nearly half of those who remained unvaccinated gave doubt of the vaccine's efficacy as the primary reason.[24]

Even though HCWs may know that they can transmit influenza to others and also recognize the potential severity of the influenza illness in their high-risk patients, they may still choose not to receive the vaccine. A study at one United States institution documented a vaccination rate among HCWs of only 16.2%, this despite the finding that over 90% of the physicians and nurses surveyed recognized that HCWs could transmit influenza to patients and that the patients could die from the illness.[29] Although knowledge of the severity of influenza illness and the efficacy and safety of the vaccine does not insure a HCW's acceptance of it, misperceptions about influenza illness and the vaccine can be significant barriers to being vaccinated.[22,26,29]

Many HCWs are unaware of ACIP's recommendations regarding which population subgroups should be vaccinated for influenza.[20-23,26,29] In some instances, this may influence their decision to be vaccinated. For example, Nichol and colleagues found that 8% of unvaccinated HCWs said that the most important reason for not being vaccinated against influenza was that they did not think they were in a target group for receiving it.[20] In addition, four studies discovered that between 2% and 15% of unvaccinated HCWs declined the vaccine because they were pregnant or breastfeeding,[21-23,29] although neither pregnancy nor breastfeeding is a contraindication to influenza vaccination.[4] In fact, the ACIP recommends that women who will be pregnant during the influenza season receive vaccine because they are at risk for complications from influenza illness.[4]

Finally, some unvaccinated HCWs simply believe that they are not at risk for influenza infection. [21-23,28] Harbarth and colleagues found that over half of the unvaccinated HCWs cited either their strong host defense or a low risk of getting sick from influenza as the primary reason not to be vaccinated.[28]

The belief of some HCWs that they are not at risk may stem from confidence in their host defense mechanisms or an ability to avoid influenza through personal prevention strategies.[21,28,30] For example, Manuel and colleagues found that the 81% of never-vaccinated HCWs believed that hand washing was more important for preventing illness from influenza than the vaccine.[30] In comparison, 67% of vaccinated HCWs held the same opinion. In the same study, 73% of never-vaccinated HCWs and 48% of vaccinated HCWs believed that a healthy diet and regular exercise were more important for preventing influenza than vaccination.

Improving HCW Immunization Rates

Influenza vaccination among HCWs in the United States remains below 40% despite continued nosocomial outbreaks of influenza, the availability of a safe and effective vaccine, and a long-standing recommendation by the nation's leading committee on vaccination guidelines that HCWs be vaccinated. Administrators of hospitals, long-term care facilities, and home-health agencies, among others, need to respond to this situation by developing programs to improve yearly influenza vaccination coverage among their staff. Such programs would not only put these employees into compliance with ACIP recommendations, it would also benefit the institutions by reducing absenteeism, nosocomial influenza transmission, and the associated economic losses and disruption of routine hospital operations.

Healthcare institutions should design their influenza immunization programs around the inactivated, injectable vaccine. Although an intranasally-administered influenza vaccine became available in 2003, it is a live, attenuated influenza vaccine (LAIV) with several limitations that make it impractical to use in an institution-wide campaign. For instance, it is only approved for young, healthy persons (between five and 49

Box 2: Keys to Increasing Healthcare Worker Vaccination Rates

1. Top management and administration need to become strong advocates to ensure healthcare workers get vaccinated to accomplish:
    a. better infection control
    b. reduced absenteeism
    c. cost savings
2. Make vaccination convenient
3. Reduce or remove cost barriers
4. Remind healthcare workers that CDC recommends influenza vaccination annually
5. Educate healthcare workers that:
    a. Injectable influenza vaccine cannot cause influenza
    b. Influenza virus is easily transmitted between healthcare workers and patients, putting already ill patients at risk for influenza illness and its complications

From the National Foundation for Infectious Diseases. Call to action: influenza immunization among health-care workers 2003. Bethesda, MD: National Foundation for Infectious Diseases, 2003. Available at http://www.nfid.org years);[4] people with an array of chronic conditions, including diabetes and heart disease, should not receive LAIV. In addition, LAIV is not recommended for HCWs who care for severely immunosuppressed patients.[4] Further, from an institutional perspective, the cost and the storage and handling procedures make LAIV undesirable compared to the injectable vaccine.

The National Foundation for Infectious Diseases (NFID) recently issued a call to action for employers to improve HCW influenza vaccination rates.[31] The key elements of the NFID's action plan (See Box 2) provide a solid foundation from which to develop a comprehensive influenza vaccination program. NFID recommends that top management become strong advocates of HCW influenza vaccination and that cost and access barriers be removed. The Foundation also suggests educating healthcare workers about the ACIP's recommendations and about nosocomial transmission of influenza, as well as debunking the common myths and misperceptions regarding the virus and the vaccine itself.

The educational component of an immunization campaign will likely require the most extensive planning and implementation. According to the NFID, increasing awareness among healthcare workers of the ACIP recommendation regarding them as a target group to receive the vaccine should be directed at all healthcare workers—those who already know the ACIP recommendation and those who do not. Some who know the recommendation may disagree with it.[20] Therefore, the rationale behind the recommendation must be included in the educational messages. HCWs should be made to understand that they can spread influenza to their patients, even in the absence of symptoms. When it is appropriate, documentation of nosocomial outbreaks can be used to illustrate this point.

Knowledge of ACIP recommendations and the ramifications of nosocomial influenza will not be enough to convince some HCWs to participate in a vaccination program. As discussed in the previous section, the fear of side effects or doubts about efficacy are often the principal factors in the decision to not receive the influenza vaccine. Therefore, educational campaigns should also highlight the low risk of side effects from influenza vaccine as well as its proven efficacy.

Influenza Vaccination of Healthcare Workers Remains a Priority

Kristina Simeonsson, MD, MSPH

On October 5, 2004, one of the two manufacturers of inactivated influenza vaccine for the United States announced that it would be unable to deliver any of its vaccine because of contamination problems. This loss of more than 40 million doses of influenza vaccine has significantly reduced the projected supply for the United States, creating a severe shortage of vaccine for the current influenza season. In response, the Advisory Committee on Immunization Practices (ACIP) amended its list of recommendations for vaccination groups in an attempt to target the remaining supply to reduce the risk of influenza complications for those at highest risk.[1] These interim recommendations define eight groups of equal priority to receive influenza vaccine:

- all children aged six-23 months;
- adults aged 65 years and older;
- persons aged two-64 years with underlying chronic medical conditions;
- all women who will be pregnant during the influenza season;
- residents of nursing homes and long-term care facilities;
- children aged six months-18 years on chronic aspirin therapy;
- healthcare workers involved in direct patient care; and
- out-of-home caregivers and household contacts of children aged less than six months.

Individuals who are not in one of these priority groups have been asked to forego or defer vaccination for the 2004-2005 influenza season. These interim recommendations no longer include persons 50-64 years or household contacts of high-risk individuals as groups for which influenza vaccine is recommended.

Despite the change in vaccination recommendations due to this season's shortage, the ACIP still includes healthcare workers (HCWs) as a priority. The decision to include HCWs in the priority groups underscores that HCW-vaccination is essential to control the spread of influenza to high-risk patients.

Even for individuals in the eight priority groups, gaining access to vaccination this season may continue to pose significant challenges. HCWs who are not offered vaccination at their workplace should make every effort to get vaccinated on their own. Certain categories of HCWs have two options for influenza vaccination: (1) They can receive either the injectable influenza vaccine or (2) the intranasal, live attenuated form of influenza vaccine (FluMist). FluMist is indicated for healthy individuals five-49 years of age. According to the ACIP, HCWs who meet these criteria and do not care for severely immunosuppressed patients can receive the intranasal form of vaccine.[2] Healthcare facilities may choose to develop institutional policies pertaining to the use of FluMist for their HCWs. Regardless of whether HCWs are successful in finding influenza vaccination this year, the message about HCW vaccination is clear. Annual influenza vaccination of HCWs remains a top priority.

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Access to influenza vaccination must also be ensured. Several studies document that the location and schedule of vaccination administration influence whether HCWs will participate.[20,22,26,28] Access, however, includes not only logistical issues such as locations and times for vaccine administration, but also the cost to the worker of being vaccinated. One study found that one-third of vaccinated HCWs at one institution would not accept influenza vaccine if they had to pay for it themselves.[21] A recent position statement of the Association for Professionals in Infection Control and Epidemiology urged institutions to provide their employees with influenza vaccination at no charge—just as these institutions provide masks, gloves, gowns, and hand-washing products to employees at no charge.[32]

In short, the educational and access components of vaccine programs will likely be multi-faceted. Thus, assessing the employees' knowledge and concerns about the influenza vaccine, and therefore their willingness to be vaccinated, and removing the barriers to gaining access to vaccination, are both critical steps in planning a campaign. HCWs are a heterogeneous group who vary greatly in terms of their healthcare knowledge, educational level, and primary work environment, as well as race and culture. These variations may influence both the workers' educational needs and their ability to surmount the access barriers with respect to receiving influenza vaccination.[22-26,28]

Begue and colleagues found that addressing all of the issues expressed by HCWs during the educational component of the campaign increased their vaccination rate by 50%.[23] Other studies have demonstrated that some HCWs—attending and resident physicians, for example—are more likely than others to cite time and convenience as important reasons behind their failure to be vaccinated.[22,25,26]

One successful strategy to improve access is linking the vaccination campaign to a required activity. At one institution, a HCW vaccination rate of 62% was achieved for the 1999-2000 influenza season when vaccine was offered to HCWs during their mandatory tuberculosis screening, which was scheduled for a one-week period in October.[21] Offering the vaccine in a setting where employees are screened for other occupational health issues may also provide an opportunity to address individual concerns about the vaccine in a private manner. Other institutions have noted that offering the vaccine to the HCWs in the units where they work has proven to be an effective strategy.[20,22,28]

The ACIP recommendation that HCWs receive influenza vaccination every year is not a new one. However, new strategies to improve vaccination coverage of HCWs are necessary because the rate of vaccination has not changed significantly in the past 20 years. The challenge of increasing HCW influenza vaccination calls for a paradigm shift. Institutions should view influenza vaccination of HCWs as an integral part of a comprehensive infection control program designed to protect both patients and staff.[33] Vaccination remains the most effective way to prevent influenza illness, and vaccination of HCWs is essential to preventing the spread of influenza in healthcare settings. **NCMJ**

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ARTICLE

Racial Disparities in Health between White and African American Family Practice Patients:

Clinical Implications

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Abstract

Objective: *To identify differences in self-reported health status and prevalence of chronic disease between African American and white patients.*

Study Design: *A representative sample of African American and white adult patients from a stratified sample of family practices in North Carolina completed a questionnaire that included self-reported racial status, certain sociodemographic data, health risk factors, chronic conditions, and health status measures.*

Data Source: *The North Carolina Health Project, a practice-based cohort of adult patients from a representative sample of family practice offices in North Carolina.*

Principal Findings: *African Americans report poorer general health status than whites. Obesity, insufficient exercise, high blood pressure, and diabetes are more prevalent among African American than white family practice patients, even after adjusting for age, gender, and educational attainment.*

Conclusions: *This study complements previous evidence of disparities in chronic disease and health risk factors between African Americans and whites, and it highlights specific factors that may be important in the primary care setting.*

Relevance: *By focusing clinical attention on the prevention or treatment of specific factors that are known to be more prevalent among certain racial groups, primary care providers may help to reduce racial differences in healthcare.*

Key words: *Health Disparities, Race, Ethnicity, Family Practice Network, Risk Factors, Health Conditions, Health Status*

Introduction

Compared with other ethnic groups, African Americans have a disproportionately high prevalence of many risk factors and diseases, and these are associated with increased morbidity and mortality. For clinicians to better serve African American patients, they must understand the disparities that exist, their causes, and practical means of intervening. African Americans have historically had less access to and use of ambulatory care services, and there appear to be potentially important differences in the ways that African Americans and whites perceive their health status.[1-4] African Americans may also differ from whites

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in how they perceive benefits or harms that they associate with certain medical or surgical interventions.[5,6] It is unclear to what extent race contributes directly to disparities in perceived health status, as opposed to serving as a proxy for other, more directly pertinent factors such as socioeconomic status. Race, however, is a salient attribute for many individuals, either in how they identify themselves, or how they are identified by others, including healthcare providers. It is useful and informative, therefore, to assess the extent to which actual and perceived health status differs between members of different races who reside in the same community and who receive medical care from the same provider.

The primary care physician's office practice constitutes an important site for both prevention and treatment of health problems. Therefore, it is important for primary care physicians to be sensitive to race and ethnicity-related issues in their patients, to be aware of the care their patients receive, and to provide complete and accurate information about healthcare options to all of their patients.

This study compared general health status, health risk factors, and chronic disease rates between African American and white patients in a representative sample of family practices in North Carolina. The study aimed to identify how perceived health status, as well as healthcare needs and access, differ by race, so as to better inform the delivery of health interventions that are appropriate to African American and white patients in the primary care setting.

Methods

Data for this study are from the North Carolina Health Project (NCHP), a network of 13 family practices with 16 location sites in North Carolina. The study selected practices by a purposive sampling method that ensured representation of rural and urban sites in each of the state's three geographic regions (west, central, and east), and that preferentially selected practices serving high proportions of racial/ethnic minorities. Rural and urban status was designated based on the United States Department of Agriculture's (USDA) rural-urban county codes for the county in which the practice was located.[7] All selected practices agreed to participate in data collection.

The study placed research assistants at each participating site for a four-week data collection period. The research assistants offered a four-page, self-report questionnaire, available in English or Spanish, to each non-emergency adult patient who presented for an office visit. As needed, the research assistants explained the questionnaires and consent forms, answered participants' questions, and assisted them with questionnaire completion, which took place in the healthcare provider's office at the time of the visit.

The questionnaire included the following measures:

- **Sociodemographic data:** age, race, gender, marital status, work status, education level.
- **Physical measures:** weight and height. Body mass index (BMI) was calculated from the reported weight and height.
- **Health risk behaviors:** exercise habits and smoking status.
- **Chronic health conditions:** high blood pressure, heart disease, osteoarthritis, depression, chronic back pain, and diabetes.

Table 1.

Selected Characteristics of African American and White Adult Patients in North Carolina Family Practice Settings

	African Americans (N=900) % or Mean	Whites (N=3,481) % or Mean	p Value*
Female Gender	75.9%	69.5%	0.018
Age in Years	46.0	48.0	0.342
Residence in Rural County	48.1%	53.1	0.781
Educational Attainment			
Less than high school	29.6%	16.5%	
High school diploma	31.7%	30.1%	
Beyond high school	38.7%	53.4%	0.031
Marital Status			
Married	32.7%	65.4%	
Widowed	12.1%	8.4%	
Living w/ partner	5.3%	2.7%	
Separated/divorced	22.6%	13.4%	
Never married	27.3%	10.3%	0.016
Currently Working	49.2%	58.7%	0.062
Health Risk Factors			
Smoking now	24.2%	25.4%	0.482
No exercise	56.3%	41.6%	0.001
Obese (BMI > 30)	53.4%	35.5%	< 0.001
Chronic Conditions			
High blood pressure	48.6%	31.9%	0.004
Heart disease	9.8%	11.4%	0.295
Osteoarthritis	24.7%	23.8%	0.763
Depression	23.7%	26.4%	0.185
Chronic back pain	24.1%	25.1%	0.503
Diabetes	21.6%	12.0%	0.006
General Health Status			
"Fair" or "poor" health	36.6%	24.3%	0.009

** Significance tests for comparisons were calculated using Pearson's chi-square test for categorical variables and the 2-sample t-test for continuous variables, adjusted for stratified sampling design using SUDAAN 8.1*

- **Health status:** self-rated health status as assessed by the question, "In general, would you say that your health is: excellent, very good, good, fair, poor?"

Research assistants mailed completed and incomplete questionnaires to the principal investigators on a weekly basis. All data were then entered into an Access database.

The investigators stratified the subjects' demographic and clinical characteristics by race (African American vs. white) and excluded data from subjects who did not identify themselves as either African American or white from these analyses. We used Pearson chi-square analyses and 2-sample t-tests to measure the significance of differences between the two study groups, and we dichotomized the five-point scale for general health status into two categories: fair/poor *versus* excellent/very good/good. We analyzed educational attainment in three categories: less than a high school diploma, high school diploma, and more than a high school diploma. In calculating odds ratios between African Americans and whites, we used logistic regression, with health habits, risk factors, chronic conditions, and health status as dependent variables, and age, gender, and education level as co-variates. All statistical tests were two-sided (alpha=0.05) and were adjusted for the clustering of residents within clinics using Taylor series expansion methods,[8] as implemented in SUDAAN software.[9]

Results

Response rate

In the 16 practice sites, we found 7,680 eligible patients, of whom 4,760 consented to participate, yielding a recruitment rate of 62%. Approximately 10% of respondents required support from study research assistants to complete the self-report questionnaires. Sixty-nine (1%) respondents identified themselves as belonging to more than one racial group (mixed race), and 310 (7%) checked neither "black" nor "white." Of these, 95 (31%) identified themselves as either "Mexican, Mexican-American, or Chicano" or "Other Spanish, Hispanic, or Latino." We omitted these respondents from the analyses. The total analysis sample consisted of 4,381 respondents, 3,481 (79%) of whom identified themselves as white and 900 (21%) who identified themselves as black. In this paper, we use the term African American to refer to the participants who checked "black" in accordance with convention in the medical literature, even though the African ancestry may be distant for many of the individuals in this sample. All of the respondents included in this study completed the English version of the study questionnaire.

Demographics

Demographic data for the study sample, stratified by race, appear in Table 1. Within the study sample, 76% of African Americans and 70% of whites were female (p=0.018). The mean ages in years for African Americans and whites were 46 and 48, respectively (p=0.342). Approximately half of the sample of both African Americans and whites resided in a rural county. Whites tended to have higher educational levels, with a greater percentage of whites having had more than a high school education than African Americans (p=0.031). More whites (65%) than African Americans (33%) reported being married (p=0.016). More whites (59%) than African Americans (49%) also reported being currently employed, either full-time or part-time (p=0.062).

Health risk factors

We found no significant difference in smoking status between African Americans and whites; approximately one-quarter of both groups were smokers. There was, however, a significant racial difference in the percentage of the population whom we defined as obese (BMI > 30), with 54% of African Americans *versus* 36% of whites meeting this criterion (p<0.001). African Americans also tended to be more sedentary; 56% of African Americans compared to 42% of whites reported getting no exercise on a typical day (p<0.001).

We report the odds ratios for selected risk factors and conditions among African Americans and whites, adjusted for age, gender, and education level, in Table 2. Compared to white patients, the adjusted odds for African Americans are lower for current smoking status (OR 0.76, 95% CI 0.61-0.94) and higher for reporting no exercise on a typical day (OR 1.63; 95% CI 1.29-2.05) and for being obese (OR 1.92; 95% CI 1.61-2.30).

Chronic conditions

Of the self-reported chronic conditions selected for analysis, we found that the frequency of heart disease, osteoarthritis, depression, or chronic back pain did not differ by race. However, African Americans did report more high blood pressure (49% vs. 32%, p=0.004) and diabetes (22% vs. 12%, p=0.006) than did whites (See Table 1). After adjusting for age, gender, and education, this difference still held: African Americans were more likely than whites to report high blood pressure (OR=2.44; 95% CI 2.05-2.91) and diabetes (OR=2.16; 95% CI 1.66-2.78) and less likely to report depression (OR=0.74; 95% CI 0.58-0.95) and chronic back pain (OR=0.81; 95% CI 0.71-0.94). The adjusted odds of reporting heart disease or arthritis were not statistically different from 1.00, when controlling for age, gender, and education (See Table 2, Model 1). However, after controlling for the additional variables of current smoking, exercise status, and obesity, the odds of African Americans reporting heart disease were significantly lower than for whites (See Table 2, Model II; OR=0.73; 95% CI 0.60-0.88).

Health status

More African Americans rated their general health as "poor" or "fair" than whites (37% vs. 24%, p=0.009) (See Table 1). This difference remained significant even after controlling for age, gender, education, current smoking, exercise status, and obesity (OR=1.47; CI 1.06-2.04) (Table 2).

Discussion

The United States is becomingly increasingly diverse racially and ethnically. Racial disparities in health and in the receipt of healthcare in the United States are well documented.

Table 2.
Adjusted Odds Ratio of Selected Health Indicators among African American Patients Compared to Whites in Family Practice Settings

	Odds Ratios (95% CI)	
Dependent Variables	Model I[a]	Model II[b]
Health Risk Factors		
Smoke now	0.76 (0.61, 0.94)	—
No exercise	1.63 (1.29, 2.05)	—
Obese (BMI > 30)	1.92 (1.61, 2.30)	—
Chronic Conditions		
High blood pressure	2.44 (2.05, 2.91)	2.11 (1.67, 2.67)
Heart disease	0.88 (0.71, 1.08)	0.73 (0.60, 0.88)
Osteoarthritis	1.10 (0.86, 1.39)	0.97 (0.75, 1.25)
Depression	0.74 (0.58, 0.95)	0.65 (0.53, 0.78)
Chronic back pain	0.81 (0.71, 0.94)	0.72 (0.60, 0.85)
Diabetes	2.16 (1.66, 2.82)	1.83 (1.37, 2.45)
General Health Status		
"Fair" or "poor" health	1.59 (1.23, 2.06)	1.47 (1.06, 2.04)

Odds ratios calculated using logistic regression with race as the explanatory variable, and adjusted for stratified sampling design using SUDAAN 8.1.

[a] Model I: adjusted for subject age, gender, and education.
[b] Model II: adjusted for subject age, gender, education, current smoking, exercise status, and obesity.

Maintaining and improving the nation's health will, therefore, be dependent in part on reducing the factors that lead to health status disparities between minority groups and whites.[10] This study confirms that African American patients report poorer health status and greater prevalence of certain risk factors for poor health, particularly obesity, sedentary lifestyle, and high blood pressure, compared to their white counterparts in the primary care setting of North Carolina. The purpose of this study was to confirm and measure these health disparities in the family practice setting in order to illustrate the challenges that face primary care providers in North Carolina. Because the offices of primary care physicians are common sites of medical care for persons with risk factors who have not yet developed overt disease, primary care physicians could play an important role in decreasing the observed disparities in health outcomes.

Data for this study were obtained only from individuals who received medical care from family practice providers in the state of North Carolina. Our findings may therefore not be readily generalized to other regions of the United States, or to other medical practice settings. An additional limitation is that the data were obtained by patient self-report, which makes the health risk factors and chronic condition reports subject to bias or inaccuracies due to misunderstanding of medical diagnoses by some respondents. On the other hand, the study has a unique strength: it is the first to examine health risk factors, chronic conditions, and self-reported health status among a representative sample of family practice patients across an entire state.

There are many plausible explanations for observed disparities in health, including potential differences in socioeconomic status, educational attainment, access to healthcare, health-related behavior, discrimination, and racism. In our study, disparities in risk factors and chronic conditions persisted after adjusting for educational attainment (See Table 2). Furthermore, every study participant had at least some access to primary care, although we did not assess the quality or quantity of healthcare services available to individual patients. It therefore seems unlikely that access to healthcare is a major contributor to the race-related differences observed in this study. Other explanations must be considered, including the possibility that some forms of discrimination or racism occur in the community or in the healthcare setting. Evidence that suggests that a patient's race may influence providers' decisions or actions has been found in studies that reveal that physicians may sometimes perceive African Americans as less intelligent and less likely to adhere to medical advice compared to white patients,[11] that medical students judge black patients to have a lower quality of life than white patients with similar symptoms,[12] and that the race and sex of patients may independently influence the way a physician elects to manage chest pain.[13]

Strong evidence exists to suggest that a primary care office may be an appropriate setting to bring about change in health-related behaviors. A meta-analysis of primary-care-based intervention studies revealed that physical activity counseling is often effective, with stronger results obtained from interventions that are brief (3-10 minutes), tailored to the patients' characteristics and preferences, and that include supplemental written materials.[14] Physician intervention can also lead to smoking cessation.[15,16] Moreover, achieving a healthy weight tends to improve patients' subjective well-being.[17] It is has also been shown that minority and economically disadvantaged patients are less likely to receive screening[18] and behavioral interventions[19] from their physicians. Finally, steps to increase cultural competency among healthcare providers may help to reduce the tendency toward racial and ethnic bias in the provision of care. Elements of cultural competency within the practice setting include: a culturally diverse staff that reflects the community served; bilingual providers and/or translators when significant language barriers exist; providers who are knowledgeable about different health beliefs, cultural practices, or values among their patients; patient education materials that are culturally and linguistically appropriate; and a practice that engages in community outreach activities.[20] **NCMJ**

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ARTICLE

Diabetes Awareness among African Americans in Rural North Carolina

Angela K. Antony and Walid A. Baaklini, MD, FCCP

Abstract

Objective: *To evaluate the extent of diabetes unawareness in rural North Carolina.*

Methods: *Randomly administered an eight-question survey to African Americans age 15-74 living in Halifax County, North Carolina.*

Results: *Ninety-five out of 116 eligible participants completed the survey (82% response rate). Most (67%) of the participants reported having two or more major risk factors for Type II diabetes (diabetes mellitus). More than half (51.6%) of the participants were obese. Most (96.8%) of the participants reported having been tested for diabetes at some point in their lives (10% tested positive, only 8.4% of the remaining 90% reported ever having a second test).*

Conclusion: *Diabetes mellitus is a very prevalent problem among the African American population of Halifax County, North Carolina. Our study underscores the fact that patients are not systematically screened and followed-up for diabetes mellitus. More healthcare and commnity programs need to be adapted to fight this serious public health problem.*

Introduction

Diabetes mellitus is one of the most serious health problems facing the more than 35 million African Americans living in the United States—1.8 million of whom live in North Carolina.[9] Diabetes mellitus, a condition in which the body produces little or no insulin or is unable to utilize insulin properly, results in dangerously high blood sugar levels; this can lead to coma, death, or a myriad of other health complications including blindness, kidney failure, foot or leg amputations, stroke, and heart disease. Diabetes impairs lives of countless African Americans is the seventh leading cause of death of African Americans in the United States.[8]

There are two major categories of diabetes, Type I and Type II. With Type I diabetes, the body produces almost no insulin at all so the afflicted individual must take exogenous insulin to survive. In Type II diabetes, also known as adult onset diabetes mellitus (AODM), the body either produces insufficient amounts of insulin or experiences insulin resistance, a condition in which the body cannot properly utilize insulin. Type II diabetes accounts for 90-95% of all diabetes cases.

Over the last 30 years, the number of African Americans diagnosed with diabetes nationwide has more than tripled. Presently, over 2.8 million African Americans are plagued with this serious disease.[1] Studies show that in North Carolina, African Americans are three times more likely to develop diabetes than whites of a similar age. Compared to white Americans, African Americans experience higher rates of three serious diabetes complications: blindness, kidney failure, and amputations. In addition, African Americans also experience greater disabilities from these complications.[9] However, despite the staggering statistics, diabetes awareness within the African American communities of North Carolina is alarmingly low. In fact, diabetes awareness is such a problem that more than half of African Americans with diabetes are totally unaware of their medical condition. This means that for every African American diagnosed with diabetes, there is at least one undiagnosed case.[3]

This study was conducted to investigate the level of diabetes awareness within the African American population of rural North Carolina. In this study, the targeted population was that of Halifax County where African Americans comprise over 53% of the total population.[9] Research found that many of the African Americans in Halifax County fell into the high-risk category and exhibited several of the genetic, medical, and lifestyle risk factors characteristic of diabetes.[5] However, many of these individuals had not been tested for diabetes, and of the few who had been tested, the majority had not gone back for a second testing. This study was conducted in Halifax County with the hope that it would encourage similar studies elsewhere in rural North Carolina, thereby aiding in the imperative task

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Figure 1.
Diabetes Survey

1. **Please specify your age group:**
   ☐0-20 ☐20-39 ☐40-49 ☐50-59 ☐60-74 ☐75+
2. **What is your sex?** ☐Male ☐Female
3. **What is your race/origin?**
   ☐Caucasian ☐African American ☐Hispanic
   ☐Asian/Pacific Islander ☐Other: _______________
4. **Do you visit a doctor regularly?**
   ☐Yes ☐No
5. **When was the last time you visited a doctor?**
   ☐last week ☐last month ☐last year ☐1-2 years ago
   ☐more than 2 years ago
6. **What is your height and weight?**
   Height: ___feet ___inches Weight: ___lbs
7. **Which of the following describe you?** *(please mark all that apply):*
   ☐ I have been diagnosed with obesity.
   ☐ I have an immediate family member with diabetes.
   ☐ I exercise regularly. (at least three times a week)
   ☐ I am a woman who has delivered a baby weighing over 9 pounds.
   ☐ I have high blood pressure or hypertension.
8. **Have you ever been tested for diabetes?** If yes, please circle your test result.
   ☐Yes (positive / negative) ☐No
   If you answered yes and positive, are you being treated for diabetes? ☐Yes ☐No
   If you answered yes and negative, have you been tested again for diabetes since? ☐Yes ☐No

of increasing diabetes awareness throughout the African American population of North Carolina.

A questionnaire was developed to evaluate how much the rural African American population understood about the various risk factors of Type II diabetes mellitus. We categorized the risk factors of Type II diabetes into three groups: genetic, medical, and lifestyle. Genetic risk factors include inherited traits and family ancestry; medical risk factors include obesity, hyperinsulinemia, insulin resistance, and impaired glucose tolerance; lifestyle risk factors include diet and physical activity. Included in the questionnaire was a survey (See Figure 1), which assessed the risk level of each individual and inquired whether the individual had been tested or treated for diabetes. Our survey responses were analyzed to determine the number of people unaware that they were at high risk for diabetes. A presentation and lecture on diabetes risk factors and prevention was given to the participants after they completed the survey. Our study was aimed at evaluating the severity of diabetes unawareness in rural North Carolina, which would ideally generate interest in how to deal with this issue and increase awareness in the African American community.

Methods

Before embarking on our campaign to research diabetes awareness, we first assessed the current diabetes knowledge of the African American population in question. The five members of the survey research team were Dr. Walid Baaklini; North Carolina School for Science and Mathematics Senior Angela Antony; registered nurse and diabetes educator Susan Liverman; and two local volunteers. We devised a survey (See Figure 1) on diabetes awareness and risk factors and distributed it randomly to citizens in several African American concentrated areas of Halifax County, North Carolina. Out of 116 eligible participants, 95 individuals participated in the study yielding a response rate of about 82%. The survey included questions that identified the individual risk factors of diabetes such as age, physical activity level, family history, and other genetic, medical, and lifestyle factors. Individuals who were at high risk for diabetes based on their answers to the risk factor questions were then asked additional questions assessing their awareness of this high-risk condition. In addition, we asked individuals if they had ever been tested for diabetes. If they had and were found to be non-diabetic, we inquired whether they had gone back for a second testing. Finally, we requested the height and weight of each person surveyed and used a Body Mass Index Chart to assess whether these individuals could be at risk because of their weight since obesity is another major risk factor for diabetes.

Results

African Americans between the ages of 15 and 74 completed the survey. Upon analysis of the data, we found that 67% of the studied population had two or more of the major risk factors for Type II diabetes, which classified them as “high risk.” However, only three of these high-risk individuals had visited a doctor within the last year. Fortunately, the findings also showed that 96.8% of the surveyed population had been tested for diabetes at some point in their lives, and 10% of those tested were found positive for the disease and were given treatment. However, of the 90% that had tested negative, only 8.4% had gone back for a second testing. This is unfortunate, given Halifax County’s high-risk reputation and the wide range of ages in which diabetes can develop.

Another of the major risk factors of diabetes is heredity, and the survey found that 10% of the population had an immediate family member with Type II diabetes. Those taking the survey were also asked whether they exercised regularly, because research has proven that exercising at least three times a week can significantly reduce the risk of developing diabetes.[3] Unfortunately, only 3.3% of the surveyed population reported regular exercise—a group that included less than 6.7% of the female population. One other major risk factor of diabetes is obesity, which was also inquired about in the survey. Using the Body Mass Index (BMI) chart, we found an alarming 51.6% of the population to be obese, meaning they had scored over 29 on the BMI scale. In several extreme but common cases, the obesity in question had become especially dangerous. One male in the over-75 age group stood at 5'2" and 189 pounds, scoring a 34.5 on the BMI scale. Another male in the 50-60 age group, measured 5'3" tall but weighed 200 pounds, scoring a 36 on the BMI chart. One of the most alarming cases observed, however, was that of a female in the 60-74 age groups. Standing at 4'5", a normal height for a schoolchild, the woman in question weighed 175 pounds, putting her off the charts on the BMI scale. We estimated her score to be roughly 38 or 39.

Unfortunately, although over half of the randomly chosen participants in our study were obese, only 6.45% of these cases had been diagnosed. Even more alarming, a full 71.1% of the undiagnosed obesity cases claimed to visit a doctor on a regular basis.

Conclusion

Diabetes, once relatively uncommon among African Americans, is now the third leading cause of death from disease among this population.[2] Studies have found that African Americans, both in North Carolina and throughout the United States, are more prone to this disorder for numerous reasons. African Americans have a higher prevalence of obesity, a fact also observed in this study, which is a major risk factor for Type II diabetes. In addition, African Americans are known to have a higher occurrence of hypertension, a disorder strongly associated with diabetic complications such as eye, kidney, and heart disease. Lastly, African Americans tend to have less access to financial, social, health, and educational resources that would otherwise improve their current health status and level of diabetes awareness.[10]

Still, there are many ways to alleviate this problem and to improve the present health situation of our state and nation's African American population. First, obese individuals, through proper diabetes education and instruction, can effectively manage or prevent diabetes through diet, weight control, and exercise if they act early. With more advanced obesity cases, treatment with oral hypoglycemic agents or insulin can make a difference. In addition, proper diabetes education and management can reduce the risk of suffering from the major diabetes complications such as blindness, kidney failure, heart attack, stroke, and amputations. The factors that aggravate these complications include delay in diabetes diagnosis, delay in treatment, denial of diabetes, abnormal blood lipids, high blood pressure, and cigarette smoking, all of which can be avoided or alleviated through increased diabetes awareness.

Ultimately, the key is spreading the word. This study was intended to motivate clinics, hospitals, and medical professionals to aid in the crucial task of increasing diabetes awareness. Already throughout Halifax County, the word is beginning to spread: diabetes support groups, fundraisers, and public presentations are becoming increasingly more common. Awareness is paramount if we want to see more favorable diabetes statistics for the African Americans of Halifax County, North Carolina, and the entire United States. **NCMJ**

Angela Antony was senior in high school at the North Carolina School for Science and Mathematics when she completed her study and this article. She is now a freshman pre-med student at Harvard University. Her work here is remarkable at this early stage in her career. We are proud to produce young students like Ms. Antony in North Carolina and hope that she will return to North Carolina to practice.

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Thanks from the *North Carolina Medical Journal*

Without the voluntary assistance and carefully executed reviews of a number of anonymous reviewers, no journal can offer the kind of peer-review for submitted manuscripts that can assure its readers the highest quality of published articles. We are fortunate in having the service of a number of individuals who have given generously of their time and expertise in service to the *North Carolina Medical Journal* this past year, and we are pleased to have this annual opportunity to acknowledge their efforts.

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POLICY FORUM
Eliminating Racial and Ethnic Health Disparities

> ***"The fundamental need for eliminating health disparities is to preserve the health of the nation. Health is not just the absence of disease, but rather the presence of both physical and mental well-being."***

COMMENTARIES

INTRODUCTION

Policy Forum:
Eliminating Racial and Ethnic Health Disparities

In our continuing effort to present clear and broad-spectrum coverage of key health and healthcare issues facing North Carolinians, this issue of the *North Carolina Medical Journal* focuses on a national policy agenda having significant implications for our state. When former President Clinton and Surgeon General Dr. David Satcher announced a major new initiative to decrease or eliminate the disparities that exist in the United States affecting groups defined by racial/ethnic, socio-economic/income, gender, geographic, age, disablement, or sexual orientation characteristics, they were calling to our attention some of the most pervasive and embarrassing realities of American health status and healthcare. Not only are these disparities in the incidence, prevalence, and burden of illness associated with common health conditions huge in many cases, but addressing these issues is made all the more difficult by the sheer complexity of these disparities and the factors that may have contributed to them.

Although disparities exist when comparisons are made between the health status and healthcare accessibility experienced by most middle- and upper-class American whites and persons in several minority population categories, the predominant emphasis in discussions of health disparities has been on those related to race and ethnic status. These discussions often are more narrowly focused on differences between whites and African Americans. In this issue of the Journal, we bring attention to the broader set of problems under the rubric of "health disparities," but our focus, like that of others, is limited, for the most part, to racial/ethnic disparities. We have tried to expand the discussion to include minority groups other than African Americans.

We have invited Anissa I. Vines, PhD, MS, and Paul A. Godley, MD, PhD, of the University of North Carolina, Co-Directors of the Program on Ethnicity, Culture, and Health Outcomes (ECHO), to write an Issue Brief on this theme. In their Issue Brief, these authors provide a conceptual overview of the topic, as well as illustrations of many dimensions of the broader set of problems along which attempts have be made to address these issues. Vines and Godley raise questions about the utility of the concept (and labels) of "race" and "ethnicity" in assessing the health significance of disparities. Even though they do not deal with disparities beyond those involving race or ethnicity, Vines and Godley clearly demonstrate the reasons why this area of public policy development has been very difficult and a substantial challenge to those who work in the healthcare field.

We have invited a number of commentaries from persons and organizations who are working in our state to address these issues, including information on the extent of these problems among the state's American Indian and Latino populations; the extent to which healthcare access differs among racial and ethnic populations; the adequacy of numbers of healthcare professionals from racial/ethnic groups; the efforts of state governmental agencies, community health centers, and local public health departments to address the health and healthcare needs of the state's minority populations; the role of faith-based voluntary organizations in meeting the challenge of health disparities; and the importance of minority group participation in health and medical research. In addition, we have included recently received scientific papers addressing these issues in the front of this issue.

Despite the narrower focus on racial and ethnic group disparities in this issue of the Journal, we hope that we have presented a set of ideas and supporting information through which these issues may be elevated on our state's public policy agenda for the future. We continue to invite comments from our readers on these and other topics addressed in the Journal.

Gordon H. DeFriese, PhD
Editor-in-Chief and Publisher

Kristie Weisner Thompson, MA
Managing Editor

ISSUE BRIEF

The Challenges of Eliminating Racial and Ethnic Health Disparities:

Inescapable Realities? Perplexing Science? Ineffective Policy?

Anissa I. Vines, MS, PhD and Paul A. Godley, MD, PhD

One of the most important new foci of American health policy deliberations since the late 1990s has been widespread concern over racial and ethnic disparities-that is, the disproportionate burden of diseases and other adverse health conditions among specific populations. Serious discussions about inequity in access to care and the epidemiological patterns of illness, disability, and mortality began during the Clinton Administration and through the personal efforts of former Surgeon General Dr. David Satcher. Wide variations in the provision of health and medical care and in health outcomes among racial, ethnic, and other social groups have been viewed as inseparable from issues of social justice and equity in our country.

As health disparities have been examined in the United States or in North Carolina, the predominant emphasis has been on disparities that exist for particular race and ethnic groups (also referred to as persons of color), especially those whose race or ethnicity is identified as African American, Latino/Hispanic, American Indian or Alaskan Native, or Native Hawaiian or other Pacific Islander. These groups collectively represent nearly a third of the nation's and North Carolina's populations and are expected to grow. Latinos now represent our nation's largest minority group (12.5%), with African Americans comprising 12% of the population. North Carolina has experienced one of the most rapid increases in its Latino population among all states, with Latinos now representing 4.7% of the state's population, increasing from 1.04% in 1990.[1] African Americans are now 21% of the state's population and remain as North Carolina's largest minority population group. Recent reports from the North Carolina State Center for Health Statistics show that African Americans, American Indians, and Latinos are more likely to have poorer health than whites in North Carolina. Given the predicted growth of minority populations—populations experiencing poorer health—our ability to successfully identify and address health disparities will significantly influence the health of our state and nation.

Racial and ethnic health disparities are intricately woven with socio-economic status and the ability to access other educational and social supports. Indeed social and environmental factors, such as having a low income, living in poor housing, having limited education, living with violence in communities, and the limited access to recreational facilities, are important to consider in health disparities research. But, health disparities cannot be fully explained by differences in socio-economic status alone. Health disparities are due to a complex interaction of many factors,

> *"The promise and potential of the American healthcare system is often beyond the reach of persons of color or is culturally inadequate when accessed. The continuance of health disparities lowers our nation's overall health status and poses social, environmental, and financial risks for everyone."*

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including: individual behaviors and preferences, cultural beliefs, biological factors, environmental factors, differential health interventions, potential bias among treating providers, public and private health policies, and differential access to healthcare services, in addition to socio-economic factors.[2]

Latinos, for example are relatively healthy compared to whites or African Americans despite their low incomes and poor working and living conditions. This may be due to their recent immigration to the United States (e.g., the so-called "healthy migrant effect") and relatively young age. Latina birth outcomes are much better—with lower rates of infant mortality and low-birth weight—than other racial or ethnic groups.[3] Yet, Latinas tend to delay or omit prenatal care more often than other groups. Unfortunately, studies from states with more mature Latino communities suggest that, over successive generations, the favorable birth outcomes among Latinos will rapidly disappear.[4] Culturally and linguistically appropriate interventions need to be developed before these recent immigrants become acculturated to the diet and lifestyle prevalent in the United States. Health literacy issues must also be addressed for this population. Not only do many Latinos have trouble understanding our healthcare system, but many Latinos are faced with a healthcare system that does not understand their culture and providers who cannot assess their health needs and preferences because of language barriers. These problems/differences present a number of health policy dilemmas. To achieve health equity, the priority in all areas of health policy should be to address health differences among population groups.

A nation that boasts as having the world's best medical care cannot overlook differential healthcare and health status outcomes where the system's performance, in some cases, is among the world's least equitable. The *promise* and *potential* of the American healthcare system is often beyond the reach of persons of color or is culturally inadequate when accessed. The continuance of health disparities lowers our nation's overall health status and poses social, environmental, and financial risks for everyone. A focus on health and healthcare disparities offers the opportunity to re-examine all that we do (and say) in regard to our highest ideals in American healthcare policy and practice. In addition, it gives us the opportunity to identify programs and policies that need strengthening and to better target resources so that we may attain these important national health goals and objectives.

Measures of Health Disparities

Five principal measures of health disparities are of greatest salience with respect to national and state health policy. First, there are issues related to the epidemiologic distribution and variation among population subgroups in the *incidence/prevalence* of specific health conditions. Second, there are issues related to *accessing* basic healthcare services when the need arises. Third, there are issues related to the *types of treatment* provided when services are obtained. Fourth are issues related to the *quality* of those services that are provided. Finally, there are issues related to the *outcomes* (or the *effectiveness*) of the services for which access has been possible. Though these five dimensions are interrelated, the measurement of health disparities has often given emphasis to one or the other of these dimensions individually, without consideration of their interrelationship.

Typically, most discussions (occurring prior to the late

Table 1.
Age-Adjusted Death Rates (per 100,000 populations) by Race and Ethnicity and Cause of Death, North Carolina Resident Deaths

	White	African American	American Indian	Hispanic/ Latino	Asian	Total
All Causes[5] 1999-2002	874.2	1,138.9	958.4	410.6	374.4	921.5
Heart Disease[5] 1999-2002	240.1	295.9	292.4	87.0	75.0	249.6
Prostate Cancer[6] 1997-2000	28.2	79.6	52	7.6	11	
Breast Cancer[6] 1997-2000	24.4	35.5	24	10.4	6.7	
Stroke[5] 1999-2002	68.3	96.5	75.8	33.2	73.2	42.0
Diabetes Mortality[6] 1999-2002	21.5	55.6	52.7	18.1	17.5	27.4
AIDS[5] 1999-2002	1.5	21.4	4.0	4.4	0.3	5.7
Motor Vehicle Injuries[5] 1999-2002	19.2	20.7	41.6	28.3	12.9	19.6
Chronic Liver Disease & Cirrhosis[5]	8.9	10.5	8.7	3.8	3.2	9.2
Homicide[5]	4.6	17.0	18.1	13.3	4.4	7.6

Table 2.
Key Indicators of Health Disparities by Race and Ethnicity in North Carolina

	White	African American	American Indian	Hispanic/ Latino	Asian	Total
Infant Mortality[6] (per 1,000 live births)	6.3	15.4	11.2	5.8	5.2	8.6
Diabetes Prevalence[7]	6.7	11.0	11.6	2.4	4.8*	7.4
Arthritis[7]	28.3	26.0	31.8	11.4	6.0*	27.0
Adolescent Pregnancy Rate[5] (Ages 15-19)	62.4	103.0	95.7	168.0	NA	75.1
HIV Rate[5]	6.5	64.2	14.5	14.7	6.2	19.4
STD Rate[5]	172.0	1,758.3	580.6	477.9	243.5	515.0
Obese[7]	20.9	36.0	26.6	19.8	3.5*	23.5
No Healthcare Coverage[7]	12.8	18.3	26.5	58.9	11.0	15.9

* Percentage is based on less than 20 events in the numerator

Table 3.
Summary Health Indicators for White and Non-White Minority Populations in North Carolina by Gender, 2002[8]

	Years of Healthy Life	Years of Poor Health	Life Expectancy
White Men	62.4	10.6	73
White Women	66.6	13	79.6
Minority Men	53.3	14.7	68
Minority Women	59.3	16.5	75.8

1990s) of health disparities have focused on the differences in the incidence or prevalence of specific health conditions. Key indicators of health disparities among racial and ethnic groups include such rates as infant mortality, life expectancy at birth, cardiovascular disease morbidity and mortality, diabetes incidence and prevalence, and musculoskeletal morbidity (including arthritis and other related conditions). For example, African Americans have higher death rates for stroke, diabetes, septicemia, nephritis, homicide, and AIDS; and lower death rates for chronic lung disease and suicide.[5] American Indians have high death rates for diabetes, motor vehicle injuries, and homicide. Latinos also have high death rates for motor vehicle injuries and homicide. The incidence and prevalence of different health problems do not affect all racial and ethnic groups equally. For example, Latinos have high death rates for AIDS, but low death rates for chronic diseases. Asians have low death rates for every cause.[5] The data in Table 1 depict mortality rates attributable to these conditions among racial and ethnic populations in North Carolina. Table 2 provides indicators of the impact of health disparities among racial/ethnic groups in North Carolina. The data in Table 3 summarize more general indices of health status for white and non-white populations, by gender, in North Carolina.

Several gaps in the health of minorities are much wider in North Carolina than they are in the nation as a whole. For example, African American North Carolinians shoulder a disproportionate burden from prostate cancer than their counterparts in other states.[9] Although the incidence rate for prostate cancer is lower for North Carolina African Americans than African Americans nationally, the mortality rate for prostate cancer is greater and more than three times that of white North Carolinians. Pockets of extraordinarily wide health disparities, such as those found in our state among prostate cancer patients, will be particularly challenging for healthcare practitioners and researchers alike. This is an area that needs basic etiologic research to understand the factors that account for the differential incidence of prostate cancer and the poorer health outcomes for some minority populations.

Over the past 50 years in the United States, health status has improved in many areas, such as infant mortality, cardiovascular mortality and morbidity and in reductions in musculoskeletal morbidity through joint replacement. These improvements have occurred among many ethnic groups, yet the gap in health outcomes between black and white, between Latino and non-Latinos, persist even after differences in socio-economic status have been taken into account. Rates of heart disease among adults illustrate the point; black men ages 25 to 64 years have higher death rates from heart disease than those for whites regardless of income. Only at older ages do the rates converge.[8]

Racial and Ethnic Minorities are More Likely to be Uninsured

Racial and ethnic minorities are more likely to be uninsured than whites. In North Carolina, 14% of non-Hispanic whites are uninsured, compared to 19.9% of African Americans, and

55.7% of Latinos.[10] Latinos are least likely to have health insurance coverage because many of the Latinos in North Carolina are recent immigrants, and recent immigrants have a much harder time obtaining public health insurance coverage, regardless of their income,[a] and many are employed in jobs offering little or no health insurance coverage.

Individuals who lack health insurance coverage face financial barriers which make it difficult for them to access health care services. For example, 41% of the uninsured respondents from the 2003 North Carolina Behavioral Risk Factor Surveillance Survey reported that there was a time, in the last 12 months, when they needed to see a doctor, but were unable to obtain such care because of the costs (as compared to only 9.5% of people with insurance coverage).[11] This differential insurance coverage, coupled with lower socio-economic status, makes it difficult for some racial and ethnic minorities to access needed services.

Disparities with the Utilization of Lifesaving Treatments

Disparities in healthcare are more easily measured as differences in the *use* of services than as differences in the quality of those services actually used or provided. Differences in insurance coverage do not address all the differences in use of health services. Cardiac catheterization in patients with chest pain, kidney transplants in dialysis patients, thoracic surgery in lung cancer patients, and acute reperfusion therapy for myocardial infarction are illustrations of areas where inequitable utilization (or provision) of life-saving or life-improving therapeutic procedures have been documented, even after controlling for insurance status. Some of these studies are briefly noted here.

One of the most striking health disparity studies used Medicare data to examine surgery rates among 10,984 black and white early-stage lung cancer patients.[12] Bach and his colleagues compared the surgery rates of black and white Medicare patients with stage I or stage II small cell lung cancer (for which surgical resection has been shown to be beneficial). Compared to the white patients, black patients underwent lung cancer surgery less frequently than whites (64.0% vs. 76.7%, $p<0.001$). Black patients who underwent thoracotomy had mortality rates that were at least equivalent to those of white patients, but overall, blacks had a lower five-year survival rate than whites (26.4% vs. 34.1%, $p<0.001$). The study attempted to control for socio-economic factors as well as comorbidities that might preclude surgery. Even after controlling for these factors, the authors were unable to determine why black patients had a lower rate of resection than white patients, whether this difference was due to patient preferences in treatment options, or whether black patients are offered this procedure less frequently.

Investigators at the Cecil G. Sheps Center for Health Services Research at the University of North Carolina at Chapel Hill plan to conduct a follow-up study that surveys both physicians and lung cancer patients to determine why some patients eligible for potentially life-saving surgery do not undergo the procedure. In their preliminary analysis of data from patients treated in Chapel Hill and Greensboro, these investigators have found that a surprisingly high proportion of North Carolina lung cancer patients refused to believe their diagnosis or declined surgery and chose to seek non-medical or alternative medical treatments.[13]

Godley et al. used Medicare reimbursement data merged with Surveillance Epidemiology and End Results (SEER) files from the National Cancer Institute to examine racial differences in prostate cancer treatment outcomes among 43,989 patients with clinically localized disease.[14] The investigators found that unlike the lung cancer study, black patients who received the same treatment as whites (whether surgery, radiation or watchful waiting) continued to experience poorer survival, particularly among the surgery patients (median survival after surgery was 1.8 years less for blacks than for whites). Black patients tended to choose surgery less often, watchful waiting more, and radiation at about the same rates as white patients. The challenge that this study posed is not necessarily why treatment is different, but why mortality differs significantly when treatment is similar, and potential confounders are taken into account. In contradistinction to lung cancer, prostate cancer patients tend to live for many years after diagnosis, even without treatment, allowing non-prostate cancer causes of death to account for a substantial proportion of the racial differences in overall mortality.

A study by Bradley et al.[15] of 70,030 patients with ST-segment elevation myocardial infarction or left bundle branch block, used data from the National Registry of Myocardial Infarction to find that non-white patients, as identified by healthcare workers, had significantly longer waiting times before receiving emergency coronary intervention. African Americans waited 41.1 minutes in door-to-drug times (fibrinolytic therapy) and 122.3 minutes in door-to-balloon (percutaneous coronary intervention), Hispanics waited 36.1 and 114.8 minutes, respectively, compared to whites, who waited on average 33.8 and 103.4 minutes. All of the differences were statistically significant. A third of the difference for blacks and 75% of the difference for Hispanics were accounted for by the differences in the hospitals to which the patients were admitted. However, significant

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[a] The Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (PRWORA) significantly changed the eligibility of non-citizens for Federal means-tested public benefits, including Medicaid and the State Children's Health Insurance Program (SCHIP). As a general rule, only citizens or legally documented immigrants may be eligible for coverage. Most immigrants cannot be eligible for coverage for five years from the date they enter the country as a legally documented and qualified immigrant. In North Carolina, there are several different groups of individuals who qualify for Medicaid benefits. All have income limits and some have resource limits. To be eligible for Medicaid one must meet the income restrictions and be among one of the following groups: older adults (65 and older), blind, or disabled persons; a person in need of long-term care, a pregnant woman, a child (age 18 or younger), age 65 or older, a caretaker/relative of (living with and caring for) a child under age 19 who receives Medicaid.

differences remained even after adjusting for socio-economic characteristics, insurance status, and clinical and hospital characteristics. The disparity in this case is at least partially due to healthcare access, if not quality of care.

Another article by Bach et al.[16] also emphasizes the importance of hospital resources in health disparities. The study used data from 150,391 Medicare patient visits linked to 4,355 primary care physicians who completed the 2000-2001 Physician Survey component of the Community Tracking Study. The authors concluded that black Medicare patients received their medical care from a small group of physicians who, when compared to their colleagues practicing in other settings, were less likely to be board-certified (77.4% vs. 86.1%), less likely to be able to provide high-quality care to all of their patients (19.3% vs. 27.8%), and more likely to "not always" be able to access high-quality sub-specialists for their patients (24.0% vs. 17.9%) or not able to arrange non-emergency hospital admissions (48.5% vs. 37.0%). All of the differences were statistically significant. These findings reinforce the observation by Bradley et al. that black patients not only receive care from physicians with different training, but also receive their care in hospitals that have diminished capacity to access needed healthcare resources.

The findings by Bach et al. suggest that disparities in the allocation of healthcare resources may be due to more than a lack of patient education or bias on the part of healthcare providers. The findings project an image of a "shadow healthcare system" that is largely separate and unequal, often offering blacks suboptimal services from less-credentialed physicians who work at relatively resource-poor hospitals and clinics. If this dual system of healthcare is corroborated by subsequent investigations, alternatives to the usual solutions based on interventions with healthcare professionals and patients, will need to be explored.

One possible area to investigate is the efficacy of increased resources for the subset of physicians caring for minority patients. Equalizing access to specialist referrals and expensive procedures for these physicians may help equalize the disparities documented for their patient populations—a kind of "trickle-down" approach to solving the problem of disparities in healthcare. An editorial accompanying the article by Bach et al. suggests that longstanding societal discrimination plays a role in blunting opportunities for patients to obtain high-quality healthcare. Some problems, such as facilitating the granting of admitting privileges to local well-equipped hospitals, may be easy to address, especially in urban areas. Other issues may be more difficult, particularly in more rural areas of the country like North Carolina, where minority patients and their physicians may be geographically isolated from well-equipped medical facilities and sub-specialist physicians. It is also not clear whether the deficit in board certification among the physicians predominantly caring for black patients contributes to health disparities, or if differential access to healthcare resources alone would explain the differences in utilization of medical services.

Are Disparities Caused by Structural Inequalities or Biological Differences?

If available evidence (as just cited) indicates that minority populations (African Americans in particular) are served by *different* healthcare providers (who differ by their training and credentials; their ability [not their desire] to arrange for sub-specialty referrals, diagnostic studies, or non-emergency hospital admissions; and by the quality of the hospitals with which they are affiliated), then are these *structural* facts of American healthcare sufficient to explain the wide variations in the health status outcomes that exist among racial and ethnic groups when they experience similar diseases or health conditions as the majority populations? Are there studies that have been conducted in closed healthcare systems in this country that presumably assure access to the same services for all patients, regardless of racial and ethnic status? It turns out that there *are* such studies conducted within the United States Veterans Health System and in large staff-model managed care systems. These studies have documented that patients served in systems that purport to provide the same services to every eligible patient in fact *do* show patterns of lower quality care for persons of color.[17,18,19] It should be noted that while a number of Veterans Affairs hospitals have demonstrated disparities, a number of them have not found disparities. Thus, the differences in the structural systems of care provided to racial and ethnic minorities and the interpersonal bias of health professionals and patients contribute to health disparities. It is essential that in our search for policies to address health disparities that we take *both of these explanations* (or factors) into account and develop approaches that will deal with each.

One of the inescapable conclusions from the existing research in this area is that the socio-economic status of patients has much to do with *where* care is received, *what* care they receive, and of what quality, from *which* healthcare providers. The study by Bach et al., mentioned previously, attempted to adjust statistically for the socio-economic status of patients through the use of postal ZIP Codes of both the physician's practice and the patient's residence. Neither adjustment procedure altered the results of their research, although they point out (in a response to letters to the editor of the *New England Journal of Medicine*)[20] that "ZIP Code-based estimates (of socio-economic status) are imperfect surrogates for measures at the individual level." In the final analysis, the significance of the study by Bach et al. is that it clearly indicates the importance of inequality and race as contributing factors to what we now collectively define as "health disparities."

Recent information has surfaced that has raised the question of whether some of the disparities now seen in outcomes (or the effectiveness) of medical therapeutics are a result of the way (or systems within which) those therapies were delivered, or whether an explanation may lie in the biological differences among racial and ethnic groups that may moderate the effects of pharmaceuticals and other therapies. The November 11, 2004 issue of the *New England Journal of Medicine* included a controversial report,[21] which described a single-race clinical trial of a fixed-dose combination of two drugs previously approved by the United States Food and Drug Administration (FDA), isosorbide dinitrate[b] and hydralazine[c] for the treatment of heart failure among blacks (a condition from which mortality for blacks has been argued to be disproportionately higher than for whites, although the evidence for these differences is now questionable, as noted below). The combination pill carries the commercial name "BiDill®" and the trial of its use was co-sponsored by the Association of Black Cardiologists. Irrespective of the controversies raised by this publication over granting patents for race-based formulations of therapeutic agents, or the way in which the FDA approval of this new combined regimen may have been assured, there are serious questions about the way racial status is defined (or self-identified by study subjects) and the appropriate interpretation of the results of such trials.

This study, the African American Heart Failure Trial (A-HeFT) study, found that the drug combination being evaluated, when combined with conventional therapy, reduced relative one-year mortality for blacks by 43%, a truly remarkable finding. Bloche,[22] in an editorial accompanying the trial's publication, points out problems relying on single-race studies or self-identified race as a crude proxy for clinically-relevant genetic differences among people. First, studies that focus exclusively on the evaluation of therapeutics in a single race or ethnic group are not able to discern whether there are differential effects of these therapies among groups that are attributable to race alone. Second, when research subjects are asked to self-identify their racial and ethnic status, it is likely that such categorizations are influenced by the social and cultural definitions of race, not an index of the genetic or biologic variables that may determine one's response to illness or therapies. Racial groups originating from Africa, as well as other racial groups, are genetically heterogeneous. Focusing exclusively on race as a proxy for genetic predispositions may also mask the psychological, economic, cultural, environmental, and social factors that are known to influence human physiology.

The day after the results of the A-HeFT findings were published, the significance of these controversial findings was underscored by an editorial in the *New York Times*,[23] which offered these observations:

> "...there are reasons to go slow in moving toward race-based medicine. The chief drawback is that race is too superficial and subjective a concept, mostly based on skin color, to match up well with any underlying genetic or physiological differences that may affect how an individual responds to a disease or a drug treatment. Medical scientists are using race as a crude surrogate for what they assume are genetic differences yet to be identified.
>
> But there is considerable genetic variability within any racial group, so it is likely that the new pill may fail some black patients, while white patients who could benefit may not get it because they don't fit the racial profile. The ultimate goal, still years or decades away, is to develop medical treatments based on an individual's genes and life experiences, not on membership in some poorly defined racial or ethnic category. Race-based prescribing makes sense only as a temporary measure."

There are substantial questions about the scientific veracity of statements about the variability of response to treatment among groups defined by self-identified sociologic/cultural criteria, which overlook the genetic variability within "racial/ethnicity" categories.

The controversy over the BiDil® trial did not start with the publication of the trial's results. Nearly two years prior to publication of these findings there were numerous papers in the medical, ethics, and social policy journals questioning the inherent logic and rationale for the study. Kahn[24] demonstrated the fallacy of arguing a clear disadvantage of blacks in regard to mortality associated with heart failure. The 2:1 mortality ratio advanced by so many to justify the search for a race-based therapy has been shown not to be supported by available epidemiological evidence at the time. The ratio established by the Centers for Disease Control and Prevention (CDC) is approximately 1.1:1, but the 2:1 ratio has been repeated in numerous publications without attribution as a rationale for further clinical trials to address this problem.

The real worry about such efforts to find race-specific therapies is that the investment in these endeavors, and the controversies over the meaning and measurement of "race," may deflect attention from the basic problem of inequities in American healthcare—allowing those who may deny the existence or extent of these disparities to advocate for further delays in addressing these issues.[25]

Steps toward the Elimination of Health Disparities

One of the first steps being recommended by the National Research Council of the National Academies (NRC/NAS) is to strengthen the national informational technology infrastructure through which the data pertinent to health disparities may be documented and tracked for future progress. A recent report of the NRC entitled *Eliminating Health Disparities: Measurement and Data Needs*[26] has called attention to the need for individual-level data on race, ethnicity, socio-economic position, and acculturation (e.g., language use, place of birth, generational status), which are essential to documenting the nature of disparities in healthcare and to developing strategies for intervention. Not only are individual-level data severely limited, but the data that are available suffer from limited accuracy, completeness, and detail. State governmental data collection in programs like Medicaid, the State Children's Health Insurance Program (S-CHIP), and various registry systems, are potentially valuable for tracking health disparities, but data from these programs are collected in non-standardized ways. Hence, the NRC report

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[b] Isosorbide dinitrate is used primarily to prevent and treat angina, and in the treatment of acute heart attacks and heart failure.

[c] Hydralazine is used to treat high blood pressure.

The University of North Carolina at Chapel Hill Launches ECHO Program to Address Health Disparities in North Carolina

The Program on Ethnicity, Culture, and Health Outcomes (ECHO) has been created at the University of North Carolina at Chapel Hill (UNC-CH) to support and strengthen existing health disparity research, training, and education activities and to develop additional initiatives within the university. Recognizing the importance of an interdisciplinary focus, the deans of the UNC Schools of Public Health and Medicine, as well as the deans of the UNC Schools of Dentistry, Nursing, and Pharmacy and the College of Arts and Sciences, provide the executive oversight for the program.

Directed by Paul A. Godley, MD, PhD, Timothy S. Carey, MD, MPH, and Anissa I. Vines, MS, PhD, the program has employed multiple approaches to address health disparities in North Carolina. The program has helped to sponsor research by UNC-CH faculty on an intervention study of obesity prevention among Latino children, the effects of massage therapy on diabetes control among African Americans, laboratory-based experiments of genetic polymorphisms related to prostate cancer; pilot awards, designed to fund innovative health disparity research and to enhance the careers of young health disparity investigators who are faculty members at North Carolina's historically black educational institutions; a 10-credit hour Inter-disciplinary Certificate Program in Health Disparities open to all UNC-CH graduate, professional, and continuing education students.

One of ECHO's primary goals is to help communities identify and solve community health problems through facilitation of increased student and faculty involvement in community-oriented research. One of the most innovative ECHO initiatives has been to establish Centers for Community Research to facilitate constructive communication between community groups and researchers, and to provide an enduring UNC presence in communities across the state. ECHO's mission is to work with communities to identify and develop resources in the community to meet healthcare challenges and to build strong relationships with community groups. The Centers are based at two of the 13 Area Health Education Centers (AHECs), covering 13 North Carolina counties, and provide continuing education and related services to health professionals in all 100 North Carolina counties. Locating the Centers within the AHECs allows the ECHO program to establish relationships with local healthcare providers as well as faith-based organizations and not-for-profit agencies within the AHEC's catchment area. These relationships will be critical to the success of the Program's community research efforts.

ECHO also provided the administrative and organizational structure for the, "Carolina-Shaw Partnership for the Elimination of Health Disparities," a National Institutes of Health, National Center for Minority Health and Health Disparities (Project EXPORT) center grant. This Center provides $6 million to UNC-CH and Shaw University over a period of five years to address health disparities in North Carolina using novel faith-based interventions. The most innovative Carolina-Shaw Project EXPORT center components include: a recruitment core tasked with building a database of minority candidates who have an expressed an interest in participating in clinical trials; a community outreach core that will connect to the internet 25 African American churches in five regions in eastern and central North Carolina to form a network of congregations interested in participating in health promotion research, and a new survey research unit created at Shaw University that will have specific expertise in surveying minority populations.

The ECHO program is an initial step to develop concentrated research efforts that will build on decades of minority research at UNC-CH. The challenge of eliminating health disparities lies with all of us—health professionals, policy makers, researchers, and citizens. We must move from merely reconfirming the documented disparities to documenting the social inequities that perpetuate these differences. This is necessary in order to disentangle issues of racism, access to care, and mistrust.

makes a number of suggestions for how these informational resources could be made more useful for documenting the extent of current disparities as well as for monitoring the success of efforts to reduce or eliminate disparities.

Administrative data such as those collected through the operations of health service delivery programs often are limited in scope to records of service use, costs incurred, and expenses covered. They rarely give any information about the processes of care (including the range of healthcare professionals with whom a patient may interact, the clinical decision-making processes involved in rendering care, and the types and results of diagnostic studies carried out in making such decisions). If race, or the more obvious race and ethnic characteristics of patients, is but a shorthand index or "place marker"[22] for a much more complex social and cultural set of phenomena, there is a need to know far more about how these shorthand indices lead healthcare providers to presume certain characteristics of patients and then factor these categorical notions into their recommended treatment strategies. There is a need for a much better understanding of the roles of stereotyping, uncertainty, and bias in clinical decision-making by all types of healthcare providers, as well as evaluated demonstration efforts designed to offset the potential influence of these factors in the care of patients.

Because so much of biomedical research in this nation has, until recently, been conducted exclusively among majority populations, the National Institutes of Health mandated, in 1993, following passage of the NIH Revitalization Act, that research funded by any of the National Institutes of Health should include adequate numbers of both women and minorities, or provide substantial justification for their lack of inclusion. This has been an important development in the American health science community. Yet, there remain substantial problems in encouraging minority participation as subjects in health research, for reasons explained by Dr. Giselle Corbie-Smith elsewhere in this special issue of the *North Carolina Medical Journal*.[27] Until there is evidence to clarify the presence/absence of differential effects of clinical interventions among minority populations, we are unable to ascertain the extent to which biological disparities exist, or, if they do, to what extent they matter.

Low Health Literacy Levels Contribute to the Health Disparity Problem

As previously mentioned, there is growing awareness of the problem of patient "health literacy" in this country that deserves serious attention in any attempt to address issues of disparities in either health status or healthcare access and outcomes. Though language-related problems for non-English speaking population subgroups are significant, issues of health literacy go beyond language facility. There is now substantial evidence to suggest that large segments of the United States population (regardless of native language) simply cannot comprehend, and thereby comply with, disease-related information and other instructions offered by healthcare providers. Even for native English language speakers, there are substantial numbers of United States adults who lack the basic skills to read and understand the information contained on a conventional prescription bottle or in a drug package insert.[28] This is a huge problem that will require broad-sweeping efforts on the part of public education *and* healthcare systems. Efforts currently underway at the University of North Carolina School of Medicine dealing with the health literacy of patients with diagnoses such as diabetes have shown remarkable levels of success in achieving critical clinical outcomes.[29]

Cultural Differences

Some racial and ethnic groups, especially those who are more recent immigrants to the United States, will require intensive and more focused efforts that offer healthcare services in a manner consistent with cultural patterns to which these populations have been accustomed in their native countries. For example, it appears that Latinos do not experience (and therefore do not interpret) the symptoms of ill health in ways similar to the majority white or African American populations. The matter of Latino culture and belief systems would not be major concerns if we were dealing with the health and medical care needs of this population in their native countries. There, both the patients and their healthcare providers would share the same culture and spoken language. But this lack of a common understanding of the etiology of health—exacerbated by language barriers—may lessen the potential effectiveness of healthcare services and interventions offered by healthcare professionals to the growing Latino population. Language and cultural differences, along with lower education levels, make it difficult for Latinos to access and use the United States healthcare system and may lead them to seek care in inappropriate places (tiendas, emergency departments, etc).These healthcare challenges faced by the Latino population are ripe for more intensive investigation by health disparity investigators. Moreover, the lessons to be learned from these studies may lead to interventions applicable to other racial and ethnic groups in the United States who are not recent immigrants, and for whom teasing apart the cultural, lifestyle, and dietary contributors to health disparities from issues of racism, healthcare access, and mistrust of the medical system may be more difficult.

The Role of Institutional Racism

Racism also has links to disparities in health due to race and ethnicity.[30] Racism leads to many stress-related reactions such as changes in eating patterns, a lack of sleep, high blood pressure, and an increased reliance on alcohol and other substances.[31] Institutionalized racism is another factor that impedes the narrowing of the health gap between whites and non-whites. Despite legislation to end segregation and other blatantly racist practices, many structures and policies that shape the health of this nation are racially and culturally biased. In a recent study by Vines et al., 23% of African American women in metropolitan Washington, DC perceived experiences of racism in the medical care setting.[32] The persistence of racism and its manifestation in the built environment are contributors to both physical and mental health problems as well as the persistent racial profiling in medical care.

Summary

Despite the accomplishments of American medical science and the impressive array of healthcare facilities and service delivery models available in this country, the existence of significant health disparities is a matter of urgent national and state health policy priority. Policies to address these issues should address fundamental problems having to do with access to care (such as health insurance coverage and the availability and the geographic and culturally-appropriate accessibility of personal health services), the educational preparation of healthcare professionals for the challenge of caring for the increasing diversity of patients in a truly "patient-centered" healthcare system of the future, efforts to deal with widespread problems of health literacy that reduce the likely impact and effectiveness of healthcare, and a more aggressive effort to assure that future medial science continues to include minorities and women (and they continue to participate) as subjects in clinical trials of innovative therapeutic interventions.

The policy agenda to address these issues is both broad and demanding, as would be expected of any set of problems which is so widespread and complex. But, America is no stranger to challenges, and few are more worthy of the effort than this. **NCMJ**

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COMMENTARY

Perceptions of Racial and Ethnic Differences in Access to Healthcare

Damon M. Seils, MA, and Kevin A. Schulman, MD

Interest in racial and ethnic differences in health and healthcare during the past 15 years has tended to focus, with growing sophistication, on differences in procedure use, referrals, and health outcomes. This research has been accompanied by studies of communication in provider-patient relationships and, more recently, an increasing interest in patients' and physicians' perceptions of barriers to high-quality healthcare for different racial and ethnic groups. In this commentary, we briefly review some recent studies of perceptions of barriers to care. We focus especially on our group's recent research in Durham County as a way of highlighting the importance of focusing on the experiences of local communities in studies of barriers to care.

Public Perceptions

The Henry J. Kaiser Family Foundation (KFF) conducted a survey in 1999 of a nationally representative sample of 3,884 adults in the United States.[1] The survey explored public perceptions of associations between race/ethnicity and healthcare and found that these perceptions varied by race and ethnicity. Black and Latino respondents perceived greater unfairness in the nation's healthcare system and expressed greater concern about financial barriers to healthcare than did white respondents. Following on the KFF national survey, our group collaborated with The Duke Endowment, El Centro Latino, and North Carolina Central University to conduct a similar survey in Durham County. Friedman et al.[2] sought to understand perceived barriers to care in the Durham County healthcare system and how those local perceptions compared to the national findings of the KFF survey.

The Durham County survey has provided data for several analyses. Van Houtven et al.[3] found that residents of Durham County who perceive that they are treated unfairly in the healthcare system have greater odds of delaying or forgoing medical tests and treatments, controlling for economic constraints such as unemployment and lack of health insurance. Hong et al.[4] examined associations between self-rated health status and barriers to healthcare (i.e., lack of health insurance, lack of a usual source of care, problems with transportation, limited English-language ability, and perceived scarcity of physicians in the area). Greater barriers or perceived barriers on all but the variable for usual source of care were associated with lower self-rated health status. Voils et al. examined levels of concern among respondents that their health would be harmed by disease, diet, lack of exercise, and inability to follow physicians' recommendations.[24] Latino and black respondents in Durham County tended to be more concerned than white respondents about their ability to follow physicians' recommendations.

According to another study by Voils et al.,[5] racial and ethnic groups in Durham County also have differing levels of trust in health institutions, and perceived trustworthiness differs by type of institution. For example, Latinos in Durham County were more trusting overall than white and black respondents. Also, whereas Latinos tended to trust various types of health institutions equally, white and black respondents were less trusting of insurance companies and state and federal governments and were more trusting of physicians, public hospitals, and county health services. Williams et al. recently completed an analysis of respondents' trust in sources of health information in Durham County.[25] They found that black and Latino respondents were more likely than white respondents to trust the health department, ministers and churches, and television and radio as sources of health information. Trust in physicians, nurses, friends, and relatives was similar across racial and ethnic groups; however, Latinos were less likely to trust pharmacies as sources of information.

Physician Perceptions

Research on physicians' perceptions of racial/ethnic disparities and barriers to healthcare is limited. A study by Schulman et al.,[6] using identical case descriptions presented by patient-actors of

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different races and genders, identified a race-gender interaction term as a significant predictor of referral for cardiac catheterization. The investigators also found racial differences in physicians' perceptions of patients' personality characteristics and socioeconomic status. These secondary outcomes pointed to some additional areas of potential concern.

In a series of reports, researchers examined physicians' and patients' beliefs regarding access to kidney transplantation. They found racial differences in patients' preferences and expectations, but these did not account for differences in referral for transplantation.[7] Epstein et al.[8] found that racial differences in kidney transplantation could be explained both by differences in clinical characteristics and by underuse among black patients and overuse among white patients. The investigators also found that physicians were more likely to believe that black patients would not experience a survival benefit from kidney transplantation.[9] Many physicians also viewed donor availability, patient adherence, and patient preferences as explanations for why black patients are less likely to be evaluated for kidney transplantation.[9]

> *"Latino populations in Charlotte, Greensboro-Winston-Salem, and Raleigh-Durham have experienced 'hypergrowth'—increases of more than 300% (i.e., twice the national average) in the 20-year period from 1980 to 2000."*

Another recent study by Bach et al.,[10] using the 2000-2001 Community Tracking Study Physician Survey, found that primary care visits by black Medicare beneficiaries were concentrated in a small subgroup of physicians and that visits by black patients tended to be with physicians who were not board-certified. Moreover, visits by black patients were more often with physicians who reported limited access to high-quality medical services. In other words, physicians in the study who were most likely to see black patients reported having less training and restricted access to high-quality specialist, hospital, and ancillary services.[10]

Preparatory work for our group's Durham County survey provided some information about physicians' views of racial/ethnic disparities in healthcare. In a small survey of physicians practicing in Durham County, our group asked respondents to identify the "special challenges" they faced in treating patients from different cultures.[11] Three quarters of the physicians identified language barriers as a problem, ranging from some patients' lack of English-language ability to physicians' difficulty understanding regional English-language dialects. Several physicians noted problems obtaining access to translators for Spanish-speaking patients, and others emphasized the lack of Spanish-speaking physicians and other providers.

Local Research for Local Circumstances

Accompanying the report of the KFF national study in *Medical Care Research and Review*,[1] Waidmann and Rajan[12] reported racial and ethnic differences in access to and use of healthcare resources both nationally and in individual states. They concluded that "efforts to eliminate disparities in access to quality healthcare may need to be tailored to the specific needs of states." Strategies for one racial or ethnic group in one location will not necessarily be successful for other racial and ethnic groups in other locations. For example, the Latino populations of Florida, New York, and Texas differ considerably in their ethnic and cultural characteristics (e.g., national origin). Not surprisingly, their experiences with and demands on the healthcare system also vary.[12]

From 1990 to 2000, for example, the Latino population of the Raleigh-Durham metropolitan area increased by 631% as a proportion of the overall population.[13] Latino populations in Charlotte, Greensboro-Winston-Salem, and Raleigh-Durham have experienced "hypergrowth"-increases of more than 300% (i.e., twice the national average) in the 20-year period from 1980 to 2000.[13] Growth in Latino populations has also been accompanied by growth in Asian-Pacific Islander communities. In Durham County, for example, the proportion of Asian-Pacific Islander residents increased twofold, a trend mirrored in neighboring Orange and Wake Counties.[14]

Because the large majority of Latinos in Durham County were born outside of the United States, compared to only about half of Latinos nationwide, it is reasonable to expect that Durham Latinos have unique attitudes, concerns, and patterns of behavior about health and healthcare. In their effort to identify concerns unique to Durham County, Friedman et al.[2] compared findings from their survey of Durham County residents to findings from the KFF national sample. They found a number of important differences in the perceptions and experiences of respondents from Durham County, as compared to the national survey. These included substantial differences among Latinos with respect to demographic characteristics, English-language ability, and health insurance status. Durham Latinos were relatively young, and a much greater proportion of them were men, compared to the national sample. Latinos in the Durham County survey also expressed greater concern than those in the national survey about their clinical encounters, including perceptions of being treated unfairly because of their ethnicity.

Several studies have documented the unique experiences of Latinos in North Carolina. For example, Buescher[15] describes how the major health problems of North Carolina Latinos can be tied to the population's relative youth and limited access to healthcare services. Many of the recommendations of the

Latino Health Task Force[16] emphasize the need for more bilingual healthcare providers, and several studies have pointed to links between North Carolina Latinos' health needs and the large number of recent immigrants and migrant workers in the population.[15-19]

Heterogeneity at regional, state, and local levels—in racial/ethnic composition, socio-economic status, health infrastructure and resources, and any number of other community characteristics—has important implications for the ways researchers, providers, and policy makers approach public health issues. As readers of the *North Carolina Medical Journal* know, collaborations between community organizations, foundations, academic institutions, and local and state governments can foster important research in these areas. They will also lead to the development of innovative, sophisticated methods for targeted public health interventions.[20-22]

Concern about health disparities in local communities leads to a broader question about meeting the needs of patients in a complex healthcare system. Barriers to high-quality healthcare may reflect, in part, individual encounters with individual providers. However, it is more likely that barriers arise in a series of complicated steps in the medical decision-making process. For example, Einbinder and Schulman[23] described eight steps in the referral process for invasive cardiac procedures—from the patients' recognition of symptoms through the physician's referral for a procedure—and discussed the evidence for racial/ethnic differences and disparities in each step. Healthcare is a process, not a single encounter, and at each step in that process the most vulnerable patients are the least likely to successfully navigate the system and receive the healthcare they need. Efforts to understand racial and ethnic differences and reduce disparities will have to take an account of a broader range of clinical, socio-economic, and structural variables than have been considered to-date. **NCMJ**

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COMMENTARY

Health Issues Facing the State's American Indian Populations

Ronny A. Bell, PhD, MS

According to 2003 Census estimates, approximately 108,000 North Carolina residents identify themselves as American Indians/Alaska Natives, representing about 1.2% of the state's population.[1] The state's American Indian population is largely represented by eight recognized tribal groups (Coharie, Eastern Band of Cherokee, Haliwa Saponi, Lumbee, Meherrin, Occaneechi Band of Saponi Nation, Sappony, Waccamaw Siouan) and four American Indian Urban Centers (Cumberland County Association for Indian People, Guilford Native American Association, Metrolina Native American Association, Triangle Native American Society).[2] North Carolina represents the largest state concentration of American Indians east of the Mississippi River.

Limited information available from research studies and publicly available data sources indicate that significant disparities exist for many health conditions in American Indian communities. For example, the prevalence of diabetes and other cardiovascular disease risk factors are substantially higher for North Carolina American Indians compared to whites.[3-5] Diabetes-related complications, such as lower-extremity amputation and end-stage renal disease, have been reported to be three and six times higher, respectively, among the Eastern Band of Cherokee Indians compared to the rate for United State whites.[6-7] The diabetes death rate for North Carolina American Indians is three times higher, and the death rates for stroke and heart disease are at least 25% higher, than the rates for non-Hispanic whites.[8] Other health concerns, such as unintentional injuries and homicides, are dramatically higher for American Indians compared to whites.[8] These conditions lead to higher rates of premature mortality; the average years of potential life lost per death (YPLL) in North Carolina is 22.2 for American Indians, compared to 15.2 for whites and 20.5 for African Americans.[9]

> *"The diabetes death rate for North Carolina American Indians is three times higher, and the death rates for stroke and heart disease are at least 25% higher, than the rates for non-Hispanic whites."*

Disparities in Health Are Linked to Socio-economic Status

These disparities are believed to be reflective to a large extent of the significant socio-economic burden in many American Indian communities. Nearly one-quarter of North Carolina American Indians live below the poverty level, and rates of unemployment are at least two to three times higher in this population compared to whites.[10] About three-quarters of American Indians in the state have a high school education or less, compared to 56% of whites.[8]

Access to healthcare is a major concern in American Indian communities. Only one of the eight tribal groups in the state, the Eastern Band of Cherokee Indians, is authorized to provide healthcare through the Indian Health Service (IHS). However, barriers such as limited resources and inadequate transportation for many tribal members still exist that limit effective appropriation of healthcare. Statewide, American Indians are twice as likely to report that they have no healthcare coverage, and to report they

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were unable to see a doctor in the past year due to costs. Approximately 38% of pregnant American Indian women do not access prenatal care during the first trimester, compared to 18.4% for whites and 21.8% overall.[11] Inadequate healthcare among North Carolina American Indians is likely due, in addition to the high rates of poverty in these communities, to other barriers. For example, nearly 70% of North Carolina American Indians live in rural communities.[8] where access to high-quality healthcare may be difficult. Cultural factors may also contribute to reluctance by American Indians to access the available healthcare system.

Limited Data

Much is still unknown about the health and healthcare of American Indians in North Carolina. One of the more significant gaps in our understanding is the limited information on the health of American Indian children. Maternal risk factors are very high among American Indian mothers, and the infant mortality rate for American Indian children is higher that the state rate. The asthma hospitalization rate for American Indian children in 1997 was reported to be nearly three times the rate for white children.[8] There is no information currently available on Type II diabetes among American Indian adolescents. This condition is documented as being on the increase among ethnic minority adolescents in general, and among American Indian adolescents in particular.[12] Data on chronic disease risk factors among American Indian children, such as obesity, physical inactivity, harmful tobacco use, and inadequate diet, are not readily available.

Another gap in our understanding of American Indian health in North Carolina is the lack of tribal-specific data. The eight recognized tribal groups in the state are divided not only by geography, but also by unique elements in culture and history. Much of the data on health and healthcare among North Carolina American Indians comes from one tribe, or is not segmented by tribal group, which limits our ability to interpret this information for every tribe. Some tribes are relatively small, and some do not have organized tribal rolls, making research efforts difficult in these communities.

Cultural Differences

Culture is a significant but often overlooked contributor to health and healthcare in the United States. Culture can influence lifestyle behaviors, attitudes toward health, living arrangements, and receipt of healthcare. The extent to which culture, relative to other factors, such as socio-economic status, contributes to the observed disparities among American Indians in North Carolina is not well understood. Similarly, little is known about whether racism influences health, health behaviors, and healthcare for North Carolina American Indians.

North Carolina Commission on Indian Affairs

The North Carolina Commission on Indian Affairs, created in 1971 by the North Carolina General Assembly, has been instrumental in advocating for issues related to American Indian health. The Commission was instrumental in organizing three statewide American Indian Summits since 2001. The goals of these conferences have been to raise awareness of the health needs of American Indians, develop and implement healthcare best practices guidelines, and to develop networking opportunities for healthcare providers and organizations interested in healthcare. The Health Committee of the Commission has also been instrumental in identifying and participating in research and health priorities for American Indian communities. These priorities include an initiative to provide diabetes education in American Indian churches and anti-smoking cessation efforts targeting American Indian youth.[13]

American Indian Health Task Force

The American Indian Health Task Force has been developed as a collaboration between the North Carolina Department of Health and Human Services, the Office of Minority Health and Health Disparities, and the North Carolina Commission on Indian Affairs. The Task Force was initially convened in July 2004. The Task Force is represented by a diverse group of healthcare providers, administrators, and academicians from across the state and from various American Indian tribes. This Task Force is charged with developing recommendations to address the health disparities of North Carolina's American Indian population. This Task Force is examining issues related to the availability of health-related data, sovereignty and governmental issues, and access to prevention and care services.

Conclusion

Despite substantial gaps in our understanding, the existing information available point to significant health disparities for North Carolina American Indians. Chronic diseases such as diabetes and cardiovascular diseases, and other concerns such as unintentional injury and homicide, contribute substantially to these disparities. The causes of these disparities are more than likely multi-faceted, but our understanding of these factors is limited. On-going efforts in the state involving numerous agencies will hopefully address these gaps and reduce the health burden in this population. **NCMJ**

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COMMENTARY

Health Disparities among North Carolina's Latinos:

Our Point of View

H. Nolo Martínez, EdD, and Andrea Bazán Manson, MSW, MPH

The fact that Latinos are a growing presence in North Carolina is well known among the public health community and other sectors. From 1990 to 2000, the state experienced the fastest growing Latino population of any state in the nation. Today, at least 5% of the state's residents are of Hispanic origin. And due to undercounts and the fast growth of the community, it is estimated that the proportion is much higher. The United States Bureau of the Census announced last year that Latinos are now the largest minority group in the country. Latinos are today a vital part of the North Carolina economy, having initially been recruited to work in low-skill jobs and industries, and now settling in with young families in every county of North Carolina.

North Carolina initially began addressing Latino health disparities during the 1990s, at the time when the state began experiencing a large influx in Latinos. The term 'health disparities' had then gained national and local attention, and public health leaders were charged with getting a better sense of the disparities that existed in our own state. But, little was known about the newly arrived population, and basic questions needed to be answered first: Who were they? Why were they coming in such numbers? And what was public health's role in this? Indeed, the state of North Carolina was confronting the health disparities of a community it did not fully understand. Information on ethnicity was not generally collected in the health data systems, so the state did not have an accurate picture of Latino health. To address this gap in knowledge, some initial studies were conducted by the North Carolina Center for Public Policy Research, the then-called Office of Minority Health and the State Center for Health Statistics within the North Carolina Department of Health and Human Services, and other groups. As a state and a public health community, we began to learn more about our new neighbors.

> *"...North Carolina does not yet have the infrastructure, including bilingual personnel and culturally appropriate policies, to fully tackle disparities among Hispanics in the state."*

Indeed, the work of the early to mid-1990s contributed significantly to our understanding of health disparities among Latinos. It is disappointing, however, that although some progress has been made in translating this knowledge into practice, North Carolina does not yet have the infrastructure, including bilingual personnel and culturally appropriate policies, to fully tackle disparities among Hispanics in the state. Latino health disparities in most cases have been addressed independent of policy change. North Carolina Latinos are at a disadvantage when it comes to sound healthcare policies that address their unique health and healthcare needs.

And the disparities persist. Latino children are more likely to be obese than other children. They are more likely than whites and other minorities to have asthma. National data indicate that Latino children and adults are more likely to have dental caries than those from other races or ethnic groups. Latinos are more likely to die in car crashes than any other group. Although not much concrete data exist to support it, we are aware that mental health issues are becoming increasingly serious among Latinos—and that they are largely untreated. Latinas in North Carolina have the highest rate of adolescent pregnancy in the country. Of concern, too, is the number of Latino adolescents

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who are reporting depression to their peers and teachers. And among the North Carolina Latino worker population, there are disproportionate rates of injuries and deaths.

These are serious differences. But beyond specific healthcare issues, we see language barriers as the principal healthcare 'problem,' as defined by both the provider and the Latino community. Until the language differences are addressed, we will make no progress in addressing health disparities for the North Carolina Latino population.

And, in order to fully address the healthcare challenges among Latinos, not just the healthcare access problem, it is critical to recognize that policy plays an increasingly vital part.

Federal Laws Complicate the Provision of Healthcare to Latinos and Other Immigrants

Although Latinos have lived in North Carolina for generations, the 'core' of the community is a newly arriving one. The large immigration wave that occurred over the past ten years is due to the need for low-skilled workers in industries such as poultry plants, construction, restaurants, and agriculture. Many of these workers are not documented. An increasing number of them have young children who were born in North Carolina, and who make up 'mixed-status families.' Some workers may be here on temporary visas and may stay beyond their allotted time. The legal status of a family is crucial, and influences every aspect of a person's life in this country—including access to healthcare.

Immigration policy, however, is mainly an issue that is addressed at the federal level. It is one of the most controversial and complicated issues to tackle. It is also capricious—often influenced by politics, campaigns, and money. Immigration policies impact on the ability of Latinos to access healthcare services.

For example, undocumented immigrants, and other lawful permanent residents who recently arrived in this country, are generally ineligible for publicly funded health insurance coverage, such as Medicaid or NC Health Choice. Medicaid will pay for emergency services provided in a hospital for these immigrants. In addition, the Medicare Modernization Act has funding to pay for emergency services for other undocumented immigrants (who would not otherwise qualify for Medicaid). The Centers for Medicare and Medicaid Services (CMS) earlier this year initially proposed rules that would require hospitals to ask immigrants about their immigration status in order to qualify for these new funds. While this policy may appear innocuous on its face, it would have discouraged immigrants from seeking hospital services for fear that their status would be reported to the Office of Homeland Security (formerly known as Immigration and Naturalization Service). It would put healthcare providers in the role of immigration agents. This policy also could have created public health hazards if people with communicable diseases failed to obtain needed healthcare services. And, it could have cost states more in the long run if emergency healthcare issues were not treated immediately.

Hospitals, providers, and advocates criticized this proposal, and CMS eventually backed down. The proposal, however, re-ignited the debate of uncompensated care for immigrants.

The state did recently receive some good news. A Medicaid family planning waiver to expand Medicaid income eligibility for family planning services to 185% of the federal poverty level was approved on November 5, 2004. This expansion will provide Medicaid funding to cover family planning services to Latinos who would otherwise be eligible for Medicaid. It also addresses a vital need among the young population—family planning.

Title VI of the Civil Rights Act Requires that Healthcare Providers Make Their Services Linguistically Accessible

Title VI of the Civil Rights Act of 1964 states that organizations or providers that receive any amount of federal funds cannot discriminate against people because of race, ethnicity, or national origin. The federal government has interpreted this "national origin" provision to mean that individuals have a right to receive services in a language they understand. This means that patients who go to such facilities should be able to communicate effectively with their providers, and should be able to comprehend the written instructions as they walk out with their prescribed medicines.

In 2001, the Office of Civil Rights within the United States Department of Health and Human Services reviewed North Carolina for its compliance under Title VI, and the state did not receive a good grade. Under the leadership of the Secretary of the North Carolina Department of Health and Human Services, North Carolina has been working hard to ensure that local plans are in place to meet the language needs of both providers and the community. In addition, the Department is also exploring ways to pay for interpreter services for individuals with limited English proficiency who receive Medicaid services. However, more work is needed to make sure that language barriers are removed so that individuals with limited English proficiency can communicate effectively with health and human services providers.

A State Plan

North Carolina has done some groundbreaking work in establishing priorities for the Latino population. *The 2003 Task Force on Latino Health Report*,[1] produced by the North Carolina Institute of Medicine in collaboration with El Pueblo, Inc., is perhaps the most comprehensive summary of Latino health status produced to-date. It also contains specific recommendations on how to improve that health status. The most important premise of the report is that, if North Carolina adopts the recommendations of this comprehensive plan, Latino health disparities will be significantly reduced and/or removed. The report answers the following questions. What are some challenges and opportunities that Latinos face? How can we change the challenges into opportunities? What are some actions and activities (e.g., policy, legislative, and administrative) that can be implemented to improve the health of Latinos? Which agencies and organizations are responsible for making these recommendations happen?

The report provides a thorough explanation of the gaps between services and programs provided by local health departments, community health centers and migrant clinics, other state programs, and the current local Hispanic community. The strong collaboration, inclusion, and partnership built and maintained by those involved in the Task Force guaranteed that North Carolina healthcare professionals, advocates, and policy makers would be aware of the wide range of health issues facing Latinos. On November 10, 2004, the North Carolina Institute of Medicine and El Pueblo re-convened the Task Force to review progress since the Report's publication. Positive steps have been taken to begin implementation on more than three-quarters of the recommendations. It is commendable work for such a diverse group of agencies, policy makers, and advocates.

However, the General Assembly has not made the level of commitment needed to ameliorate the access barriers and healthcare disparities faced by the growing North Carolina Latino population. While the General Assembly did recently enact legislation to expand the availability of services offered to the uninsured through community health centers, health departments and rural health clinics (many of whom are Latino), these funds are not sufficient to meet the growing needs. For example, there are some estimates that health departments are providing more than $10 million in uncompensated prenatal care, largely to Latinos; yet only $1 million was allocated to health departments to meet the primary care needs of the uninsured. Further, no funds were allocated to train interpreters or to assist in recruiting bilingual providers.

There are some local programs that exemplify collaborations among sectors that have been implemented, thanks to private funding. The most promising are the lay health advisor programs. They utilize models that take into account Latinos' native language as well as their strong sense of community and family. Lay health advisor programs do this by training local volunteers to become advocates for health. El Pueblo began such an initiative in March 2004 with funding from The John Rex Endowment. The initiative has trained a group of "promotoras," or health promoters, to work directly with families at the community level. Promotoras become formal leaders in Latino communities across the state. They receive needed up-to-date health information and develop connections with existing health services, which were once unfamiliar to them. The Chatham Hospital Immigrant Health Initiative has been implementing a lay health promoter program for several years. It has been able to establish a positive and effective collaboration among the hospital, local churches, two local poultry factories, and the University of North Carolina Department of Family Medicine.

In language training, too, there are some promising efforts. "A Su Salud," a recently-launched program at the University of North Carolina at Chapel Hill, provides hands-on Spanish-language training for healthcare providers and students. Area Health Education Centers across the state continue to offer an array of courses for providers who are interested in improving their knowledge about the Latino culture and learning the Spanish language, as well as training programs for interpreter services.

A Commitment to System Change Is Needed

There is a lot of activity from the North Carolina Latino community itself. English classes are offered by various centers and volunteer groups and church-sponsored English classes are usually filled to capacity. Latino non-profit organizations are creating innovative programs to help engage the community in state affairs related to health and human services. The Spanish-language media has emerged as a crucial source for information and is actively utilized by Latino leaders and providers.

Some of the efforts described here are promising, but they are not enough. We have a plan to ensure that all North Carolinians have the same chances. A set of policy recommendations that can take care of our disparities has been developed. We have been challenged by the report, the initial collaborations, and the groundbreaking work of many organizations across the state.

The reduction of Latino health disparities will require North Carolina leaders, elected officials, business and healthcare administrators to commit themselves to system changes. Any efforts will have to take federal immigration policies into account.

Latinos represent more than demographic changes. Latinos represent an important part of North Carolina, contributing significantly to its economic development and culture. It is due time that the Latino community be recognized for this, and that we continue the initial work that has begun. **NCMJ**

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COMMENTARY

North Carolina's Response to the Challenge of Health Disparities

Barbara Pullen Smith

The North Carolina Department of Health and Human Services has embraced the national public policy agenda to eliminate health disparities by the year 2010. Key state and national policy decisions have played a pivotal role in elevating the issue of eliminating health disparities in our state.

History

North Carolina has a long history of defining and addressing these issues. Focused attention on the disproportionate burden of disease among racial/ethnic minorities has been gaining momentum since the first minority health report was published in 1987, "The Health of Minorities in North Carolina."[1] That report initiated a response by the former State Health Director, Ronald H. Levine, MD, MPH, who established a workgroup to study the issues surrounding minority health in North Carolina and make recommendations for action. As a result of this early work, two entities were created by the North Carolina General Assembly in 1992: House Bill 1340, part 24, Section 165-166 led to the establishment of the Office of Minority Health and Health Disparities (OMHHD) and the Minority Health Advisory Council (MHAC). The fifteen member advisory council is charged with advising the Governor and cabinet Secretary of Health and Human Services on minority health issues. The mission of the OMHHD and MHAC is to "promote and advocate for the elimination of health disparities among all racial and ethnic minorities and other underserved populations in North Carolina." Both entities provide leadership to increase resources for addressing health disparities, advocate for policies to improve minorities' access to prevention and care services, identify promising practices in target communities, improve the collection of health data by race/ethnicity, inform leaders and policymakers about the issues, and engage minority leaders in new ways of promoting health.

> *"The mission of the OMHHD and MHAC is to "promote and advocate for the elimination of health disparities among all racial and ethnic minorities and other underserved populations in North Carolina."*

In 1998 the elimination of health disparities became a national priority. That year, President Bill Clinton and his Surgeon General, Dr. David Satcher, articulated the goal of eliminating disparities in six key health categories by 2010.[2] This important public policy challenged states to increase efforts to address the persistent disparities in health between racial/ethnic minorities and whites. The national initiative focused on cardiovascular disease, cancer screening and management, infant mortality, diabetes, HIV/AIDS, and immunizations. These six health areas were selected for emphasis because they reflect areas of disparity that are known to affect multiple racial and ethnic minority groups at all life stages. Resources were allocated to invest in disparate communities and seek solutions to the nation's growing disparities. Addressing "health disparities" is the cutting edge of public health practice.

The year 2001 marked an important milestone in North Carolina's efforts to address the health challenges facing racial/ethnic minority populations. With the appointment of Carmen Hooker Odom as Secretary of the North Carolina Department of Health and Human Services (DHHS) came a heightened focus on eliminating health disparities. Secretary Hooker Odom included eliminating health disparities as one of her top four priorities, along

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with early childhood development, mental health, and long-term care further emphasizing the fact that the cutting edge of public health practice includes addressing health disparities.

The vision guiding the Department's work is for "all North Carolinians to enjoy good health regardless of their race and ethnicity, disability, or socio-economic status." In order to achieve that vision, the Department recognizes that all state sectors will have to embrace and invest in efforts to address and eliminate health disparities. The solutions are local. All sectors including individuals, families, the professional medical community, academic institutions, business/industry, faith-based, and other community leaders must play an active role. Although one department cannot do it alone, the Department of Health and Human Services has assumed a key leadership role in addressing these issues and serves as a model for other state Departments. Leadership and commitment are key elements to systems change.

Secretary Hooker Odom challenged all Divisions/Offices in the Department of Health and Human Services to participate in efforts to identify service gaps and come up with creative solutions to increase access to programs and services for racial/ethnic minorities and other underserved populations. The OMHHD was directed to lead the Department in the systems change process. An integrated, comprehensive, and coordinated approach has been outlined to identify and reduce service barriers throughout the Department's programs and services. The approach is driven by the concept that eliminating health disparities is not another "special initiative," but must be incorporated as an integral part of good business and public health practice for Department of Health and Human Services. Three overarching principles guide the systems change process: integration, investment, and accountability. The process has been implemented in three phases.

Phase I. Internal Capacity-Building/ Team-Building

The Eliminating Health Disparities (EHD) Steering Committee was organized and includes representatives from 14 Divisions and Offices of the Department. This internal team has been mobilized to build the capacity of the Department to identify and address access and service disparities. The mission is to use health disparities data to guide program and funding decisions and to establish priorities for effective outreach to diverse communities, with a major emphasis on creating culturally competent services and programs, workforce diversity, and investments in community strategies.

During the initial phase, considerable time and effort was spent to build the capacity of staff within the Department through in-service training sessions on health disparities, Healthy People 2010 goals/objectives, promising practices, and organizing disparity teams within each organization. Building the capacity of the Department was a critical first step to ensure that the staff, programs, and services are effective in reaching and engaging racial/ethnic minority communities throughout the state. The training was effective in demonstrating the importance of integrating health disparity intervention programs and services of the Divisions and Offices of DHHS.

To establish baseline information, the selected Divisions and Offices completed a Disparity Assessment Tool that provided an internal perspective of the Department's existing strategies to identify and address disparities within each program area. Divisions/Offices were directed to assess current data, resources, and programs focused on reaching underserved and minority populations; identify gaps in services/programs/resources; identify issues around workforce diversity and current processes for making funding decisions.

Phase II. Plan Development

Developing a comprehensive, coordinated, Department-wide action plan with a systematic approach was the goal. A strategic process was implemented to ensure broad-based input into the Department's action plan. Community leaders, service providers, researchers, policy makers, administrators, educators, and faith leaders were engaged using multiple strategies, including, but not limited to, two focus group sessions and three regional forums. Minority health experts consisting of community leaders, researchers, service providers, and agency administrators were invited to participate in the focus group sessions. The focus group participants provided insights on recommended state and local strategies for addressing the ongoing health challenges experienced by racial/ethnic minorities in our state.

The Healthy Carolinians Program sponsored three regional forums with support from the OMHHD to hear directly from communities impacted by health disparities. Forum participants included local public health departments, human service agencies, medical clinic/hospitals, educators, and faith leaders as well as other community leaders. Local solutions to eliminate health disparities were documented. The forums increased awareness about health disparity issues and generated recommendations for action at the local and state levels.

Information collected by the Disparity Assessment Tool, focus groups, and regional forums was incorporated in the Department's action plan. The resulting document is entitled, "From Disparity to Parity in Health: Eliminating Health Disparities Call to Action."[3] The plan serves as the operational framework for the North Carolina DHHS Division/Offices. The nine recommendations contained in the plan focus on increasing awareness, championing best practices, enhancing community capacity, monitoring progress, promoting customer-friendly services, investing in eliminating the gaps, building a diverse workforce, advocating for key public policies, and ensuring accountability. Using the nine recommendations as a guide, each Division/Office developed an implementation plan that includes action steps tailored to their programs and services. Priority areas have been determined; internal/external resources identified and timelines/evaluation measures are included.

Phase III. Implementation/Accountability

Keeping the issue of eliminating health disparities in the forefront is key to continued progress. The EHD Steering Committee meets monthly to learn about each other's programs/services, discuss progress, talk about challenges, solicit suggestions, share innovative strategies, and identify opportunities to share resources and develop joint projects. To ensure accountability, Division/Office progress reports are submitted every six months to the OMHHD. Regular meetings are held to brief the Secretary on progress.

Moving in the Right Direction: State Progress

The North Carolina DHHS Divisions/Offices continue to operate at different stages in this systems change process. However, Divisions/Offices have demonstrated progress in building the Department's internal capacity to identify and address disparities and to engage minority communities as evidenced by the following short-term impacts:

- Improved data on the health status of racial/ethnic minorities continues to be a priority. Strategies are in place to increase access to health information for all minority populations. The State Center for Health Statistics and OMHHD published two reports, "Racial and Ethnic Disparities in North Carolina: Report Card 2003" and "Racial and Ethnic Differences in Health in North Carolina: 2004 Update."[4,5]
- Programs have completed internal assessments of their service history. The resulting reports document current gaps in data, existing disparities, and service gaps. For example, the Division of Mental Health, Developmental Disabilities, and Substance Abuse Services' (MH/DD/SAS) report in 2003 documents racial and ethnic disparities in the delivery of mental health services in North Carolina. The draft report is entitled "Health Disparities by Race and Ethnicity: Access to Care, Expenditures and Consumer Satisfaction."
- Disparity issues are incorporated in policies, program guidance, and contract language with local agency partners. For example, Title VI of the Civil Rights Act of 1964 requires that language services be provided for limited English Proficient (LEP) clients. This requirement is included in the service contracts for local public health departments. The Governor's Healthy Carolinians Task Force has incorporated a focus on eliminating health disparities in their standards for certification and re-certification for local Partnerships.
- Workshops on minority health, cultural competence, and health disparity issues are included in conferences/forums on an ongoing basis. The result has been increased awareness among audiences outside of the traditional public health and healthcare arenas. An increased understanding of the impact of all health and human services on the health of the people in our state is a fundamental first step in the systems change process.
- The Department has established key policy initiatives around the provision of language services for Limited English Proficient Clients. A team, lead by the Division of Medical Assistance is in the process of establishing protocols for Medicaid reimbursement for language services.
- Health disparities data are included in grant proposals to leverage additional funds. Additional funds have enabled Divisions/Offices to invest in disparity issues in new ways. For example, the OMHHD was awarded an AmeriCorps grant from the North Carolina Commission on Volunteerism and Community Services. The grant will support 21 full-time AmeriCorps members. The majority of the members, called "Health Disparity Fellows," are placed in local health and human service agencies, community-based organizations, and faith-based organizations throughout the state. These new partnerships will expand our efforts to identify promising practices to eliminate health disparities.
- DHHS Division/Offices have established internal teams to organize their systems change process and discuss strategies across programs/services. The Disparity teams have been instrumental in keeping disparity issues in the forefront of Department of Health and Human Service program planning and operations.
- Disparity issues have become a part of the routine work of program managers and a part of regular discussions by management teams. DHHS Divisions/Offices have incorporated eliminating health disparities activities in staff work plans and in job descriptions. This level of accountability has been key to ensure that Divisions/Offices maintain eliminating health disparities as a priority issue for staff.
- New partnerships have been formed between Divisions/Offices around health disparity issues and joint projects are underway. For example, a regional health disparities elimination project focusing on diabetes prevention and control among African Americans received a grant from Bristol Myers Squibb. Partners in this demonstration project include the Office of Rural Health, OMHHD, Division of Public Health, and the Old North State Medical Society (the professional organization of African American physicians in North Carolina).
- Department of Health and Human Services divisions are implementing cultural competence training and minority recruitment strategies to increase the availability of culturally and linguistically appropriate programs and services. The Division of Mental Health, Developmental Disabilities, and Substance Abuse Services has enhanced its efforts to reduce barriers to services and improve access for diverse communities through cultural competence training and skill development of staff in all levels of the organization.

Progress has also been made at the community level. The network of minority, community-based, and faith-based organizations have expanded tremendously throughout the state. More and more minority leaders are taking on the health challenges in their communities. Their focus is on prevention, early detection, linking to existing resources, forming new partnerships with health providers, reducing access barriers, and holding local healthcare and human service providers accountable for the community's health. These community groups have created effective avenues for engaging and reaching racial/ethnic minority groups included among the targeted populations of the Department.

North Carolina DHHS Divisions/Offices have demonstrated success in working more closely with communities across the state, with increased funding going directly to support minority community-based and faith-based projects. The many promising practices funded throughout North Carolina focus on a variety of health disparity issues, including increased access to prevention and early detection services for diabetes, HIV/AIDS, cancer, and infant mortality to name a few. The ongoing challenge continues to be the fact that many of the projects can demonstrate improved health outcomes among the population reached, but the projects are often limited in duration, funding, and scope. As a result, good projects are not able to affect county-level health status data over time. However, without these community-based efforts, the health disparities data would be even worse.

While there is significant work to do to reduce and eliminate health disparities, North Carolina is moving in the right direction. We are challenged to mobilize all sectors of our state around these issues. We are challenged to engage racial/ethnic minority communities in new ways. We are challenged to invest in closing the gaps. **NCMJ**

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3 NC Department of Health and Human Services: From disparity to parity in health: eliminating health disparities call to action 2003. Available at http://www.ncminorityhealth.org
Recommendations from this Call to Action:
(1) Increase awareness of health and service disparities, especially disparities related to race/ethnicity, disability, and socio-economic status.
(2) Communicate, document, and champion best practices in eliminating health disparities.
(3) Promote, develop, and enhance communities' capacity to engage in healthy living and elimination of disparities in health status.
(4) Monitor progress towards the elimination of health disparities.
(5) Promote customer-friendly services that meet the needs of underserved populations (i.e., the poor and minority groups).
(6) Increase resources and investments to eliminate health status gaps.
(7) Build, support, and fully utilize a diverse workforce capable of working in cross-cultural settings.
(8) Identify and advocate for public policies that aid in closing the health status gap.
(9) Demonstrate accountability and ownership for health outcomes.

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COMMENTARY

Community Health Centers and Their Role in Reducing Healthcare Disparities in North Carolina

D. Alden Smith, MBA, CEO, and E. Benjamin Money, Jr, MPH

INTRODUCTION

One of the most effective national strategies for reducing health disparities in the United States has been the development of community health centers. Community health centers are not-for-profit organizations partially funded by the federal government and have local boards of directors, the majority of whose members must be users of the center's services. Community Health Centers, also known as "Federally Qualified Health Centers (FQHCs)," base their fees on locally prevailing rates. Community Health Centers (CHCs) use a sliding-fee schedule to discount their charges to patients with incomes of 200% of Federal Poverty Guidelines and below. There were 890 community health centers in the United States with over 3,400 sites in calendar year 2003 providing a medical home for 15 million Americans.[2] North Carolina has 23 community health centers with over 73 sites serving more than 260,000 North Carolinians every year; about 50% of these patients have no insurance.[3]

Community health centers were born in the crucible of the 1960s to serve Americans regardless of race, religion, insurance status, or ability to pay. The first centers were the migrant health centers created by the federal government in the aftermath of Edward R. Murrow's documentary "Harvest of Shame." Shortly thereafter, the Office of Economic Opportunity created neighborhood health centers. Rural health centers were soon developed under a federal rural health initiative. One of the earliest documentaries showing the impact of these centers on rural communities was Dr. Jack Geiger's "Out in the Rural." These unique public-private partnerships have been studied extensively since their inception. A recent paper by the National Health Policy Forum described CHCs as the "dominant model of federal grant funding for primary care in the healthcare safety net" and reviewed the background, services provided, people served, financing, and high quality care provided by community health centers.[4]

Community health centers serve the most vulnerable populations. The national patient population of CHCs in 2003 was represented by 64% from racial and ethnic minorities. About 90% of this patient population had household incomes under 200% of the federal poverty level.[5]

A 2000 study showed that health centers provided 4.2% of the total primary care visits in the United States. However, they provided 14.6% of the visits by ethnic minorities and 28.7% of the visits by ethnic minorities with Medicaid or no insurance (See Figure 1).[6] Since this study used 1994 data, and given that the number of uninsured patients at CHCs has grown from 3.5 million in 1998 to 5.9 million in 2003, we would expect that these percentages are even more dramatic now.[7]

> *"One of the most effective national strategies for reducing health disparities in the United States has been the development of community health centers."*

At community health centers, 74% of the patient population is uninsured or covered by Medicaid. In private medical practices only 19% of the patients are uninsured or on Medicaid.[8]

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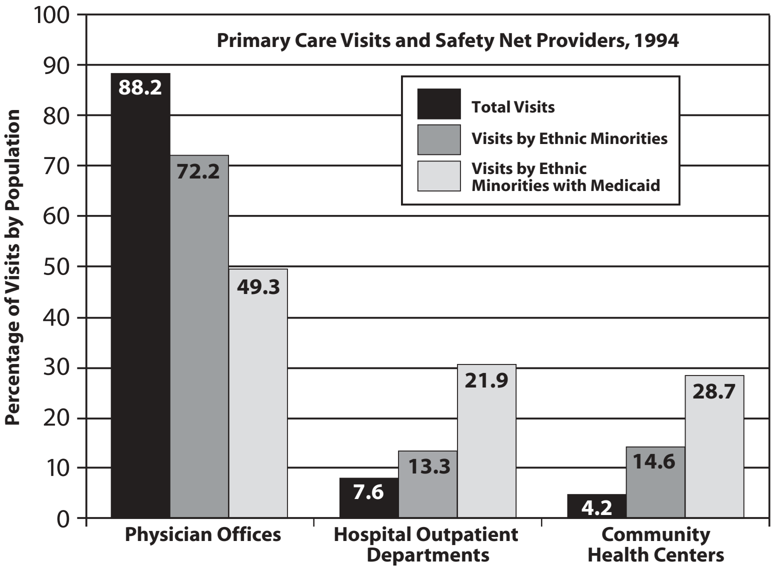
Figure 1.
Health Centers Serve a Greater Proportion of Racial/Ethnic Minorities and Those on Medicaid and Uninsured than Other Providers.[6]



Numerous studies have examined the quality of care provided by community health centers. One study in 2001 showed that community health centers exceeded the national average for providing appropriate pap smear screenings.[9] Another study showed that racial/ethnic disparities in the provision of digital rectal examinations seen in other primary care practices were not evident in community health centers (See Figure 2).[10]

A 1996 study by the Office of Data Evaluation and Research (ODEAR) in the Bureau of Primary Health Care, Health Resources and Services Administration, United States Department of Health and Human Services showed that diabetics receiving care at community health centers were more than twice as likely to receive appropriate glycohemoglobin testing than a United States comparison group.[11] Another study by ODEAR showed that African American and Hispanic hypertensive patients at CHCs were three times as likely to report controlled blood pressure than a United States comparison group.[12]

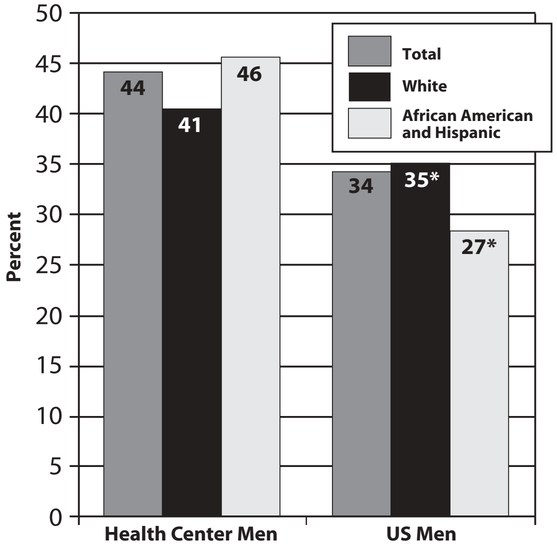
Community health centers were shown to provide better continuity of care than other providers in a 2000 study. A CHC patient is nearly twice as likely to return to the CHC for a new problem than they are likely to return to private physician or a hospital outpatient department (See Figure 3).[13]

Numerous studies of community health centers have documented their role in improving the health of the communities that they serve.[14] A recent study by George Washington University School of Public Health and Health Services showed that greater levels of health center penetration in a given market "were associated with significant and positive reductions in minority health disparities."[15]

Community health centers have shown significant success in improving prenatal care and infant health outcomes.[16,17] Communities served by a CHC have infant mortality rates between 10 and 40% lower than communities that do not have a CHC.[18-21] Community health center patients have also been shown to have higher immunization rates than the general population.[22]

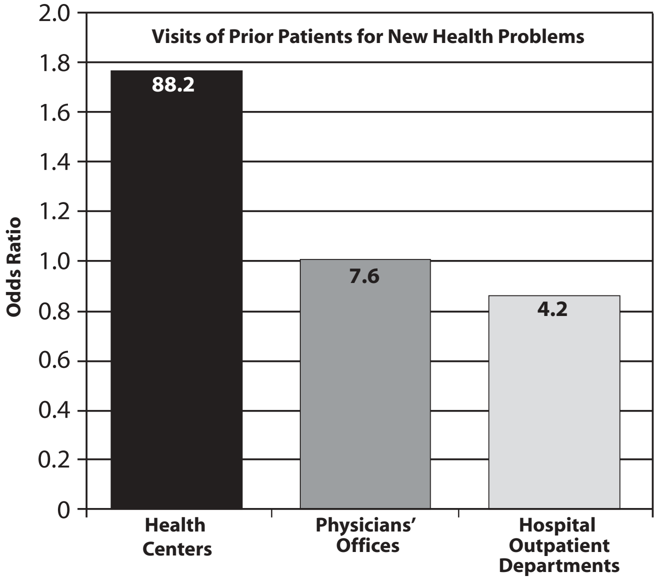
In addition to increasing access to primary and preventive care services, community health centers have been designated

Figure 2.
Health Centers Do Not Show Racial/Ethnic Disparities in Digital Rectal Examination Rates.[10]



**Statistically signifigant at p<0.05*

Figure 3.
Health Centers Provide More Continuity of Care Than Other Safety-Net Providers.[13]



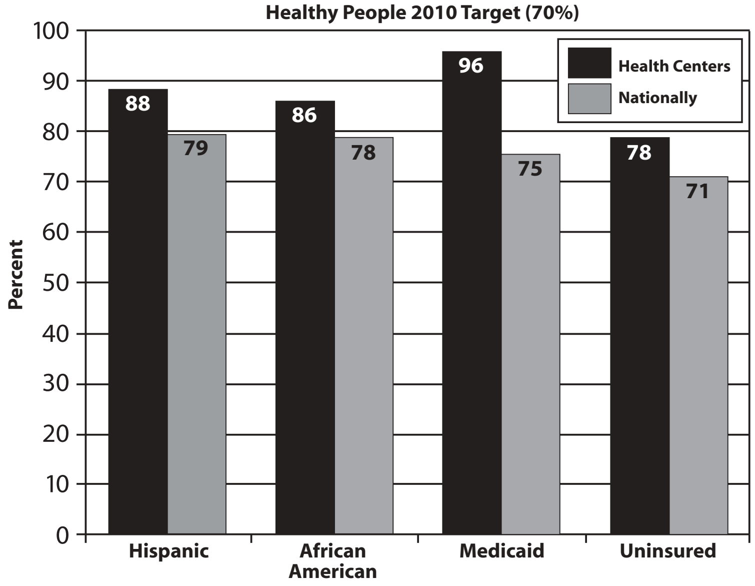
by the federal Office of Management and Budget as one of government's ten most successful and cost-effective programs.[23] In fact, the same study ranked the community health center program as the most effective program in the federal Department of Health and Human Services. These centers also have been recognized as a very effective vehicle to reduce health disparities by the federal General Accounting Office.[24-25]

In fact, these health centers have been called the "most important in the country for serving underserved populations... CHCs run the best primary care delivery systems in the United States."[26] The reasons for these successes are varied and include community boards, culturally-appropriate services, outreach, case management, eligibility assistance, partnerships with other local and faith-based organizations, and other health and human services located in one comprehensive system.

In the late 1990s, health centers refocused their efforts on health disparities through the development of the chronic care collaboratives. The Institute for Healthcare Improvement (IHI) trained the community health centers in the chronic care model with the support of the Bureau of Primary Health Care, Health Resources and Services Administration, a division of the United States Department of Health and Human Services. Clinical foci have included diabetes, asthma, cardiovascular disease, depression, and cancer. In each collaborative, appropriate clinical outcome measures are tracked and reported back to the health center providers. Some of the data from individual health centers around the country have been remarkable, for example:

- Grace Hill, Neighborhood Health Centers in St. Louis, Missouri has achieved an average decrease of HbA1c levels from 10.76 to 8.23.
- La Clinica Campesina in Lafayette, Colorado reduced average HbA1c levels from 10.5 to 8.5.[27]

Figure 4.
Percent of Women Receiving Mammograms at Health Centers vs. Nationally[29]



These collaboratives have both formalized and provided the theoretical underpinning for the system of care long provided by CHCs. The results from the collaboratives initiative show further improvement in quality over the earlier studies. More than half of the CHCs participated in these collaboratives as of 2003.

A study published in the *Journal of the American Medical Association* in 2002 showed that community health center patients with chronic disease were more likely to be healthier than white, insured patients with chronic disease in the private sector because of the prevalence of collaborative care and self-management education in community health centers versus the traditional care model used in most private practices.[28]

A 2002 study compared the percentages of CHC women over 40 receiving mammograms to all women under 200% of federal poverty level. The study showed that CHCs exceeded both the national averages and the Healthy People 2010 targets for both minorities and Medicaid uninsured populations (See Figure 4).[29]

METHODS

Since racial and ethnic health disparities remain a major problem in the United States, particularly in the southeast, we designed this study to present preliminary data from individual community health centers in North Carolina in order to investigate whether there were improvements in the state that mirrored the national data. Health Centers in North Carolina in 2003 served a patient population that was 40% African American, 27% white, 25% Hispanic, and 8% other.[30] Through clinical work groups in the 1990s, health centers began tracking clinical indicators. In recent years, health centers participating in the various federal and state chronic disease collaboratives have entered data into clinical tracking and reporting systems called Cardiovascular and Diabetes Electronic Management System (CVDEMS) or Patient Electronic Care System (PECS). These systems generate reports on a quarterly basis. CHCs in North Carolina were asked to submit copies of these reports to the North Carolina Community Health Center Association. These reports were submitted by five of 11 (45% response rate) community health centers in North Carolina.

In addition, the North Carolina Community Health Center Association and the North Carolina Diabetes Prevention and Control program have partnered to implement the models of the national Health Disparities Collaboratives (HDC) in a state-based collaborative. University health systems, integrated delivery systems, health departments, rural health clinics, free clinics, health education centers, and other settings involved in healthcare delivery are also able to participate and learn the Chronic Care Model[31] and the rapid cycle improvement model. For Community Health Centers, the state-based initiative serves as a mechanism to support North Carolina CHCs in ramping up for HDC participation; it also serves as a vehicle to sustain and spread after participating in the initial year of learning with the HDC.

RESULTS

The results as of September 2004 are presented in numbered form below:

1. Greene County Health Care in Snow Hill reported a diabetic patient population that was 70% minority with an average HbA1c level of 7.8.
2. Person Community Health Center in Roxboro reported that over the two years in the collaborative, the average HbA1c rate dropped from 12 to 7.8 and that blood pressures dropped from 140/110 to 120/70's to mid 80s.
3. Tri-County Community Health Center in Newton Grove reported that they joined the diabetic collaborative in November 2000 with an average HbA1c level of 9.5. By the end of September 2004, the average had dropped to 8.3.
4. Robeson Health Care Corporation in Robeson County reported lowered HbA1c levels from 9.1 to 7.9 with 1,763 patients in the registry.
5. Robeson Health Care Corporation also reported that among cardiovascular patients, 50% of 2,304 cardiovascular patients had blood pressures under 140/90.
6. Lincoln Community Health Center in Durham reported its diabetic patient population of 2,354 patients (76% minority) had an average HbA1c rate of 8.2, down from 8.5, last year and from over 9.0 five years ago.

These results mirror large studies including the one that showed a lowering of the HbA1c level from 9.0 to 8.0 in 23 health centers with 8,000 diabetes patients and a January 2004 article, which analyzed a diabetes quality improvement initiative in 19 midwestern health centers and found that the collaboratives dramatically improved diabetes care in one year using a variety of outcome and process measures.[32,33]

Also, the North Carolina Diabetes Collaborative, the pilot state-based collaborative, was able to mirror the successes of the national Health Disparities Collaborative. With 13 participating centers during the 2003-2004 year, 1,379 patients were entered into the registry. The aggregate HbA1c declined from 7.96 to 7.81, with the number of patients receiving two HbA1cs annually increasing from 4.4% to 24.7%. Significant strides were made in the following measures: annual foot exam rates increased from 15.1% to 48.8% and annual dilated eye exams increased from 6.2% to 24.2%.[34]

DISCUSSION

CHCs clearly play a major role in reducing or eliminating health disparities, as the numerous examples already cited have shown. Some of the reasons for this include: the CHC mission; federal grant requirements; frequent location in areas with large minority populations; provision of culturally-sensitive care; federal mandate to serve all regardless of race, religion, country of origin, or ability to pay; community involvement; and diversity in staffing.

The improvements in the control of chronic disease at North Carolina CHCs measured by specific clinical outcome measures mirror the improvements shown in the national literature. More formal studies need to be conducted. Longitudinal studies would be particularly useful in tracking improved clinical outcomes over time. Data from the North Carolina CHCs participating in federal and state collaboratives should be published as soon as it becomes available.

A major research opportunity has been created by five community health centers in Eastern North Carolina. Beginning in 2001, these centers began to implement a common electronic health record system and build a clinical data warehouse to track clinical outcome measures using sophisticated report writing software. The record systems for three CHCs are currently operational and two more will be operational within the next six months. As more patients are enrolled in this system, the data will be both readily accessible and comprehensive. By 2006, there will be data on nearly 75,000 patients. These data present a major research opportunity to improve and disseminate outcome documentation among all community health centers serving these highly diverse, and underserved, populations in North Carolina. **NCMJ**

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Churches, Academic Institutions, and Public Health:

Partnerships to Eliminate Health Disparities

Moses V. Goldmon, EdD, and James T. Roberson, Jr., PhD

Introduction

The disproportionate burden of preventable illness and death suffered by racial and ethnic minorities and/or other persons from low-socio-economic status backgrounds—health disparities —came into focus with the release of the 1986 landmark document titled the Report of the United States Secretary's Task Force on Black and Minority Health (the Heckler Report). This report, along with *Healthy People 2000 and 2010*, has spurned a number of research, education, and service initiatives aimed at eliminating health disparities. Despite many efforts to address these disparities, health professionals continue to experience difficulty reaching minority populations with sustainable research, education, and service initiatives. Obstacles include, but are not limited to, mistrust due to past misuse and abuse, culturally insensitive methods and materials, and one-way research and intervention efforts that benefit academic and public health institutions, but fail to provide tangible benefits to church and community members.[1] These obstacles hinder progress in addressing health disparities. African American and other racial and ethnic minority populations continue to suffer a disproportionate burden of preventable disease and death.[2]

Broad partnerships between community-based, academic and public health institutions have emerged as a plausible solution to overcoming the obstacles to engaging hard-to-reach populations in efforts to eliminate health disparities. Interdisciplinary and/or inter-institutional partnerships (involving pastors, physicians, parish nurses, lay health advisors, chaplains, community leaders, theological educators, health educators, researchers, and other stakeholders) engage a diverse group of people in the discovery and transfer of new knowledge that could provide solutions to the complex issues that cause health disparities. More specifically, research suggests that engaging the black church in health disparities partnerships is an effective way to develop sustainable culturally-appropriate research, education, and service projects that are acceptable to African Americans.[3,4,5]

Drawing upon current literature and our experiences as pastors, health and theological educators, and practitioner-researchers[6] who are actively engaged in several health disparities partnerships, this commentary explores the development of sustainable partnerships between African American churches and academic and public health institutions.

> *"churches are uniquely situated to facilitate participation of people from hard-to-reach populations."*

Why Churches?

Community members, universities, and government agencies see churches as institutions that should be included in public health partnerships.[7,8,9,10] Reasons include: (1) churches share a mutual concern with public health institutions about the issues that impact the health knowledge, attitudes, behavior, access, and outcomes of racial and ethnic minority, low-income, and other underserved populations, (2) the faith tenets of most churches encourage the promotion of holistic health, healing, and living, (3) churches are the historical center of comfort, guidance, and inspiration, particularly in African American communities, (4) churches offer a variety of resources (human, intellectual, capital, social, and spiritual), and (5) churches are uniquely situated to facilitate participation of people from hard-to-reach populations.

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Increasing Emphasis on Church Involvement in Health Initiatives

Recently, the number of health research, education, and service initiatives implemented by or including churches has increased. For example, the number of "faith and health" initiatives in North Carolina that have some connection to the North Carolina Office of Minority Health and Health Disparities has increased by 78% (from 11 to 48 over the past five years).[11] Health disparities partnerships that include churches are encouraged and participated in by state and local governments, universities, corporations, hospitals, professional associations, and community groups.[1,7,12,13,14,15]

The increased emphasis on partnerships in general, and the engagement of churches specifically, as a mechanism to effectively address health disparities is encouraging. However, concerns about the difficulty associated with effectively engaging and sustaining African American churches has been expressed by church, community, university, public health, and government representatives. These concerns highlight the need for a strategic approach to the development of broad partnerships that include churches. Below is a set of principles that could help to address these concerns.

Principles for Engaging African American Churches in Health Disparities Partnerships[i]

These principles are informed by the current literature and our experiences as pastors, health and theological educators, and practitioner-researchers.[10,16,17,18,19,20]

Principle Number 1: Identify and Prioritize Potential Partner Churches

Identification of churches begins with a deliberate choice to prioritize churches that will comprise a pool of *potential* participants. A common mistake associated with efforts to engage the "the church" is a failure to recognize the diversity that exists among churches. This diversity stems from the fundamental beliefs that people of faith have about "their god" and the corresponding doctrine, polity, and denominational structure employed to guide their understanding, devotion, worship, and service. There is also a great deal of diversity within and among churches that share the same doctrine and to a lesser degree polity and denominational affiliation. For example, there are eight different *historical* denominations categorized as African American Protestant churches.[ii] In recent years, we have also experienced a boom in the growth of other denominations as well as "Non-Denominational" Protestant Churches. A working understanding of the basic doctrinal beliefs, polity, and organizational structures of the various churches that are potential partners is a pre-requisite to recruiting and forming trusting relationships with churches.

Principle Number 2: Develop Trusting Relationships that Lead to Sustainable Partnerships

Sustainable or "true partnerships" include trusting relationships, mutually beneficial collaborations, participatory processes and shared governance. The people who are sent to interact with representatives of the potential partners are key to establishing trusting relationships. Identifying the "right representative(s)" is not merely a matter of race and ethnicity. The primary factor is a willingness to understand and develop an appreciation for the perspectives of others. When seeking to engage churches, it helps to have a translator—persons with knowledge of and experience working with both churches and public health institutions.

Previously, we mentioned the doctrinal, political, and denominational diversity within "the black church." Attempts to establish partnerships with churches without an appreciation for these fundamental tenets increase the risk that something might breech church polity. Such activities, although often unspoken, tend to deepen the mistrust that pastors and other church leaders have of "secular organizations." Mistrust stifles the reflective dialog that is essential for sorting through the inter-institutional (churches, universities, healthcare and government agencies) and interdisciplinary (public health, medicine, theology, and religion) differences and similarities. Identifying the similarities coupled with efforts to understand and appreciate the differences precede the identification and

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[i] (a) The principles are designed to assist public health representatives as they engage faith-based organizations in sustainable health disparities research, education, and service partnerships. While the premise of the principles discussed in this commentary represent a framework for engaging "the faith community," they are most applicable to collaborations that include historically African American Protestant churches. The emphasis on African American Protestant churches does not insinuate that this or any other particular faith tradition is inherently more applicable for involvement in health disparities partnerships than others. However, since our knowledge and experiences are centered in African American Protestant church and theological education traditions, we are most qualified to adequately represent this perspective.

(b) We use the term "faith community" to refer to a diverse group of people who believe and trust in a god or a religious system whose existence cannot necessarily be proven with tangible evidence. Further, we emphasize our view that African American churches are part of the larger "faith community." Similarly, we use the term churches generically to refer to organized religious fellowships. The term is inclusive of synagogues, mosques, and parishes and other fellowships.

(c) While this discussion is limited to broad principles, we distinguish *principles* from *practices*. Principles are fundamental presuppositions designed to guide the process of identifying, recruiting, and selecting churches (as well as church leaders) as partner participants. Principles are used to promote reflective dialog among a diverse group of partner participants that will lead to the establishment of mutually beneficial practices. Thus, practices are mutually agreed upon activities derived by the principles.

[ii] African Methodist Episcopal (AME); African Methodist Episcopal Zion (AMEZ); Christian Methodist Episcopal (CME); Church of God in Christ (COGIC) National Baptist Convention of America, Inc. (NBCA); National Baptist Convention, USA, Inc (NBCUSA); National Missionary Baptist Convention of America (NMBCA); and the Progressive National Baptist Convention, Inc. (PNBC)

prioritization of areas of mutual concern, which enable partnerships to build upon the strengths and minimize the weaknesses of each partner organization. Partnerships established without cultivating trusting relationships and mutually agreed upon policies and practices simply transfer traditional models of health disparities research and interventions from academic, government, and healthcare settings to churches.

Sustainable partnerships founded on trusting relationships reduce the likelihood that this will occur by ensuring that pastors and other church leaders are engaged as equal partners with other professionals.[21] This provides pastors and other church representatives an opportunity to influence and be influenced by the policy and practices of public health institutions and vice versa. Ultimately, true partnerships produce changes in the policy and procedures of all participating institutions that will lead to culturally relevant health disparities research, education, information dissemination, and service/ministries.

When engaging churches in partnerships, it is important to involve pastors from the outset. Pastor "buy in" legitimizes church and community involvement in a manner that facilitates adoption, participant recruitment, and decision-making.[22] As respected leaders in the community, pastors can help to: (1) design and plan culturally-appropriate research and interventions; (2) serve as advocates that will bridge the communication gap between health professionals, church, and community members; (3) develop comprehensive sustainable ministries of health; and (4) help to ensure a more culturally diverse healthcare workforce by encouraging church and community youth to pursue careers in the health professions.

Principle Number 3: Identify and Respect Institutional Priorities, Traditions, and Boundaries

Churches and public health institutions, particularly research-intensive universities, have divergent perspectives of how to effectively address an issue of mutual concern—health disparities. These perspectives grow out of the priorities, traditions, and boundaries (professional, intellectual, and ethical) of the respective institutions. They are rooted in the central differences between theology and science, particularly epidemiology.

Epidemiology is *the systematic, objective study of the natural history of disease within populations and the factors that determine its spread.*[23] *The core functions of public health agencies... are assessment, policy development and assurance.*[24] These functions are carried out in order to promote health and prevent disease. Theology is the science of God, and of the relations between God, *[humans]*, and the universe.[25] In African American churches, theological constructs are applied in ways that are sensitive to the language, concepts, and issues of the folk [in the African American community] in a manner that leads to edification and liberation.[26] An emphasis is placed on ministry (the provision of service) that liberates destitute, oppressed, and marginalized people.

Interestingly, the desired outcomes of both institutions focus on eradicating *dis-ease*. However, the priorities and traditions that undergird the practices appear disparate. For example, churches tend to measure the success of projects by how they helped to provide immediate solutions to "felt needs." To this end, churches desire the provision of tangible and sustainable service. Unlike the scientific process, the measures employed to determine success are sometimes "discernable," but not necessarily quantifiable. On the other hand, public health institutions (particularly research-intensive universities) often measure success by the discovery of new knowledge, theories, models, policies, and/or procedures that may not necessarily help the participants of an existing study, but will be of benefit to others in the future. Therefore, efforts can be considered successful in the public health arena without the provision of direct service that provides "immediate" solutions to the felt needs of the prioritized populations.

These divergent perspectives must be reconciled if sustainable partnerships are to be developed. A failure to recognize or respect the institutional priorities, traditions, and professional boundaries of other partnership participants hinders reconciliation. For example, health disparities research, education, and service interventions that involve churches often focus on assessment and planning. Many pastors and church leaders have often expressed concern, if not frustration, over the fact that their involvement in health projects has resulted in their "being assessed to death." However, both assessment and service are necessary if innovative ways to reduce health disparities are to be developed and sustained.

Principle Number 4: Promote the Transfer and Local Control of Tangible Power

Power refers to the knowledge, privilege, force, influence, authority and strength to accomplish a desired action. Power comes in various forms including social, mental, physical, spiritual, moral, political, and economic. These forms can be categorized as tangible and intangible. Tangible power is easy to recognize and measure, while intangible power is often invisible and difficult to measure. However, both forms are essential to the elimination of health disparities. Generally those possessing tangible power (money, budgetary authority, decision-making —particularly with respect to personnel and project goals, facilities, fund-raising ability, organized networks, the ability to determine legitimate and valid forms of knowledge, etc.) exert the greatest influence on the policies and practices that govern partnerships. In order to overcome the barriers to sustainability and to foster participation of persons from hard-to-reach populations, some tangible power should be transferred to church and community leaders where feasible.

Summary and Conclusion

The four principles represent a framework for improving the process of establishing sustainable partnerships between research, public health, and faith-based institutions that seek to eliminate health disparities. To improve the efficacy of partnerships with churches identification of potential partner churches must be deliberate, trusting relationships must be built, divergent perspectives must be communicated and reconciled, and some tangible power should be transferred to church and community leaders where feasible.

We applaud the National Institutes of Health, through the National Center on Minority Health and Health Disparities', efforts to "promote coordination and collaboration among the agencies conducting or supporting minority health or other health disparities research."[15] We recommend that the North Carolina Office of Minority Health and Health Disparities be charged with and provided adequate resources to facilitate this type of coordination and collaboration among North Carolina Department of Health and Human Services agencies that are conducting or supporting minority health and health disparities research. A special emphasis should be placed on partnerships that seek to engage communities of faith.

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The Data Collection/Data Distribution Center $(DC)^2$ Model of Engagement

The Data Collection/Data Distribution Center $(DC)^2$ is a network of 25 churches located in five prioritized regions of North Carolina. The regions and associated counties are: Northeast (Warren, Vance, Granville, and Franklin Counties); Eastern (Northampton, Bertie, Halifax, and Hertford Counties); Central (Wake, Durham, Orange, Chatham, and Johnston Counties); South Central (Duplin, Sampson, Cumberland, Bladen, and Robeson Counties) and Southwest (Mecklenburg, Gaston, Anson, and Scotland Counties). The network includes pastors and other church leaders, educators, researchers, and healthcare administrators representing various disciplines. Academic and governmental partners include Shaw University (a historically black liberal arts university), the University of North Carolina at Chapel Hill (a research-intensive majority institution), and the North Carolina Office of Minority Health and Health Disparities (established by the NC General Assembly to promote and advocate for the elimination of health disparities).

Spearheaded by the Shaw University Divinity School, $(DC)^2$ engages African American churches as an integral part of the Excellence in Partnerships for Community Outreach and Research on Health Disparities and Training (EXPORT) partnership. Funded by the National Center for Minority Health and Health Disparities, (grant #R24/P20/P60), the Carolina-Shaw Partnership seeks to eliminate health disparities between racial-ethnic minority and majority populations in a variety of ways. $(DC)^2$ is the hub of the partnerships community outreach activities. The primary goal is to investigate whether church-based information technology is an effective way for educators and researchers to communicate health issues to and receive feedback from communities about their health that could help make research, education, and service/ministry efforts more relevant. The network emphasizes a two-way flow of information where: (1) the health concerns and priorities of African American church and community members are communicated to educators, researchers, health policy makers, funding agencies, and healthcare providers to inform and influence their practices; and (2) practically useful health information is developed and disseminated to church and community members. The network also provides a mechanism for recruiting church and community members into health disparities research studies as partner-participants rather than as mere subjects. This ensures that a voice representing African American churches is included in academic research, education, information dissemination, and service projects that seek to identify solutions to African American health disparities in North Carolina.

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COMMENTARY

Health Disparities, the Faith Agenda, and Health Promotion/Disease Prevention:
The General Baptist State Convention of North Carolina Model

M. Anita P. Holmes, JD, MPH

Faith and Health and the African American Experience

As increased emphasis has been given to holistic health and lifestyle issues in American health and healthcare policy, faith-based entities are more frequently viewed, or acknowledged, as one of the "players." The intersection of faith and health to address societal "ills" has a rich history. This health and healing agenda is strongly rooted in the African American experience. Historically, "the black church" has been on the forefront of this movement as advocate for education, health, and justice. C. Eric Lincoln, a noted theologian and historian of the black church in America stated: "To understand the power of the Black Church, it must first be understood that there is no disjunction between the Black Church and the Black community. The Church is the spiritual face of the Black subculture, and whether one is a 'church member' or not is beside the point."[1]

> *"To efficiently and effectively engage 'the black church' as a partner in health promotion, requires an understanding of organizational leadership, structure, demographics, and faith orientation."*

Prior to the more formally organized black church, religious ceremonies and worship services provided a mechanism for African Americans to come together in a setting that not only facilitated worship, but enabled "messengers" to carry out human rights and freedom agendas.[2] This agenda continued as the church emerged as a leading societal institution and is well documented during the Civil Rights Movement.

Self-help movements were encouraged since resources to address emerging health and social needs were always in short supply. Various auxiliaries were established to facilitate the church's health and social ministries. For instance, nurse aide groups consisted of women appointed to help the elderly and others coping with disabilities. At a time when many insurance companies considered African Americans a poor risk for life insurance, church affiliated mutual benefit and burial societies filled this void for service immediately after slavery and gave rise to the emergence of African American insurance companies. Services were not limited to church members, but were provided to every community member as acts of goodwill and good citizenship.

Today, the need for grassroots church and community activism continues. The gains the science community has made in health knowledge are not matched with successful modes of application. Faith-based initiatives, with several notable exceptions (e.g., the Seventh-Day Adventist and Mormon churches have focused on health promotion over many years), are at the pioneering level. To address today's concerns and the greater emphasis on lifestyle issues will require mobilizing diverse community partners and resources and shifting focus from sick care to "well care" or health promotion.

Morbidity and mortality data reveal the African American population is one of the leading disparate groups. While it is increasingly common for health service organizations to enlist the support of "the black church" in attempts to reach the African American community, most are limited in scope and frequently ineffective. These efforts generally do not meet the

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definition of partnership. For instance, churches may be requested to provide assistance by announcing the availability of important health and human services, displaying exhibits and/or distributing educational materials, participating in research, and/or conducting presentations on health-related topics. There may be beneficial outcomes from these activities; however, the impact usually falls far short of need and potential. Too often, services are provided in a manner that diminishes the possibility for participation in the planning and decision-making processes and do not enable sustainability, capacity building, and/or empowerment.

More appropriate use of faith-based resources will require changing the rules of engagement. To efficiently and effectively engage "the black church" as a partner in health promotion, requires an understanding of organizational leadership, structure, demographics, and faith orientation. There must also be a conscious awareness of past history and a willingness to accommodate. Partnerships should be based on cooperation, communication, commitment, clear understandings, trust, and caring.[3] This model enables the development of working relationships that best use the strengths and resources of both churches and health advocacy organizations.

Early Scientifically-Designed Faith-Based Health Promotion Initiatives in North Carolina

One of the first scientifically-designed and evaluated health promotion initiatives utilizing black churches was a North Carolina project targeting diabetes, hypertension, and maternal and child health. Through the use of lay health educators, the project was designed to raise the level of technical understanding and to encourage beneficial lifestyle changes. This initiative, based in the Department of Health Behavior and Health Education of the University of North Carolina School of Public Health (UNC-SPH), led to discussions with the leadership of the General Baptist State Convention of North Carolina, Inc. (GBSC) and the founding of the Convention's Health and Human Services (HHS) Program.[4]

Health professionals provided technical knowledge during church-based training. Learning took place at two levels: (1) the lay leaders and (2) the health professionals. Lay leaders gained increased understanding of diabetes and hypertension, including current information regarding disease prevention and control and available disease-related resources. Healthcare providers met community leaders and learned about community perceptions of healthcare issues and concerns.[4-6]

GBSC is a voluntary association of approximately 2,000 churches and 600,000 congregation members. Sixty-two geographically dispersed Associations facilitate the work of this statewide organization. It is estimated that, on any given Sunday, approximately half of the African American worshippers in North Carolina attend a GBSC church. In addressing health promotion issues within the African American community, GBSC and its churches build on an organizational structure that formally started in 1867. For instance, one of the lay health advocates presently involved with a Faith and Health Initiative, is from the family of deacons that are direct descendents of her church's founder. The founder was a slave who gained permission to organize a church in 1838.

The first GBSC health promotion project was funded by Z. Smith Reynolds Foundation and focused on enabling selected church members/leaders to serve as lay health educators and health advocates within their respective congregations and the broader community. The GBSC Office of Health and Human Services (HHS) was established to facilitate the development of this demonstration project. Staff from HHS, with technical support from UNC-SPH, designed training programs and recruited health professionals to teach volunteers about the causes, prevention, and management of selected health problems (e.g., hypertension, diabetes, and infant mortality).

The Convention created the Health and Human Services Advisory Committee to provide oversight and guide the overall development of this evolving ministry. A Technical Advisory Committee was also formed. The Technical Advisory Committee included among its members clergy, lay leaders, health professionals from local universities (North Carolina Central University, Duke University Medical Center, Shaw University Divinity School, UNC-SPH and UNC School of Medicine), North Carolina State Division of Public Health, and civic leaders. The Committee, which included persons of other faith and ethnic backgrounds, was very helpful in identifying resources and allies from within the broader community. Through this process, learning took place at several levels. The professionals learned about church style, protocol, and church members' values. Church leadership learned the value of critical review, evaluation, and the overall assets health professionals could bring to the table.

The GBSC Model

The GBSC-HHS ministry is grounded in an awareness that many African Americans do not fully benefit from pioneering gains in health that new knowledge, medical technology, and research have made possible. The ministry is designed to build on the strengths present within the Convention and its member congregations through a strategy that draws on the combined resources, talent, and leadership of clergy, laity, and health professionals. The key methodology employed is training church-based volunteers to inform others about the causes of selected health problems, and then helping them to change behavior and gain access to necessary resources for prevention and control.

The role of the pastor is pivotal in this process.[7] GBSC-HHS programs seek the counsel and advice of clergy in determining the overall course of implementation for local and regional activities. Pastors offer sanctioning and best ways to define, refine, and reshape faith-based health models. The life experience of the pastor and lay leaders is very influential in determining interest and support. Of the six pastors responding to a local diabetes initiative, five either had diabetes or had a spouse with the disease.

Most of the work of the Convention's health ministry is carried out by volunteers and is premised on theories, research, and best practices developed in other settings.[8] These volunteers are trusted and respected persons that others come to for advice. They are a part of the web of support systems in their communities. Most have resided in their community for over 20 years.

An essential factor to the long-term success of faith-based models is the education and empowerment of clergy and lay leaders.

"The church can serve a role in bringing about a much better lifestyle, a much better health condition for all concerned. But, it has to be a situation where the ministry and the key laity in churches are educated and empowered with all the information about particular diseases and all the things that the health community would like to impart so that they might play the ambassadorial role that you [the public health community] seek."[9]

Orientation and training congruent with project goals and objectives are provided for staff and volunteers. Sessions usually take place on Saturdays or evenings, when the majority of congregation members are available. In addition to technical health information, education sessions integrate faith and theological understandings to support the technical teachings. Hours of training vary by project with initial training generally averaging about 15 hours. Following the initial orientation and training, lay health advisors provide education and social support to the congregation and other community members. Continuing education and programmatic support are provided by GBSC-HHS staff and local and area healthcare professionals throughout the project.

Lay health advisors are asked to serve a minimum of two years. However, the majority continue for the duration of the project (generally three-to-five years). Most importantly, these volunteers remain health promotion advocates within their congregation once the formal funding period has ended.

An essential role for GBSC-HHS is to serve as a support to projects after outside funding has ceased. HHS maintains contact with prior externally-funded GBSC projects in an effort to continue services. Some groups have established support systems with local resources to enable continuation.

Faith-based models provide a unique opportunity for team building between congregation members and healthcare providers. Individuals have an opportunity to learn from and support each other as they share their experiences. Healthcare providers who assist with the training gain increased understanding of community concerns and priorities and an enhanced ability to involve community leaders. During training sessions, providers come on the "turf" of congregations in a setting controlled by members. This facilitates discussion that is more open and enables the building of trust.

Successes

Evaluation has been a continuous component of GBSC-HHS projects. Many noteworthy accomplishments have been made since the ministry's inception. These have included (1) increased knowledge and understanding of beneficial health information, (2) identification of knowledge transmission patterns, (3) diffusion across faith, race, and neighborhood boundaries, (4) lifestyle and policy changes at the congregation level, and (5) increased awareness and use of healthcare resources. The basic elements identified with the importance and success of the first GBSC project funded by the Z. Smith Reynolds Foundation,[10] continue to be reflected in Convention initiatives.

There are many anecdotal stories that relay changes in behavior, lifestyle, access to healthcare resources, and effective healthcare utilization. In 1997, on a Saturday morning in Creedmoor, North Carolina, approximately 200 persons representing 20 or more churches attended a diabetes awareness session. Attendees told personal stories about what led to their diabetes diagnosis and encouraged others to be checked. A substantial number of the persons telling their story indicated that it was another individual in their network that recognized they had the symptoms of diabetes (not a physician) and encouraged them to be tested. The following Monday, in response to a significantly increased diabetes screening load, a health department staff member questioned one of the diabetes awareness session participants/screenees about the unusually large number of people coming in for testing.[11]

It is well documented that education and income make a difference in health status. During two fatherhood projects in economically deprived areas, pastors, male congregants, and other supporters mentored unemployed fathers and fathers without a high-school degree. Six months following project initiation, 100% of 25 previously unemployed fathers were employed and 100% of 18 fathers previously without a high school diploma were enrolled in a GED program.

The Convention's Health Ministry continues to sponsor health promotion programs to: (1) reduce health risks, (2) promote health, (3) improve disease states through increased knowledge, improved practices, and improved access and utilization of healthcare services, (4) increase community involvement/participation in the healthcare delivery system, (5) build and expand the helping and social support role of the church, and (6) increase community capacity to initiate and sustain health promotion programs. These goals are carried out through programs reaching congregation members and the communities they serve.

In addition to focusing on specific diseases, lifestyle modifications, and service delivery concerns, special seminars/summits have been held with GBSC leadership to address current and cutting edge issues, such as stress in ministry and end-of-life decision-making. The Office has also served as an information and referral source for congregation and community members.

Since the inception of the program, GBSC has provided about 20% direct and lots of in-kind support. The Convention has continued to seek the support of a broader range of donors from both the public and private sectors. Following the Z. Smith Reynolds funding, the W. K. Kellogg Foundation funded two major projects. In more recent years, the Convention has received funding from the Kate B. Reynolds Charitable Trust, the North Carolina Hospital Foundation, the State of North Carolina (including the North Carolina Division of Public

Health, North Carolina Health and Wellness Trust Fund, and federal funds received through state-funded projects), direct church contributions, and private donations.

Sustainability

The HHS program has gone through several stages of development, from demonstration project to permanent program. In 2002, the Center for Health and Healing, a 501(c)(3) IRS-recognized nonprofit entity, took on the health and human services agenda of the Convention. This legally independent and structurally autonomous organization is similar in character to the relationship between the Catholic Church and the Catholic Relief Society and the relationship between the Unitarian Church and the Unitarian Universalist Service Committee. Advantages include access to a broader funding base and reduced liability for the Convention.

Capacity to sustain health promotion initiatives is essential to health status change. We believe the church in the African American community can play a major supportive role in the nation's effort to encourage and sustain healthy lifestyles. This must include all the prerequisites necessary to assure the institutionalization (e.g., ownership, commitment, and resources) of faith-based health promotion initiatives. Dr. John Hatch, a UNC-Chapel Hill professor of health behavior and health education at the time, has stated that he believes the project would not have survived had resources not been placed with the Convention.[12] Evidence of sustainability at the Association and local church level is evident in several GBSC models (e.g., Faith and Wellness Auxiliaries as part of formal Associations; inclusion of the health ministry in some Association and church budgets; inclusion of ministry functions on church, Association, and Convention agendas).

In addition to building the internal capacity of communities, faith-based health programs enable the provision of community healthcare promotion programs at a time when resources are limited. A partnership with a local agency was compromised when the agency experienced the loss of a staff person that would have been able to assist with GBSC lay training. The agency director suggested a local community member to serve as a resource person. The individual she recommended was a GBSC grassroots Facilitator trained by GBSC-HHS.

Conclusion

The continued survival and growth of faith-based health initiatives will likely be dependent on a number of factors, including interest, financial, and programmatic support available from the faith-based organization, government, and private philanthropy. These ministries may vary in scope (e.g., lifestyle modification, advocacy and policy development, education, social support, self-help, information and referral, environmental change [inclusive of the church environment], demonstration/research, and career development) as a reflection of interest and resources.

However, as faith-based and other organizations continue an agenda of pursuing reductions in health disparities, partnerships between faith-based groups and health-interest organizations (public and private) are likely to continue. **NCMJ**

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COMMENTARY

Northeastern North Carolina Partnership for Public Health and Health Disparities in Northeastern North Carolina

Curtis W. Dickson, MEd, Janet G. Alexander, MSPH, Barbara H. Earley, RN, MSN, and Erin K. Riddle, MPH

The Northeastern North Carolina Partnership for Public Health (Partnership) is a collaboration of public health agencies formed in 1999 to improve the health of people in the northeastern region of the state. The Partnership's specific goal is maximizing the available resources and service potential of local health departments through cooperation with each other on public health issues. Economic and health disparities in this region provided the impetus leading ten health departments to form this collaboration and continue to guide the activities of the Partnership. The Partnership hopes that these disparities will now become the motivation for the adoption of healthy behaviors by community members and for policy and environmental changes by decision makers that will improve the health status of northeastern North Carolina.

> *"These disparity gap coordinators help to link the Partnership to community coalitions in each of the counties, such as Healthy Carolinians partnerships."*

The Northeastern North Carolina Partnership was formed when health directors in the region recognized that each of their agencies faced similar challenges in their work to protect the health of their constituents. Specifically, how could these health departments improve the health of a region that is entirely non-metropolitan, has a high rate of poverty, and a high rate of medically uninsured? How could a health department maximize its impact, given its limited resources? In 2000, 13 of the 19 counties included in the partnership were designated as *Tier One* counties by the North Carolina Department of Commerce, meaning that they are among the most economically depressed counties in the state.[1] Nineteen percent of the population in northeastern North Carolina is living in poverty,[2] between 16 and 24% do not have health insurance,[3] and 29% of adults do not have at least a high school education.[4] It has long been recognized that there is a positive correlation between economic health and physical health. These demographics became the starting point for the health departments in northeastern North Carolina to discuss innovative ways to collaborate and improve the health status of the region.

These discussions evolved into the creation of a well-structured partnership. The Partnership is currently guided by a governing board that consists of now 11 local health directors (Pamlico County recently joined) and of representatives from both the North Carolina Division of Public Health and the North Carolina Institute for Public Health at the University for North Carolina at Chapel Hill (NCIPH). The Partnership region covers 19 counties: Bertie, Beaufort, Camden, Chowan, Currituck, Dare, Edgecombe, Gates, Halifax, Hertford, Hyde, Martin, Northampton, Pamlico, Pasquotank, Perquimans, Tyrell, Warren, and Washington. The partnership has demonstrated how health departments can share some resources, such as staff, and therefore increase the capacity of all the health departments. In 2002, the partnership received a federal grant that allowed them to hire a regional epidemiologist, a regional health educator

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(regional health disparity coordinator), and eventually a paid, half-time project director. Annual membership dues for each participating agency help augment the partnership's activities. In addition, each of the health departments has allocated an existing health department staff member (a health educator) to serve as their department's disparity gap coordinator. These disparity gap coordinators help to link the Partnership to community coalitions in each of the counties, such as Healthy Carolinians partnerships. The disparity gap coordinators are also the target audience for regional training focused on cultural competencies and public health practice.

Health disparities data have continued to guide the activities of the Partnership. In 2003 the Partnership published, "Health in Northeastern North Carolina: Assessing Health Disparities of an 18-County Region," that was researched and developed by the Partnership's regional epidemiologist, the regional health disparities coordinator, and University of North Carolina School of Public Health graduate students (only 18 counties were in the Partnership at the time). The Partnership governing board used this report to help them identify priority public health problems that the partnership is now moving to address through the development of regional public health programs. This regional health report highlighted health conditions where geographic or race and gender disparities exist. Health disparities were evaluated by comparing overall disease rates for northeastern North Carolina to the state rate (geographic disparity), and by comparing rates for race and gender groups within the region to their respective state rates (race/gender disparity). Health conditions examined included: accidents, perinatal mortality, heart disease, stroke, HIV disease, diabetes mellitus, lung cancer, breast cancer, colorectal cancer, prostate cancer, chlamydia, gonorrhea, teen pregnancy, low-birth weight infants, asthma, child obesity, untreated tooth decay among kindergartners, and untreated tooth decay among fifth-graders. This regional assessment for 18 key health indicators found geographic disparities for northeastern North Carolina in relation to state rates in general in 17 of the indicators, and race/gender disparities in 13 of the indicators (See Table 1).

"Diabetes is one of the leading causes of death and disability in northeastern North Carolina. Each year there are 640 deaths due to diabetes as a primary or a contributing cause of death in these counties."

After studying these and other data for the northeast region (including county health assessments, focus groups' results, and key informant interviews), the governing board of the Partnership determined three strategic priorities for further studies and activities: (1) diabetes, (2) heart disease and stroke, and (3) AIDS and HIV.

The Partnership has just completed an intensive analysis of the first chosen priority—diabetes—and a similar process will be used to investigate the two other priority health issues. The purpose of the diabetes investigation was to assess the strengths and gaps of current public health efforts to reduce the burden of diabetes in northeastern North Carolina. This synthesis has been helpful to the Partnership as it plans regional diabetes prevention efforts.

Diabetes in Northeastern North Carolina

In its analysis of diabetes, the Partnership first reviewed, in-depth, the diabetes data that are currently available for the region. Since 2003, the Partnership has been participating in the Behavioral Risk Factor Surveillance System conducted by the North Carolina State Center for Health Statistics. This has proven to be an asset to the Partnership in its ability to monitor the burden of diabetes in the region. Because the Partnership paid for the northeastern North Carolina counties to be over-sampled in the survey, region-specific prevalence data on diabetes and its related lifestyle risk factors are available. Results of the 2003 survey showed that 12.5% of adults (39,205 people) in northeastern North Carolina reported that they have been told they have diabetes. Because about one-third of diabetes cases are undiagnosed, the true number of adults with diabetes in northeastern North Carolina is most likely higher. Diabetes is more prevalent in northeastern North Carolina than in any other region of the state (12.5% in northeastern North Carolina versus 7.9% in western North Carolina, and 7.5% in the piedmont region), and is 67% higher than the overall national rate (7.5% of adults in the United States).[5]

Region-specific diabetes mortality and hospitalization data are also available. Diabetes is one of the leading causes of death and disability in northeastern North Carolina. Each year there are 640 deaths due to diabetes as a primary or a contributing cause of death in these counties. The overall age-adjusted mortality rate for northeastern North Carolina is 1.4 times the state rate (132.2 compared to 95.1 deaths per 100,000 people). In northeastern North Carolina each year there are more than 11,000 hospitalizations, and more than 250 amputations related to diabetes, with costs totaling $126,295,426 and $5,530,115, respectively. African Americans and other minority groups are disproportionately affected by diabetes. The age-adjusted mortality rate for African Americans, Native Americans, and other non-white races combined was 1.9 times higher than for whites (189.7 compared to 98.9 deaths per 100,000).[6]

After examining the existing health data, the Partnership assessed the current diabetes programs in each of the region's

Table 1.
Health Disparities Summary Table, Northeastern Region, North Carolina, 2004.

Condition	Number Affected	Comparison of Rates				
		NENC Total ÷ NC Total	NENC White Male ÷ NC Male	NENC Black Male ÷ NC Male	NENC White Female ÷ NC Female	NENC Black Female ÷ NC Female
ACCIDENTS	207.7 deaths/year	1.1	1.0	1.4	0.9	1.0
PERINATAL MORTALITY	33.3 deaths/year	1.3	—	—	0.8	1.7 a
HEART DISEASE	1,384.7 deaths/year	1.1	1.2	1.2	1.2	1.2
STROKE	379.3 deaths/year	1.0	0.9	1.5	1.0	1.2
HIV DISEASE	91.6 new cases/year	1.1	0.4	2.1	c	2.4
	35 deaths/year	1.5	0.5	2.9	0.5	3.4
DIABETES MELLITUS	154.7 deaths/year	1.2	0.9	1.9	0.8	1.9
LUNG CANCER	329.4 new cases/year	1.0 b	1.5 b	1.8 b	0.7 b	0.4 b
	325.3 deaths/year	1.1	1.1	1.3	1.3	0.7
BREAST CANCER	315.8 new cases/year	0.9	—	—	0.9	0.9
	73.3 deaths/year	1.1	—	—	1.0	1.3
COLORECTAL CANCER	257.4 new cases/year	1.2 b	1.5 b	1.4 a,b	0.91 b	1.1 a,b
	115 deaths/year	1.2	1.2	1.3	1.1	1.6
PROSTATE CANCER	289.2 cases/ year	1.0	0.8	1.4 a, b	—	—
	69.7 deaths/ year	1.1	0.7	1.9	—	—
CHLAMYDIA	1,570 cases/year	1.3	0.1	1.5	0.4	2.8
GONORRHEA	1,558 cases/ year	1.7	0.1	3.8	0.3	3.6
TEEN PREGNANCY	346 pregnancies/year	0.5 - 1.6	—	—		
LOW BIRTHWEIGHT INFANTS	555.6 births/year	1.2	—	—	0.8	1.6 a
ASTHMA (8th graders)	diagnosed 10%; undiagnosed 18.5%	1.0 1.1	—	—	—	—
CHILDHOOD OBESITY	13.7% to 18.9%	1.1 to 1.2	—	—	—	—
UNTREATED TOOTH DECAY	24.9% of kindergarteners	1.1	—	—	—	—
UNTREATED TOOTH DECAY	5.6% of 5th graders	1.4	—	—	—	—

a Other non-white races compared to all women or all men in NC
b compared to NC total population
c unstable rate due to small number of cases among white females in NENC

KEY to COMPARISON OF RATES

1.1 - 1.3	Slightly Elevated Rate compared to NC
1.4 - 1.7	Modestly Elevated Rate compared to NC
1.8 to 3.0	Moderately Elevated Rate compared to NC
3.1 to 8.0	Highly Elevated Rate compared to NC

public health departments. Six of the ten health departments in the region have primary prevention programs to increase awareness about diabetes (health communication). Many of these take place in various community settings, such as health fairs, senior centers, schools, civic groups, or at the health department. However, none of the health departments described a multimedia approach using radio, newspapers, and/or television, or a social marketing approach to determine elements or messages that could bring about behavior change within our region. As a result, the Partnership is preparing to launch a major social marketing campaign aimed at diabetes prevention utilizing funds recently appropriated by the state legislature to the NCIPH to establish "public health incubators" across the state. Social marketing campaigns aimed at heart disease, stroke, and AIDS/HIV prevention will be developed in subsequent years.

The Partnership strengths and gaps assessment of diabetes programs also determined that five of the ten health departments have primary prevention programs that are intended to increase physical activity and improve nutrition in the community (community intervention). All health departments reported they provide screening or testing for diabetes. Eight of the ten health departments have tertiary prevention programs or diabetes self-management and education programs to prevent the incidence of diabetic complications.

Correcting the Problem Will Take a Financial Commitment from the State

It is clear that while these 11 local health departments are mounting community responses to tackle the overall diabetes problem in their respective communities and the disparity issue among people of color, the resources available to them are not adequate to deal with a health problem of this magnitude. Public health departments in the northeastern North Carolina region have come together to find creative solutions to tackle these tough issues across jurisdictional lines with limited resources. The major social marketing campaign aimed at diabetes has the potential for great impact with a limited amount of new resources. Much more must be done. The health disparities data can now serve as an advocacy tool. While knowledge of a problem alone may not be sufficient for change to happen, information on health inequalities is a good place to begin the discussion with community members and decision makers about what can be done to improve the health of northeastern North Carolina. The Partnership is attempting to convince state legislators and state public health leaders to make an ongoing commitment of funding resources to this impoverished area of the state to tackle not only the diabetes, heart disease, stroke, and AIDS/HIV health issues of pressing concern, but also strengthening the local public health infrastructure and its ability to assess, address, and assure the public's health.

The northeastern North Carolina region has been innovative in its collaborative approach to health concerns and health disparities in this hard-impacted area of the state and has a significant capability to impact health disparities in northeastern North Carolina. **NCMJ**

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Numbers of Minority Health Professionals:
Where Do We Stand?

Thomas C. Ricketts, III, MPH, PhD, and Katie Gaul, MA

Should race and ethnicity matter in the supply of health professionals? Given that we know there are demonstrated differences in patterns of care and outcomes for racial and ethnic minorities in the United States,[1] the answer is yes. But what should be our workforce goals in eliminating these differences? The simple answer to this question is that there should be equal representation among health professionals according to the race and ethnicity of the population to be served. By that standard, we have failed by a large margin.[2,3] All health professions fall well short of "population parity" measured against the proportion of under-represented minorities (URMs) in the overall United States population. According to 2000 United States Census data, African Americans, Latinos, and American Indians are 26% of the United States population. URMs constitute 20% and 16%, respectively, of the students in public health schools and baccalaureate nursing programs, with URMs constituting less than 15% of students in all other health professions. The late 1990s through 2002 saw a reversal in promising trends in increasing minority enrollment in United States medical schools, but that seems to have abated to some degree. In its review of applications for the fall of 2004, the Association of American Medical Colleges noted a second consecutive year of increase in minority applications to medical schools. The number of black and Hispanic applicants was up 2.3% and 2.5%, respectively, and actual enrollment increased by 2.5% for blacks and 8% for Hispanics, reversing decreases in first-year enrollment in 2003. This change may reflect admissions policy changes or the re-application of existing policies in the wake of the June 2003 United States Supreme Court decision on affirmative action.[4]

Table 1.
Race/Ethnicity of United States Population Compared to United States Healthcare Professions, 1999-2000[6]

	Non-Hispanic White	Non-Hispanic Black	Hispanic	American Asian/ Pacific Islander	Indian/ Eskimo Aleutian
US Population >18 years	72.0	11.2	11.0	3.8	0.7
Dentists	88.8	1.5	2.4	7.1	0.2
LPNs	72.9	18.9	4.6	2.8	0.8
Managers (med. & health)	82.6	8.4	5.3	3.2	0.4
Pharmacists	75.9	6.2	3.4	14.2	0.3
Physicians	73.1	5.5	3.8	17.5	0.1
Physician Assistants	88.2	2	5.3	4.1	0.4
RN's	81.7	9.2	3	5.7	0.4

Underrepresented minorities comprise 25% of the nation's population, but only 10% of all health professionals. Only 3% of medical school faculty, 17% of all city and county health officials, and 2% of senior leaders in healthcare management are minorities.[5] Table 1 provides an overview of the national racial and ethnic distribution of selected health professions compared to the United States population. Among blacks and Hispanics, the two largest minority groups, only in nursing is there close to parity with the population distribution, with

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Figure 1.
Race and Ethnicity of North Carolina Population Compared to North Carolina Health Professionals[7]

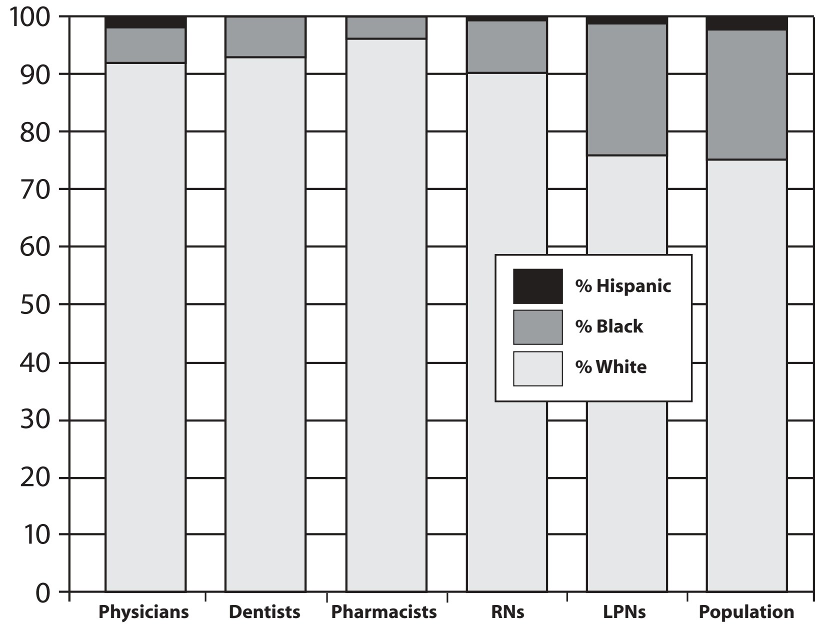
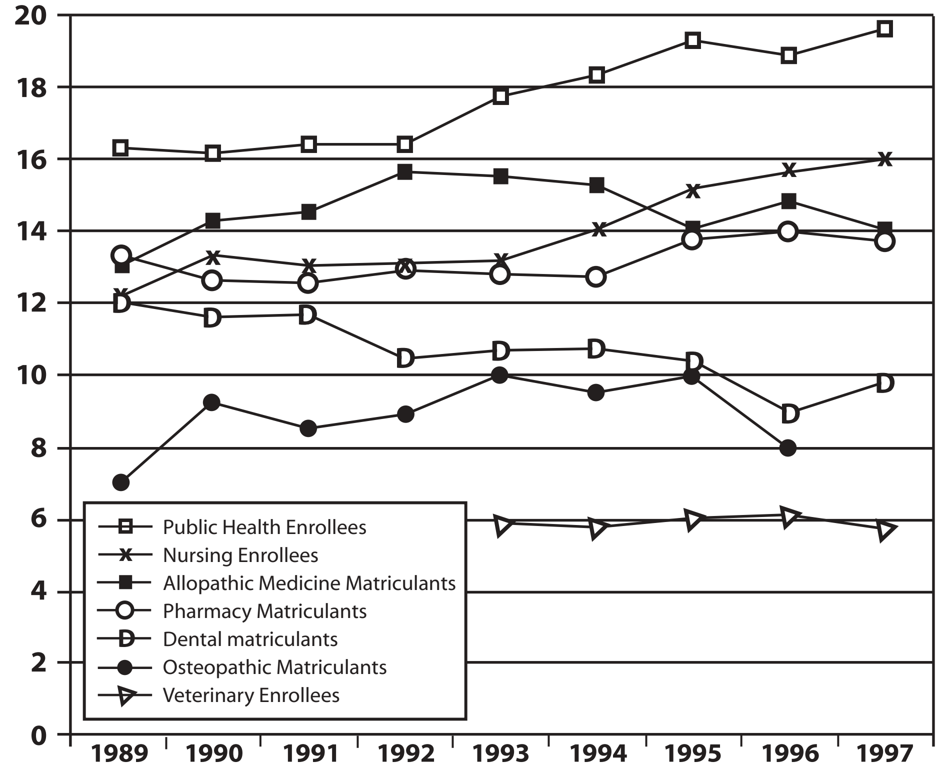


Figure 2.
Underrepresented Minorities as a Percentage of Enrollees and Matriculants in Health Professionals Schools, United States, 1989-1997[8]



Recently reported data on enrollments (see Table 2) indicate that the percentages in Figure 2 have not changed substantially over the most recent five years.

licensed practical nurses (LPNs) exceeding their overall population representation among blacks. Asians/Pacific Islanders are often "over-represented" among health professions, reflecting the more complex nature of their immigration patterns.[6]

In North Carolina, minority representation in the health professions matches national rates despite higher proportions of minorities in the population. For example, in 2002, 21% of the state's population was black, but only 5.5% of active physicians in the state were black. The 2002 estimate for the Hispanic population in North Carolina is 4.7%, and Hispanics make up 1.5% of the North Carolina physician supply. In contrast, 22.8% of the state's licensed practical nurses (LPNs) are black, but only 9% of registered nurses (RNs) and 6.9% of dentists are black. The data displayed in Figure 1 graphically compare these proportions to the state's population for selected professions. These proportions are likely to remain at their current levels due to a leveling off of minority applications and enrollments in health professional education programs.[7] Figure 2 tracks numbers of enrolled and matriculated students in selected health disciplines in North Carolina. Only public health has shown a sustained pattern of increase in the numbers of minority students and trainees.[8]

Minority Representation Enhancement Programs in the United States and North Carolina

There have been efforts on the part of the state's health professional associations and health professional schools to reduce these disparities in minority representation. Since the 1970s, the federal government, through its Title VII and VIII programs that support medical, dental, and nursing training, has given priority funding to programs that increase minority representation. These programs support a full range of interventions intended to modify the "pipeline" into the health professions. The pipeline (See Figure 3) is the metaphor used for the process of career preparation, education, and training that starts at birth and continues through

Table 2.
Medical School Graduates by Race/Ethnicity, North Carolina and United States, 2003[9]

	NC	US
White	249 (66.4%)	9880 (63.7%)
Black	53 (14.1%)	1018 (6.6%)
Hispanic	6 (1.6%)	944 (6.1%)
Asian	56 (14.9%)	3164 (20.4%)
Native American	2 (0.5%)	107 (0.7%)
Unknown	9 (2.4%)	398 (2.6%)
Total	375	15,511

early exposure to health professionals and science courses, through counseling, scholarship, placement, recruitment, and retention in careers and practice in underserved areas. These programs have, for the last several years, been the targets of both Congressional and Administration efforts to reduce federal outlays. Each year, however, the Congress has voted to restore funds roughly at the levels established in the late 1990s. For North Carolina, these programs are important because they support family medicine residencies, the statewide Area Health Education Centers Program (AHEC), basic and advanced nursing education, and the Health Careers Opportunity Program (HCOP) that focuses on minority recruitment into health careers.

A range of "best practice" programs have been highlighted in a report recently released by the Sullivan Commission (www.sullivancommission.org/). That report describes the multiple ways in which educational institutions can increase minority presence in health professions and provides a comprehensive guide to funding sources and currently active programs and initiatives.[10]

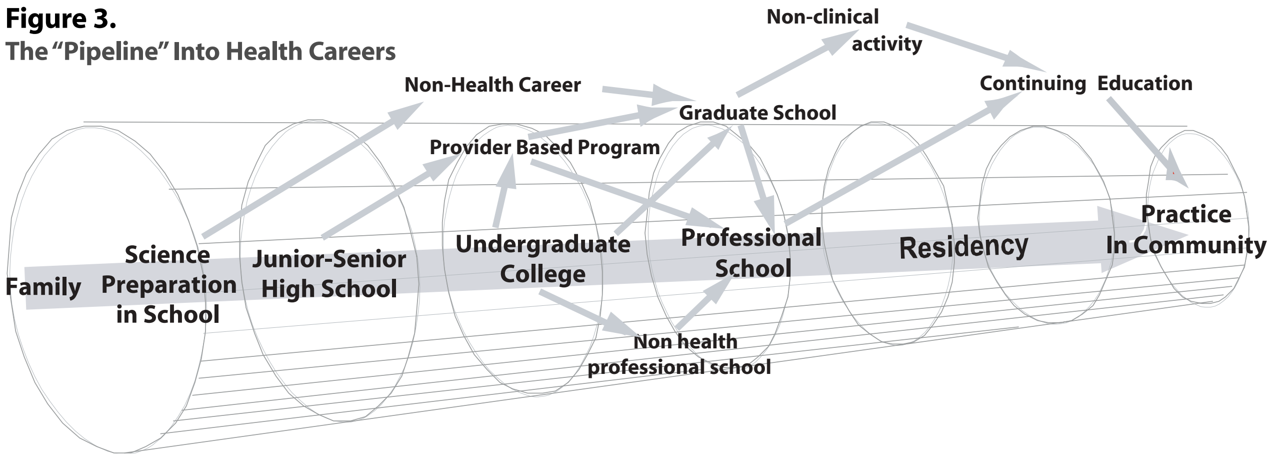


Figure 3.
The "Pipeline" Into Health Careers

One section of that report describes professional school involvement in "pipeline" programs. These efforts attempt to modify individuals' perceptions of their career options early in their schooling and help them prepare to move toward health careers sometime in the future. Nationally, 92.9% of medical schools and 100% of dental and nursing schools report doing some form of "pipeline" programming.[10] In medical schools, more of that effort is targeted to grades nine through 12, 78.6% of medical schools, 40% of dental schools, and 100% of nursing schools report programs for those grades with only 42.9% of medical schools, 40% of dental schools, and 80% of nursing schools reporting working with grades six through eight.

The University of North Carolina sponsors a multi-campus collaborative effort that supports pipeline programs under its HCOP funding. The North Carolina Health Careers Access Program (NC-HCAP) brings together the University of North Carolina at Chapel Hill (UNC-CH) School of Dentistry; the North Carolina Health Careers Access Program; the Student National Medical Association chapters in North Carolina; East Carolina University; Fayetteville State University; North Carolina Central University; North Carolina Agricultural and Technical State University; University of North Carolina at Pembroke; the school systems of Chapel Hill-Carrboro, Durham, and Orange Counties; and the state's nine regional Area Health Education Centers. In 2002-2003, through programs supported or affiliated with the North Carolina AHEC Program, 39,000 individuals participated in Health Careers and Workforce Diversity activities. These projects included shadowing and mentoring activities, summer work experiences and placements, health careers fairs, and cultural sensitivity training.

Individual schools also sponsor focused minority health career development projects. East Carolina University sponsors the Ventures into Health Careers Institute that provides two-week experiences for minority students from eastern North Carolina to observe practicing and in-training physicians, nurses, therapists, and technicians. The Pathways to Health Careers and Health Careers Awareness Programs also support local schools in developing curricula and learning modules to improve the chances of minority and rural youth to enter health careers. Wake Forest University Medical School and the Northwest AHEC sponsor several similar programs under a "Health Careers Pipeline" program. An elementary school program called "Drew Academy" works with young minority males students to develop lifestyle and learning skills; the program is held at the Rowan Regional Medical Center and Winston-Salem State University. Programs for middle school and high school students focus on the development of science and mathematics skills, SAT preparation, and financial aid.

The Wake AHEC program supports a Health Careers Academy that provides educational experiences for students from elementary through and beyond high school. The interventions are mostly workshops or involve specific health professions-related experiences including skills-building, CPR and first-aid certification, job shadowing, and recruitment fairs. The Wake AHEC also sponsors a Summer Youth Enrichment Internship and the Carolina Visions Health Careers Summer Camp, both of which offer structured exposure to health careers for young people.

North Carolina is also home to a statewide Spanish Language & Cultural Competency and Training Program funded by The Duke Endowment. This project brings together the North Carolina Department of Health and Human Services (DHHS) Office of Minority Health, the UNC-CH School of Public Health, the UNC-CH Health Sciences Library, and the North Carolina AHEC system into a coordinated approach to teach Spanish language to practitioners and increase cultural awareness and sensitivity among professionals. This program includes an online translation facility supported by the Duke University AHEC (www.hhcc.arealahec.dst.nc.us/).

At UNC-CH, the Health Professions Partnership Initiative and the Research Apprenticeship Program are designed for pre-college students to support and direct them into health careers. Established in 1996 with start-up funding from the Robert Wood Johnson Foundation and the UNC-CH Schools of Dentistry, Medicine, and Nursing, the Health Professions Partnership Initiative works with local school systems to offer information, experiences, and skills development for middle and high school minority students to better prepare them for health professions education programs. Students with the potential to pursue health careers come to UNC-CH for summer programs.

Federal efforts are supplemented by national, state, and local programs sponsored by professional associations and societies, foundations, and state government. In North Carolina The Duke Endowment and The Kate B. Reynolds Health Care Trust have been actively supporting diversity and recruitment projects. A national collaboration among the Association of American Medical Colleges, the W.K. Kellogg Foundation, and the Robert Wood Johnson Foundation has set a goal of increasing minority enrollments and minorities in practice in medicine and other health professions through its Health Professions Partnerships Initiative (HPPI). The Association of American Medical Colleges also sponsors the Herbert W. Nickens Scholarships and Faculty Awards, along with other recruitment and retention programs sharing the support with foundations and individuals schools.

Summary

This overview has pointed to a continuing racial and ethnic imbalance in the health professions that applies to North Carolina as well as the nation. Great strides have been made early in the development of programs to enhance racial and ethnic representation, but they have generally reached a plateau in terms of growth and progress. Resistance to affirmative action programs and subsequent uncertainty over their legal standing can be cited as one factor thwarting progress, but that issue has been resolved and schools, professions, and the North Carolina General Assembly can move forward with a clear understanding of how to proceed.

A full generation has matured with the benefit of positive emphasis on increasing the proportion of minorities in the health professions. The coming generations must build and expand on the programs and initiatives that brought the nation and the state to where we are now. But these goals must be re-stated, and intensified efforts are required if any reasonable parity in representation of minorities among the health professions is to be achieved. **NCMJ**

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COMMENTARY

Minority Recruitment and Participation in Health Research

Giselle M. Corbie-Smith, MD, MSc

Since 1993, all investigators funded by the National Institutes of Health (NIH) to conduct clinical research have been expected to demonstrate appropriate inclusion of racial and ethnic minorities and women in their research or clearly demonstrate why they should be excluded in order to pursue a specific research objective. This mandate, the NIH Revitalization Act, was a response to the realization that women and minorities were underrepresented in clinical research. These guidelines have mandated the inclusion of minorities in clinical research in an effort to better understand disparities in health and to improve the generalizability of research findings. While few would argue with the goals of this mandate, investigators have been challenged in its implementation. This article gives an overview of some of the challenges raised by minority participation in research and describes some of the consequences of a lack of minority involvement in research.

Challenges Raised by Mandated Inclusion of Minorities

Most of the scientific literature on minority participation in research has focused on the barriers to minority participation. The factors that impede the participation of minorities in research can be specific to the participant, the investigator, or the study. For example, since African Americans are over-represented in lower socio-economic strata; race, as a commonly measured variable, may be a proxy for other socio-demographic factors. Socio-economic status can influence the decision to participate in a number of other ways. For example, access to transportation[1] and the location of study sites significantly impact the recruitment and retention of patients in clinical trials.[2] Educational level,[3] age,[4] and marital status all have been shown to be associated with various aspects of decision making.[5,6] Among the economically disadvantaged, competing subsistence needs may outweigh any anticipated benefits of participation. Psychosocial factors such as perceived stress, community involvement, and social isolation may be powerful factors in a patient's decision to participate in a clinical trial and ability to maintain adherence to a research protocol, particularly in an older population.

In addition, trust or lack of trust is an important factor when deciding to participate in research. Fear, mistrust, and lack of knowledge were cited by minority respondents as the main reasons they didn't participate in oncology research.[7] The history of clinical experimentation on blacks during slavery laid the foundation of distrust among blacks toward medical research.[8] Yet, it is the Tuskegee Syphilis Study (1932-1972) that has become the contemporary metaphor of research that violates human rights of vulnerable groups. Several medical historians have asserted that this study, where 400 poor black men with syphilis were left untreated for 40 years, validated suspicions about ethical treatment in the context of research.[9-11] Awareness of the Tuskegee Syphilis Study among minority and other underserved groups contributes to pervasive distrust of physicians and the medical research establishment.[8,12-14] The dissemination of oral histories about the Tuskegee Study and fictional dramas may reinforce distortions in the historical record and provide moral justification for refusal to participate in any clinical research.

> *"Fear, mistrust, and lack of knowledge were cited by minority respondents as the main reasons they didn't participate in oncology research."*

The influence of culture on health-seeking behavior is

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another important influence on minority participation as research subjects. Health-seeking behavior influences where, when, and how one accesses the healthcare system. Bailey describes six culturally-based steps in health seeking behavior among African Americans.[15] He noted that patients are active participants in their health, from the perception of symptoms to eventually seeking formal medical care (whether or not their actions are considered appropriate to the biomedical model of disease). Other authors have demonstrated that the combination of socio-economic factors and culture can account for racial differences in the stage of presentation of disease.[16] Cultural differences in how the healthcare system is accessed and utilized can impact the availability and opportunities to participate in medical research.[17] In addition, expectations of medical roles and responsibilities, explanatory models of disease, and verbal and non-verbal communication patterns are all influenced by the culture framework of patients.[17,18] Investigators' cultural competency, not just their ability to speak another language or dialect, but their desire to respectfully address the patient's needs within the framework of that person's health beliefs, religious background, cultural philosophy, and social customs will ease the transition in recruiting individuals that may hold beliefs and attitudes toward health that are discordant with those of clinical researchers.

However, empirical data are lacking on how well investigators understand and are able to negotiate these cultural differences. There have been no studies of investigators' knowledge of the barriers to minority participation in clinical trials or how these recommendations have been translated into successful recruitment strategies. At the introduction of the NIH mandate, researchers were quite vocal about their concerns. Editorialists likened the mandate to include minorities and women in clinical research trials to affirmative action[19] and quota systems.[20] Investigators raised concerns about the potential added costs to recruiting more diverse study samples.[19-21] Investigators also described the ethical consideration of mandating the inclusion of women and minorities. Some authors described the potential to give minorities the "hard-sell" and therefore not fully respecting an autonomous decision not to participate in a trial.[22]

In the research community there is a general belief that minority groups may be more difficult to recruit into clinical trials,[18,23] less likely to adhere to study protocols, and more difficult to retain in clinical studies.[23] While there is some evidence that race alone is not a predictor of recruitment success,[24] the belief that minority groups are hard to reach may affect some investigator's willingness to recruit minority participants. In fact, when investigators take more innovative approaches to recruitment, these efforts have been more successful.[25-30] Community-based strategies can elicit and address differing cultural beliefs while informing the design of recruitment strategies that lead to successful minority enrollment and improved investigator-participant relationships.

Consequences of Lack of Minority Involvement in Research

While investigators have been conducting clinical research for a decade under this mandate, minorities are still under-represented in areas of known disparities in health research relative to the prevalence of disease in minority communities.[31-33] Underrepresentation of minorities as subjects in research and lack of minority involvement in research partnerships may adversely affect minority communities in a number of ways.

Clinical research is the basis of advances in all areas of medical knowledge and clinical care. The lack of minority participation in research limits the generalizability of study results to those groups that are included in research. More diverse research populations allow the generation and testing of research hypotheses that may enhance our understanding of disparities in health by race and ethnicity and the development of interventions to address these disparities.

Minority participation in research also increases the likelihood that research results are more relevant to the needs of minority communities. If minority communities are not involved in the process of research, as participants, staff, or as community advisors, interventions are less likely to be culturally-relevant and therefore less likely to be sustainable once the study has ended. Research that actively engages target communities leads to interventions that are more likely to be successful and sustained[34,35] and, more likely to lead to program institutionalization.[35,36] In addition, involvement of the target communities also enhances the relevance and usefulness of the data, as well as data quality and validity.[35,37,38] Finally, community involvement in research can also strengthen the research and program development capacity of the individuals and organizations in undeserved communities. The lack of active engagement of minority communities in research severely limits the potential of improving the health and well-being of minority communities, either directly through examining and addressing disparities in health, or indirectly through increasing the power and influence of minorities over the research process affecting the health and healthcare they receive.[35,37,38] **NCMJ**

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Running the Numbers

A Periodic Feature to Inform North Carolina Healthcare Professionals
About Current Topics in Health Statistics

From the State Center for Health Statistics, North Carolina Department of Health and Human Services
www.schs.state.nc.us/SCHS

The Health of American Indians in North Carolina

North Carolina has the eighth largest American Indian population among all states. The 2000 Census counted 99,600 residents of North Carolina who reported their race as American Indian alone, and also more than 20,000 who reported American Indian in combination with another race. More than one-half of the American Indians in North Carolina are of the Lumbee Tribe. American Indians in North Carolina experience a relatively high rate of poverty, which is associated with more health problems. The percentage of American Indian families in North Carolina living below the federal poverty level in 1999 was 21.0, compared to 22.9 for African Americans and 8.4 for whites.

American Indians in North Carolina experience worse outcomes for many health measures, compared to other racial groups. Two recent publications are available that profile the health of American Indians in our state: *Racial and Ethnic*

	American Indian	African American	White
AIDS deaths per 100,000 population	4.0	21.5	1.5
Homicide deaths per 100,000 population	18.1	17.0	4.6
Motor vehicle deaths per 100,000 population	41.6	20.7	19.2
Diabetes deaths per 100,000 population	52.7	55.6	21.5
Kidney disease deaths per 100,000 population	20.7	34.9	13.4
% of mothers with a live birth who smoked during pregnancy	25.3	11.0	15.2
% of mothers with a live birth reporting an unintended pregnancy	65.2	66.8	36.7
% of live births with no prenatal care or where prenatal care started late	23.5	24.1	12.1
Infant deaths per 1,000 live births	11.2	15.4	6.3
Deaths ages 1-17 per 100,000 population	53.8	37.5	30.0
Pregnancies per 1,000 teens ages 15-17	63.2	72.4	38.0
% of adults with arthritis	36.3	29.5	29.1
% of adults with diabetes	14.1	12.6	6.8
% of adults ever having asthma	16.4	12.9	11.1
% of adults with high blood pressure	40.2	38.6	26.6
% of adults who are obese	33.2	37.2	20.9
% of adults reporting no leisure time physical activity	32.4	33.8	23.7
% of adults with no health insurance	19.2	19.0	13.4
% of adults reporting a disability	38.5	29.7	24.9
% of adults reporting fair or poor health	25.9	25.1	17.5

RUNNING THE NUMBERS—continued on page 390

RUNNING THE NUMBERS—continued from page 389

Disparities in North Carolina: Report Card 2003 (available at http://www.schs.state.nc.us/SCHS/pdf/FinalReportCard.pdf) and *Racial and Ethnic Differences in Health in North Carolina: 2004 Update* (available at http://www.schs.state.nc.us/SCHS/pdf/RaceEthnicRpt.pdf). We briefly summarize here some of the results from these publications, emphasizing areas where health disparities are the largest. See the publications for a more complete definition of the indicators, including time periods for the data. We also use selected 2002-2003 age-adjusted percentages from the North Carolina Behavioral Risk Factor Surveillance System (BRFSS), a statewide random telephone survey of adults in North Carolina.

American Indians in North Carolina experience outcomes on many chronic disease measures (such as rates for heart disease, stroke, cancer, and chronic liver disease) similar to or only slightly higher than those for whites, and therefore these measures do not appear in the table above since the apparent disparities are not large. But these measures often rely on death certificate data, where there is probably substantial under-reporting of American Indian as the race of the decedent.

The North Carolina American Indian Health Task Force was created in 2004 by the North Carolina Commission of Indian Affairs and the Secretary of the North Carolina Department of Health and Human Services. The purpose of this Task Force is to identify and study Indian health issues in North Carolina and to evaluate and strengthen programs and services for American Indians in the state. The Task Force will be issuing a final report with recommendations for action in the Spring of 2005.

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Quality Care and Performance Improvement

To The Editor:

I am writing in reference to the fine special article "Remembering Cecil" that appeared in the September/October 2004 issue of the *North Carolina Medical Journal.* I was one of the young physicians participating in the Rural Practice Project to whom the author, Donald Madison, MD, referred in the last paragraph of his remembrance to Dr. Cecil Sheps.

After I graduated from Duke Medical School and completed my family medicine residency, I joined a public health service practice in Tooele, Utah with little appreciation of what I would confront. I had the good fortune to work with a terrific team of dedicated people in our small practice, and together we learned many important lessons about how to provide healthcare to the people we served in our rural community.

We applied for a grant from the Robert Wood Johnson Foundation (RWJF) in 1975 and were fortunate to be selected as one of the 13 grant recipients. Donald Madison was the director of this national program called the Rural Practice Project. It was established to help improve the ability of rural practices to survive in the face of some of the significant challenges that they faced at the time. Our participation as a member of the Rural Practice Project resulted in our having visitors on occasion who might not otherwise have found their way to Tooele. Cecil Sheps was one of those visitors and, in fact, one of the most memorable and notable.

I fondly recall Cecil's visit and believe it was 1978. He was stopping at several rural practices as part of a study he was conducting. He sat in my office as I was speaking with a consultant in Salt Lake City about a dying hospitalized patient I wanted the consultant to evaluate to make sure I was not overlooking a potentially reversible cause for her illness. She was an older woman and did not want to leave Tooele, but she was willing to do so at my request provided she did not have to remain in the Salt Lake City hospital for more than two days. I told the consultant over the phone what I was seeking from him both from my and from the patient's perspective. Cecil reflected after hearing the conversation that it would certainly help introduce more sanity into our healthcare system if those in primary care could "call the shots" on a more consistent basis as advocates for their patients and their patients' families.

It was inspiring for me to see Cecil's passion and observation skills. Although his time in our community was short, and although our paths crossed subsequently for only brief periods, I still remember the validation I felt as a result of his positive comments. Needless to say, we certainly could benefit from more leaders like Cecil Sheps in our world today.

David Garr, MD
Executive Director, SC AHEC
Associate Dean for Community Medicine
Professor of Family Medicine
Medical University of South Carolina
Charleston, SC

To The Editor:

I was amused at the frequency with which the authors in the current issue of the *North Carolina Medical Journal* bemoan unnecessary and duplicative paperwork as a detriment to the delivery of quality medical care and the improvement thereof. As a perpetrator and victim of quality improvement efforts in my own practice and hospital since such became fashionable in the late 1980s, I can report from experience that most of the unnecessary and duplicative documentation and reporting is a result of poorly conceived quality improvement efforts imposed on those at the bedside by governmental agencies and their surrogates like JCAHO. Such requirements are usually not supported by clinical science, but "seem like things we ought to be doing" by bureaucrats or the residents of think tanks and their accomplices at the local hospital. Thus, as those of us at the bedside continue to cope with the increasing demands of an older, fatter, sicker population, ever more belligerent attorneys, stingier paymasters, and fewer physicians in practice, we can look forward to more forms, checklists, signatures, meetings, and ever more imaginative intrusions all in the name of quality. Sadly, I have seen nothing in the last 22 years of practice to assure me that efforts at quality improvement in medicine, as laudable as they may be, can produce anything more than that.

I hope I am wrong.

Randy A. Peters, MD
Winston-Salem, NC

The North Carolina Institute of Medicine

Since January 2002, Publisher of The *North Carolina Medical Journal*

In 1983 the North Carolina General Assembly chartered the North Carolina Institute of Medicine as an independent, nonprofit organization to serve as a non-political source of analysis and advice on issues of relevance to the health of North Carolina's population. The Institute is a convenor of persons and organizations with health-relevant expertise, a provider of carefully conducted studies of complex and often controversial health and healthcare issues, and a source of advice regarding available options for problem solution. The principal mode of addressing such issues is through the convening of task forces consisting of some of the state's leading professionals, policy makers and interest group representatives to undertake detailed analyses of the various dimensions of such issues and to identify a range of possible options for addressing them.

Members of the North Carolina Institute of Medicine are appointed for five-year terms by the Governor, and each task force convened by the Institute typically includes at least one-third of its membership from among the appointed members. Topics to be addressed through task force efforts are chosen following requests from the Governor, the General Assembly or agencies of state government. In some cases, topics are selected on the basis of requests from a number of stakeholder organizations across the state where this type of analytical process is considered to have potential value.

The North Carolina Institute of Medicine assumed the role of publisher of the *North Carolina Medical Journal* in January 2002 through an agreement with the North Carolina Medical Society, which founded the Journal in 1845. The Institute views the *North Carolina Medical Journal* as an extension of its mission. The Journal provides a forum for stakeholders, healthcare professionals, and policy makers and shapers to study and discuss the most salient health policy issues facing our state. Like many states, North Carolina is grappling with issues such as an increasing number of uninsured, the unmet health needs of the growing Latino population, a critical shortage of nursing personnel, the health risks of tobacco and obesity, rising prescription drugs costs, mental health system reform, the increasing societal burden of chronic illness care, the threat of bioterrorism and the necessity of assuring adequate public health preparedness—all in the midst of an economic downturn. Each of these issues presents unique challenges to healthcare providers and state policy makers. Yet, a fully implemented task force to consider each of these sets of issues is not feasible. The Journal makes it possible to present an organized and balanced overview of some of these issues, six times per year, and allows interested persons the opportunity to engage in the ongoing discussion of these issues throughout the year. The Institute hopes that our readers of the *Journal* will, in this way, become involved in the continuing debate about the most promising avenues for assuring the highest standards of health and healthcare for all North Carolinians.

health policy

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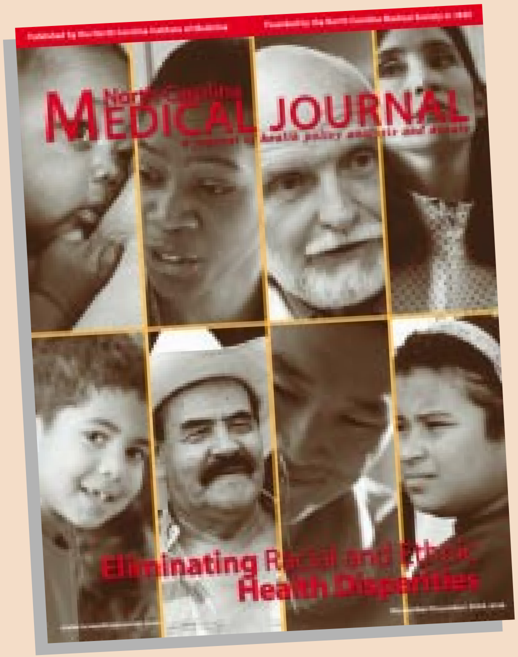
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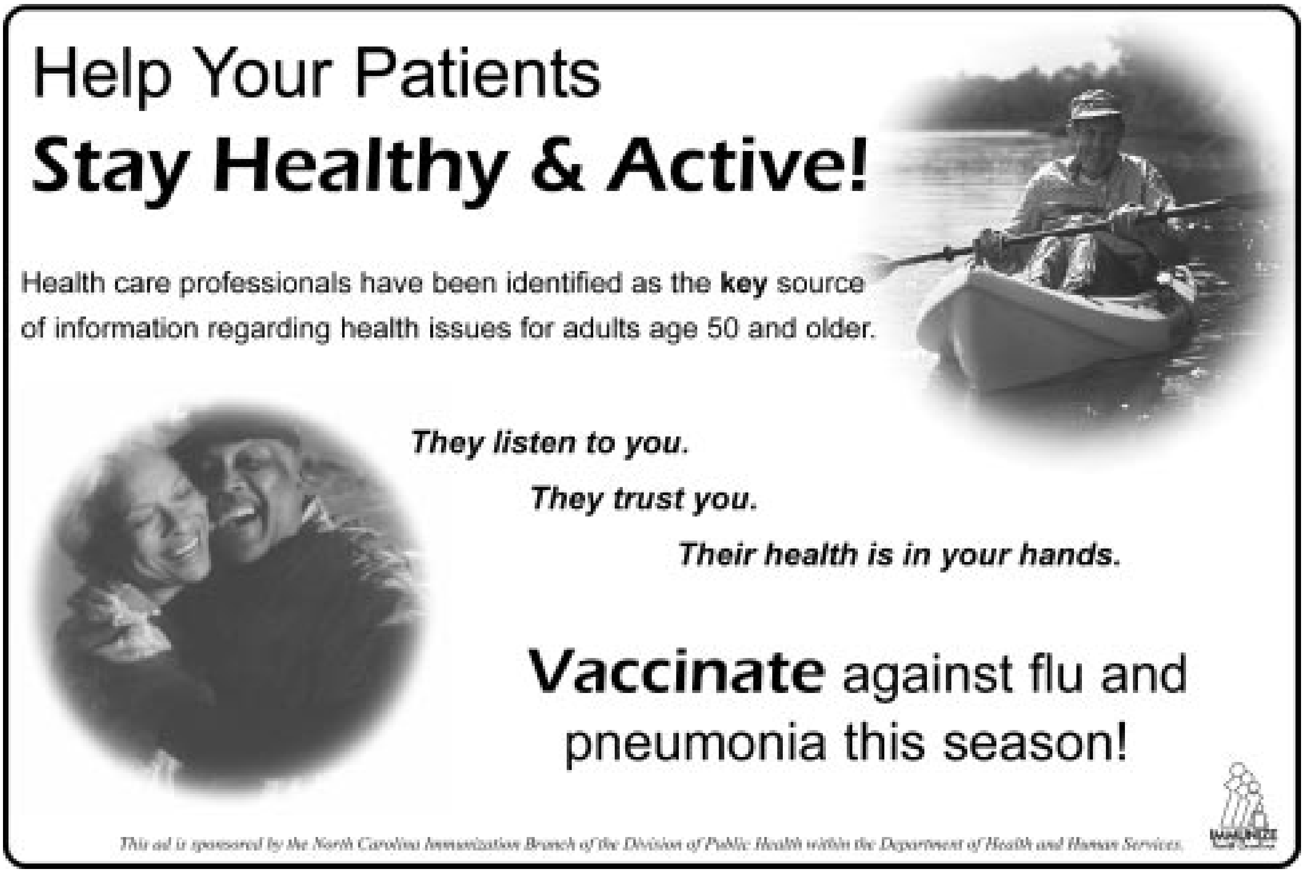

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Jeff Anderson, M.D., and W. Graham Evans, Jr, PA-C, review a patient's x-ray at BeachCare Urgent Care Centers of Morehead City and Havelock.

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Graham's contribution to the practice was so strong that I offered him equal partnership in the practice. Without Graham's commitment to the practice and our patients, the practice would not be as successful.

Jeff Anderson, M.D.
BeachCare Urgent Care Centers of
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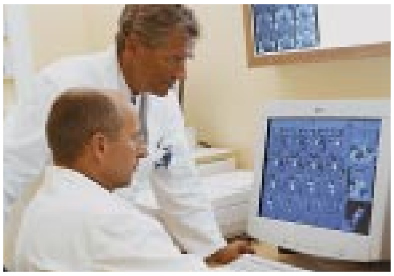
North Carolina MEDICAL JOURNAL

a journal of health policy analysis and debate

Alzheimer's Disease and Family Caregiving

www.ncmedicaljournal.com
January/February 2005, 66:1

A partnership that's working for eastern North Carolina



Better tools mean better care

Cooperation and vision are bringing leading-edge technology to help patients in eastern North Carolina who are diagnosed with brain lesions. Pitt County Memorial Hospital has received state approval to buy and install a Leksell Gamma Knife, one of medicine's newest and most powerful tools for the treatment of brain tumors and other neurological conditions. The Leksell Gamma Knife is the most recent addition to the hospital's growing armamentarium of leading-edge diagnostic and treatment technology.

The project, which is expected to be operational in the fall of this year, is the result of careful collaboration and planning involving the hospital, the Leo W. Jenkins Cancer Center, the Brody School of Medicine Department of Radiation Oncology and private physician practices including Eastern Neurosurgical and Spine Associates, Eastern Radiologists and Carolina Radiation Medicine.

The Brody School of Medicine, University Health Systems and private physicians are working together to make things happen — in the community, in the region and in the state.

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We heard you.
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Blue Cross and Blue Shield of North Carolina asked doctors across the state: How can we support you on the front lines in a battle against our epidemic of obesity?

Doctors in North Carolina told us they want to address excess weight and obesity with their patients. But you also told us there simply isn't enough time to squeeze one more health condition into an office visit.

We heard you. Blue Cross and Blue Shield of North Carolina will pay for four visits to a doctor each year specifically for the evaluation and treatment of obesity.

It's part of our new obesity initiative called Healthy Lifestyle Choices℠.

Obesity shortens lives and increases health care costs. The first step toward a healthier, more active life can start in the doctor's office – where we are encouraging a hard look at how excess weight can impact people's health.

Healthy Lifestyle Choices is a broad program that extends from online support for members trying to maintain a healthy weight or lose a few pounds – to coverage of doctor visits and prescription weight-loss drugs when medically necessary – to establishing Bariatric Surgery Centers of Excellence to identify providers of superior results in obesity surgery.

For more information about the Healthy Lifestyle Choices program or to request educational materials for your patients, e-mail your request to **quality@bcbsnc.com**.

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changing how we think about brain health in north carolina

Alzheimer's disease was first identified by Dr. Alois Alzheimer in 1906, but 95 percent of what we know has been discovered in the last 15 years. Now, for the first time, research tells us that you can manage your lifestyle to help reduce your risk of Alzheimer's and we can anticipate major breakthroughs toward prevention over the next decade.

Today 4.5 million Americans have Alzheimer's disease; unless something is done to prevent it, that number will increase by 70 percent to 7 million Americans by 2025. Simple lifestyle modifications, if adopted by everyone would have an enormous impact on our nation's public health and the cost of health care.

When we think about staying fit, we generally think about our bodies and not our minds. But brain health plays a critical role in almost everything we do: thinking, feeling, remembering, working, playing and even sleeping. The good news is we now know there are things we can do to keep our brains healthier as we age and these steps might reduce our risk of Alzheimer's disease or other dementias.

10 ways to maintain your brain

1. Head first
Good health starts with your brain. It's one of the most vital body organs, and it needs care and maintenance.

2. Take brain health to heart
What's good for the heart is good for the brain. Do something every day to prevent heart disease, high blood pressure, diabetes and stroke – all of which can increase your risk for Alzheimer's.

3. Your numbers count
Keep your body weight, blood pressure, cholesterol and blood sugar levels within recommended ranges.

4. Feed your brain
Eat less fat and more antioxidant-rich foods.

5. Work your body
Physical exercise keeps the blood flowing and may encourage new brain cells. Do what you can – like walking 30 minutes a day – to keep both body and mind active.

6. Jog your mind
Keeping your brain active and engaged increases its vitality and builds reserves of brain cells and connections. Read, write, play board games, learn new languages or skills, do crossword puzzles or brain teasers.

7. Connect with others
Leisure activities that combine physical, mental and social elements may be most likely to prevent dementia. Be social, converse, volunteer, join a club or take a class.

8. Heads up! Protect your brain
Take precautions against head injuries. Use your car seat belts, unclutter your house to avoid falls; and wear a helmet when cycling or rollerblading.

9. Use your head
Avoid unhealthy habits. Don't smoke, drink alcohol excessively, or use street drugs.

10. Think ahead – Start today!
You can do something today to protect your tomorrow.

An estimated 150,000 North Carolinians suffer from the devastating effects of Alzheimer's disease. From the mountains to the coast, individuals, families, health care professionals and the general public receive information and assistance from the Eastern North Carolina Chapter in Raleigh, the Western Carolina Chapter in Charlotte and their satellite offices. Programs and services include 800 Helplines, support groups, information and referral services, educational programs, counseling, newsletters, lending libraries of books and videos and collaborative programs with other non-profits and local, state and federal agencies.

Be an advocate for those who can no longer speak for themselves. Support the programs and services of the North Carolina Chapters and help make Alzheimer's a distant memory through research for a cause, prevention and cure.

For information about programs and services, please contact the office nearest you.

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The Journal seeks papers that convey the results of original research. We are especially interested in publishing research papers that have relevance to the health of the people of our state.

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January/February 2005, Volume 66, Number 1
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ARTICLE

POLICY FORUM

Alzheimer's Disease and Family Caregiving

COMMENTARIES

REMEMBRANCE

DEPARTMENTS

> *"Alzheimer's disease has come to symbolize worries about how the United States will deal with the aging of society."*

ARTICLE

Stroke Prevention in Atrial Fibrillation:
Are We Following the Guidelines?

Benjamin E. Pusser, DO, Sandy L. Robertson, PharmD, Mark D. Robinson, MD, Cole Barton, PhD, and L. Allen Dobson, MD

Abstract

Background: *Warfarin therapy substantially reduces stroke in atrial fibrillation (AF), yet medical literature reports it is only prescribed in 15-60% of eligible patients. No current national benchmarks for warfarin use in AF patients exist, and it is unclear whether the reported poor compliance represents current rates within primary care practices. The primary study objective was to measure the rate of warfarin use in eligible, high-risk AF patients in a large southeastern group family practice. Secondary objectives were to report the demographics, stroke-risk profiles, contraindications, and reasons for discontinuation of warfarin therapy.*

Methods: *A retrospective chart review was performed on all active patients with documented AF in a large southeastern group family practice/residency between July 1, 2000 and June 30, 2002. Data was abstracted on warfarin use, contraindications, stroke risk, and reasons for discontinuation.*

Results: *Four hundred ninety-one (491) patients were identified from the electronic billing system as potential study subjects. Two hundred eighty-three (283) patients met study criteria, with 210 patients considered to be at high-risk of stroke without contraindications to warfarin therapy. Ninety-four percent (198/210) of these patients were prescribed warfarin during the study period, and 87% (172/198) continued warfarin throughout the study period.*

Conclusions: *Family physicians in this practice prescribe warfarin in AF more frequently than published rates, demonstrating that high rates of physician adherence to standards are achievable in primary care. Most patients in this setting were considered high-risk for stroke.*

Key words: *anticoagulation, atrial fibrillation, warfarin, stroke, family medicine*

INTRODUCTION

Atrial fibrillation (AF) is the most common sustained arrhythmia affecting 0.9% of the United States population.[1] The incidence of AF increases sharply with age affecting 5.9% of people over 65 years and 10% of those greater than 80, with a median age of 75 years.[1] AF is associated with a six-fold increase in the risk of stroke, with 50% of strokes occurring in patients greater than 75 years.[2] The annual stroke rate is 6-12% in patients older than 70 years with any high-risk factor for stroke.[3-5]

AF patients on antithrombotic therapy for stroke prevention have a relative risk reduction of 70% with warfarin vs. placebo, and a 20% reduction with aspirin vs. placebo.[3-5] Given the high incidence of stroke in AF patients and the efficacy of warfarin in preventing stroke, the American College of Chest Physicians (ACCP) published grade A recommendations via the Fourth ACCP Consensus Conference on Antithrombotic Therapy in 1995.[6] These recommendations were based on level 1 evidence, and remain largely unchanged in the most recent ACCP guidelines from the Sixth ACCP Consensus Conference on Antithrombotic Therapy.[7] In these guidelines, patients are stratified into risk categories to guide appropriate antithrombotic therapy (see Table 1). AF patients are categorized as high-,

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Cole Barton, PhD, is Professor of Psychology at Davidson College and Director of the Clinical Research Institute at Northeast Medical Center.

L. Allen Dobson, MD, is President and Chief Executive Officer of Cabarrus Family Medicine, PA, and the Director of Graduate Medical Education at the Cabarrus Family Medicine Residency Program at Northeast Medical Center.

Table 1.
ACCP Stroke Prevention Guidelines 2001[7]

Atrial Fibrillation Stroke Profile	Risk Factors	Treatment Guidelines
High Risk	One or more of the following: ■ Age ≥ 75 years ■ History of hypertension ■ Prior cerebrovascular accident/ transient ischemic attack ■ Prior arterial thromboembolism ■ Poor left ventricular systolic dysfunction (ef<40%) ■ Rheumatic mitral valve disease or prosthetic heart valve ■ Two or more moderate-risk factors	Warfarin (INR 2.5, range 2-3)
Moderate Risk	No high-risk factors and one of the following: ■ Age 65-74 years ■ Diabetes ■ Coronary Artery Disease	Warfarin (INR 2.5, range 2-3) or Aspirin 325 mg/day
Low Risk	No high- or moderate-risk factors and: ■ Age <65 years	Aspirin 325 mg/day

moderate-, and low-risk for stroke based on age, hypertension, previous cerebral embolic event, poor left ventricular systolic function, the presence of valvular disease or a mechanical valve, diabetes, or coronary artery disease. Patients in the high-risk category should receive warfarin therapy unless contraindicated, whereas patients in the low-risk category should be maintained on aspirin therapy. Patients in the moderate-risk category can be maintained on either warfarin or aspirin therapy. Despite these nationally accepted guidelines, published studies report only 15-60% of eligible AF patients are prescribed warfarin, with family physicians reported as having the lowest use rates in AF.[8-15] We do not believe these low rates reported for family physicians are accurate.

Our primary study objective was to measure the current rate of warfarin use in eligible high-risk AF patients in a large southeastern group family practice. Secondary objectives were to report the demographics, stroke risk profiles of patients with AF, and the contraindications and reasons for discontinuation of warfarin therapy.

METHODS

A retrospective chart review was conducted from the 57,912 active patients, defined as seen in the clinic within two years of start of study, receiving care through Cabarrus Family Medicine Residency Program (CFMR) at Cabarrus Family Medicine, PA, (CFM) clinics. CFM operates five family practice clinics in five municipalities in North Carolina (Concord, Kannapolis, Harrisburg, Mt. Pleasant, and Richfield). These clinics function as residency training and practice sites for CFMR, within a large multi-office community practice. The 28 attending physicians and 24 resident physicians utilize NorthEast Medical Center (NEMC), the only hospital in Cabarrus County, nearly exclusively for all admissions.

The study period was defined as July 1, 2000 to June 30, 2002. Patients were included in the study if they visited a CFM clinic during the study period and AF was documented by electrocardiogram or medical records including AF as a diagnosis. For study purposes, AF included atrial flutter and any subtype of AF (e.g., paroxysmal, chronic). AF was considered remote if a patient remained in sinus rhythm throughout the study period but records indicated a history of AF.

In order to ensure that we captured as many patients as possible with AF, we searched CFM's electronic billing database (Medical Manager™) to identify patients seen in the study period and who had an ICD-9 diagnosis of atrial fibrillation or atrial flutter (427.31-427.32) any time during the preceding seven-year period. As an additional search, we used the hospital's (NEMC) electronic billing database to identify additional hospitalized patients with the same ICD-9 codes discharged during the study period with a CFM attending physician or a CFM primary care provider.

A data collection tool was developed and piloted with ten medical records. Direct, on-site abstraction was conducted by a single resident physician (BEP) utilizing a computer database on a laptop and Windows based PDA. Hospital records were utilized as needed to complete data abstraction.

Risk factor variables were recorded for the purpose of stratifying patients into high, moderate, and low stroke risk categories (see Table 1). If a patient received warfarin anytime during the study period warfarin use was recorded as positive. Contraindications and acceptable reasons to not prescribe warfarin were based on Medical Review of North Carolina, Inc.'s *National Stroke Medicare Quality Improvement Project*[16] (See Table 2) and were recorded when patients were not started or continued on warfarin.

SPSS software was used to analyze standard descriptive statistics and p values for categorical variables were calculated using nonparametric χ2 tests. Categorical variables of risk were tabled with whether or not warfarin was prescribed. Chi-square statistics were computed which compared measured rates of prescribing to recommended guidelines, or whether or not patient categories exceeded base rate expectations as supported by the literature.

RESULTS

A total of 491 potential study patients were identified by CFM and NEMC billing systems, with 490 patient charts located and abstracted. Two hundred seven patients were excluded after detailed chart reviews revealed 117 of them had

Table 2.
Contraindications to and Acceptable Reasons Not to Prescribe or to Discontinue Warfarin Therapy[11]

Contraindications/acceptable reasons patients not on warfarin therapy	
■ Syncope ■ Multiple falls/risk of falls ■ Advanced dementia ■ Hemorrhagic cerebrovascular accident ■ Patient noncompliance/refusal ■ Warfarin allergy ■ Prior serious gastrointestinal bleeding and/or untreated or unresponsive peptic ulcer disease ■ Predisposition to bleeding (thrombocytopenia, end-stage renal disease, cirrhosis, hemophilia)	■ Major bleeding (requiring hospitalization or transfusion) ■ AF lasting <48 hours and did not recur or secondary to medical condition ■ Seizure disorder ■ At risk of falls ■ Prior bleeding with anticoagulants ■ Alcohol abuse ■ Terminal/comfort care ■ Extensive, metastatic cancer

Contraindications to Warfarin Therapy in Study	**# (% high-risk patients, n=257)**
One episode <48 hours or AF secondary to medical condition	9 (3.5%)
Prior/predisposition to major bleeding	9 (3.5%)
Syncope, seizures, multiple falls	8 (3.1%)
Advanced dementia	7 (2.7%)
Prior bleeding with anticoagulants	5 (1.9%)
Patient declined warfarin	5 (1.9%)
Alcohol abuse, prior noncompliance	3 (1.2%)
Metastatic cancer, comfort care only	1 (0.4%)

remote AF only, 60 were without a diagnosis of AF, and 30 patients were not seen in the study period. AF was prevalent in 6.1% of patients age 75 and older and 0.69% of all patients (see Table 3, Figure 1). These prevalence rates are consistent with the published literature. The types of AF documented were evenly distributed between paroxysmal, chronic, and unspecified (see Table 3).

Of the 283 patients who met study criteria, 257 (91%) were categorized as high-risk for stroke by having at least one high-risk factor, or at least 2 moderate-risk factors listed in Table 1. Of these 257 patients, 47 (18%) were considered not to be warfarin candidates (see Table 2), leaving 210 patients eligible to receive warfarin therapy for stroke prevention. The most common acceptable reasons not to prescribe warfarin were: transient AF secondary to medical condition/1 episode lasting less than 48 hours, prior/predisposition to major bleeding, syncope, seizure, or multiple falls, and advanced dementia.

Ninety-four percent (198/210) of eligible high-risk AF patients were prescribed warfarin during the study period. Results were unchanged when moderate-risk patients (n=7), who are recommended warfarin or aspirin, were included in the analysis. Likewise, 87% (172/198) of active patients continued warfarin throughout the study period. Warfarin was discontinued during the study period in 26 patients; 14 patients had valid reasons documented, including major bleeding (2.5%), patient refusal (1.5%), and AF secondary to medical condition/1 episode lasting <48hrs (1.5%), whereas 12 patients did not have documentation of an acceptable reason.

The majority (11/15) of female patients not started or maintained on warfarin were noted to have the paroxysmal subtype of AF. There was no such difference in AF subtypes among males. Age and clinic location had no correlation with warfarin use.

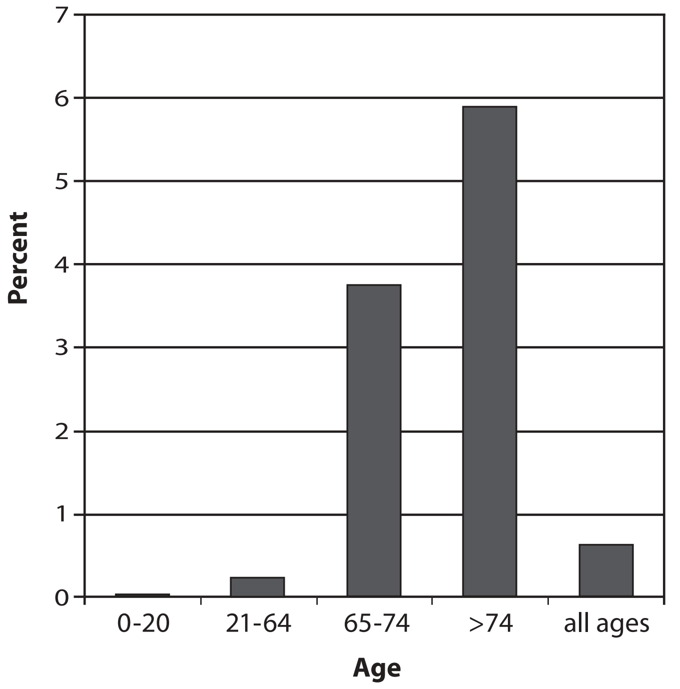
DISCUSSION

This retrospective study of warfarin use in high-risk AF patients in a large primary care setting demonstrates a high rate of compliance with national guidelines set forth by the American College of Chest Physicians and challenges the previously low compliance rates for Family Practitioners.[7] Currently, there are no published national benchmarks for achievable warfarin use in AF. CFM's 94% prescription rate is significantly higher than all other rates found in the literature ($\chi^2 = 39.00$, $P<0.001$).[8-15] We located eight publications investigating warfarin use in AF patients with most of the data collected in the early 1990's. Three of these trials investigated warfarin use in hospitalized patients admitted with AF with or without stroke,[8,10,15] while three trials reported warfarin use in long-term care facilities (LTCF).[9,13,14] The remaining two trials described warfarin use in outpatient settings over a period of time.[11-12] Each trial considered contraindications to warfarin therapy in calculating the number of patients on warfarin, and five of these trials reported the number of ideal candidates on warfarin.[8-10,12,14] The acceptable contraindications were similar to each other and to our study. Valid contraindications shared by these investigations included fall risk, bleeding history, peptic ulcer disease, and terminal illness. Our study reports 18% of patients with contraindications (see Table 2), while the other trials varied from 1% to 81%, with LTCF patients gleaning the highest proportion of ineligibility.

Table 3.
Patient Demographic Data and Prevalence of AF within Clinic System

Patient Demographics (n=283)	
Female	137 (48%)
Median age	74 years (range 21.8 - 106.2)
Age ≥ 75 years	140 (49.1%)
Age 65-74 years	70 (24.7%)
Age < 65 years	73 (26.1%)
Paroxysmal AF	32.5%
Chronic AF	28.6%
Unspecified AF	38.9%

Figure 1.
Prevalence of Atrial Fibrillation at CFMR Clinics (n=57,912)
*includes patients with remote AF documented between 1995-2000



The percentage of eligible patients on warfarin was 38% and 69% in hospitalized patients,[8,10] 25% and 53% in LTCF patients,[9,14] and 35% in the clinic setting.[12] The remaining three trials did not report eligible patients, but rather the total number of patients on warfarin. Stafford et al[11] compared warfarin use among cardiology, internal medicine, and family practice clinics from 1980 to 1993, with internal medicine having the highest portion of patients on warfarin at 40%, cardiology at 32%, and family practice at 15%. In a report by Jencks et al,[15] Medicare patients with AF in North Carolina between 1998 and 1999 had a 60% warfarin prescription rate at hospital discharge. No definite trend of improved warfarin use can be detected by these studies, despite the growing body of evidence supporting its use. It is unclear whether the quoted rates could be low due to study design, period of study compared to date of new guidelines, or whether rates in those studies represent lower compliance. A recent review of the literature describes numerous potential reasons for noncompliance with warfarin use.[17] Increasing age, perceived hemorrhage risk, and perceived noncompliance are consistent physician barriers to prescribing warfarin. Other barriers identified were difficulty in monitoring and unfamiliarity with the clinical guidelines. Physicians were found to be more enthusiastic about warfarin in patients with a history of cardioembolic stroke.

The significantly higher rates found in this study population suggest that very high compliance rates are achievable in a primary care practice. Factors which may have influenced this high compliance rate include (1) focus on education and current standards of care within a residency program, (2) close working relationship with local cardiologists, or (3) hospital disease management protocols initiated near the end of the study period. Currently at NEMC, patients admitted for AF are flagged with an anticoagulation form in which providers are asked if the patient will be discharged on appropriate anticoagulation. A summary of the guidelines are included on this form with acceptable contraindications to warfarin therapy. These strategies will continue to educate and remind providers of the importance of warfarin therapy in the treatment of AF.

There was no specific practice-based disease management system in place in the clinics during the study period. Further evaluation and study of compliance rates with current guidelines in other clinic settings is needed, including evaluation of the most effective method in achieving compliance. The authors believe that practice-based disease management systems in primary care will be key to improving care for patients in the future.

Unlike studies that focus on warfarin prescribing at hospital discharge, our study followed patients throughout a two-year period and documented an 87% continuous warfarin use rate in this population, suggesting good continuity of care and practice-based disease management. Also, our study did not differentiate between chronic AF and paroxysmal AF with regard to eligibility for warfarin therapy, despite the common belief that patients maintaining normal sinus rhythm for a period of time can safely stop anticoagulation. In the recently published AFFIRM trial,[18] the majority of strokes in both groups (rate control group versus rhythm control group) occurred in patients who had either stopped warfarin therapy or had an INR <2.0. Of the 77 patients in the rate control group with stroke, 32% had discontinued warfarin compared to 55% (44 of 80) in the rhythm control group. We posit that clinicians make the decision to stop warfarin more often in AF patients on antiarrhythmic agents assuming normal sinus rhythm will be maintained. The decision to anticoagulate a high-risk AF patient is more likely to improve outcomes than antiarrhythmic therapy. In the AFFIRM trial, antiarrhythmic therapy had no effect on mortality (trend toward increased mortality, p=0.08) and had significantly increased rates of hospitalizations, torsades de pointes, and bradycardic cardiac arrest as compared to rate control and anticoagulation alone. Moreover, AF patients are at risk of stroke whether or not they are in normal sinus rhythm (NSR) or AF. In another recently published trial of rate control vs rhythm control, 17% of strokes in the rhythm control group occurred after cessation of warfarin therapy. In all but one of these six cases, the patient was still in NSR at the time of stroke.[19]

Future analysis measuring compliance with warfarin monitoring and maintenance of INR goals is needed. Management of stroke prevention with warfarin therapy in AF patients can be effectively performed by family physicians. **NCMJ**

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POLICY FORUM
Alzheimer's Disease and Family Caregiving

Introduction
Gordon H. DeFriese, PhD, and Kristie Weisner Thompson, MA

Issue Brief: Alzheimer's Disease: The Cost and Who Pays?
Donald H. Taylor Jr., PhD

> *"Estimates provided by the National Alzheimer's Association indicate that 10% of the population over the age of 65, and almost 50% of the population over 85, have Alzheimer's disease. People with Alzheimer's disease live three to 20 years from the time of diagnosis..."*

COMMENTARIES

The Alzheimer's Association National Policy Agenda
Bonnie Hogue Duffy, MA

Special Article: Alzheimer's and the Caregiver
Donald L. Madison, MD (with Myron H. Green)

Grieving the Living
Linda E. Jordan, DMin, CT

Family Care and Alzheimer's Disease: What Do We Know and What Can We Do?
Lisa P. Gwyther, MSW, LCSW

North Carolina's Support of Family Caregivers
Christine Urso, MSW

Effective Caregiver Support
Karisa Derence, MA

Managing the Patient with Dementia in Primary Care
Sindy McCrystle, ANP-C, MSN, and Darlyne Menscer, MD

Alzheimer's Disease: A Nursing Home Perspective
Ted W. Goins, Jr, and Lori R. Reid, BSW, CSW

Preparing Families to Make Informed Decisions about Long-Term Care
Sharon C. Wilder and Kathryn A. Lanier, MS

Dementia Care: An Outpatient, Community-based, Multi-disciplinary Approach
Virginia H. Templeton, MD

Alzheimer's Disease, Family Caregivers, and Faith in Action in North Carolina
Catherine O. Ahrendsen and Teepa Snow, MS, OTR/L, FAOTA

Dementia-Responsive Acute Care at Mission Hospitals in Asheville, North Carolina
Nancy Smith-Hunnicutt

INTRODUCTION

Policy Forum:
Alzheimer's Disease and Family Caregiving

The growth of North Carolina's older adult population (in size and proportion) has serious implications for families and for the state's health and human services programs. Public policy deliberations about the impending challenges associated with the growth of this population segment often begin with concern for how we will provide care for the increasing numbers of older adults who will suffer from various forms of dementia, including Alzheimer's disease. In this issue of the *North Carolina Medical Journal*, we have collected a number of perspectives on this large and looming set of issues.

We are fortunate to begin our discussion with an extensive Issue Brief prepared by Donald H. Taylor, Jr., PhD, a health policy specialist at Duke University. Dr. Taylor describes the demographic and epidemiologic trends related to dementia and Alzheimer's disease. He also directs our attention to some of the key public policy issues in need of immediate consideration (hopefully, before these issues overwhelm existing service delivery systems) and to the tremendous burden these issues pose for the families of those affected by Alzheimer's disease. Next, Bonnie Hogue Duffy, national policy specialist for the Alzheimer's Association in Washington, DC, provides an explanation of the Association's national legislative agenda. Their papers help to underscore the scope of the problem and make it clear that early diagnosis can be beneficial in a number of ways. They also emphasize the substantial public as well as personal benefit that could be gained from badly needed clinical therapeutics designed to delay disease onset. Being able to delay onset for even five years could dramatically lessen the personal and societal burden of this disease.

We are also pleased to include a substantial interview with caregiver, Myron H. Green of Durham, North Carolina, by our Contributing Editor, Donald L. Madison, MD. Dr. Madison brings the everyday burden and frustration of spousal care for a loved one with Alzheimer's disease to our attention. We are grateful to Myron Green for sharing his personal experiences with us. No one who reads Mr. Green's story will come away without deep respect and admiration for a caregiver or without an understanding of how important respite care and other helpful services can be to "round-the-clock" caregivers. Following this interview, we include several papers by well-known specialists in North Carolina who have either developed programs for the benefit of caregivers or who administer statewide programs offering such services. The hopeful message in these commentaries is that reliable sources of caregiver support exist, but they are often stretched thin, and their ability to meet the increasing need is in doubt. In addition, we include brief commentaries by specialists who have devoted careers to serving older adults through: primary care medicine and nursing, the provision of respite and bereavement services to caregivers, a variety of faith-based services, and/or long-term care facilities.

The concerns discussed in this issue of the Journal are ones that can have a major impact on the lives of all North Carolinians, regardless of social or economic status. Any time dementia or Alzheimer's disease threatens a close friend or family member, the effects of this diagnosis are likely to be all encompassing. Initially, families nearly always try to manage the care of a loved one in the home or community setting, but the burden of this decision often leaves the caregiver isolated; over-burdened physically, mentally, and economically; and with his/her own health at risk. It is apparent that family caregivers provide an enormous service to their ailing loved ones and to the state. We hope that organizing and presenting this information will generate thoughtful discussions among healthcare providers, patients, and policy makers that will ultimately enhance our family caregivers' ability to provide this important care and, in turn, enhance the state's long-term care capacity.

We invite our readers to share their reaction to these papers, and to these issues in general, in our Readers' Forum over the coming months.

Gordon H. DeFriese, PhD
Editor-in-Chief and Publisher

Kristie Weisner Thompson, MA
Managing Editor

ISSUE BRIEF

Alzheimer's Disease and the Family Caregiver:
The Cost and Who Pays?

Donald H. Taylor, Jr, PhD

What Is It?

Alzheimer's disease (AD) is an acquired, progressive neurodegenerative disorder that is the most common cause of dementia in older adults in the United States, constituting 50-60% of all cases of dementia.[1,2] Dementia is a syndrome characterized by progressive decline in memory and other intellectual abilities, and typically results in a need for complete caregiving for the patient. Contemporary diagnostic criteria for AD were published in 1987.[3] The Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) identifies the following three criteria as being necessary for a diagnosis of dementia: (1) memory impairment, (2) cognitive dysfunction in at least one other area of cognitive functioning (aphasia, apraxia, agnosia, or inability to carry out executive functions), and (3) cognitive impairments severe enough to limit social or occupational functioning. Alzheimer's disease has a societal significance that is greater than simply being the leading cause of dementia. AD has come to symbolize worries about how the United States will deal with the aging of society.

How Common Is It?

There have been a variety of prevalence studies conducted over the past decade, with wide variance in the estimates.[4-14] The most recent published estimate is that 4.5 million persons had AD at the 2000 Census.[4] Comparing estimates is difficult because of differences in methods, settings, timing, and definitions of AD used across studies. There are four key points with respect to the prevalence of AD. (1) The true prevalence of the disease is unknown, and there are conflicting estimates. (2) All published prevalence estimates are based on geographically-based samples that are not representative of the entire United States. (3) All published estimates agree that prevalence increases with older age, and a general rule of thumb is that prevalence roughly doubles per decade of age with around half of those age 85 and older likely afflicted with AD.[10] (4) The number of persons living with AD will dramatically increase given the rapid increase in the number of Americans who are age 85 and older, and who, all studies agree, have the highest prevalence rates.

A recent study using Medicare claims records to track diagnosed prevalence of AD recorded in claims data found large increases across the 1990s using the same diagnosis method in all years.[15] Such a study provides an opportunity to see how identification of AD is changing over time, but the case definition being based on ICD-9-CM codes in claims data produces a serious undercount of the overall true prevalence of the disease. There is no obvious reason to expect that the true prevalence of AD should have risen so sharply during this time frame, so the observed increases are most likely due to an increase in the probability of being diagnosed with AD, given the presence of the disease, particularly for persons with mild symptoms over time.

In addition to age, race and gender have been shown to be related to the prevalence of AD. Women have higher rates of AD than men. There is some epidemiological evidence that AD rates are higher among African Americans compared to whites.[16-23] For example, Folstein et al.[19] found the AD rate for blacks to be 7.2% compared to 3.8% for whites. Other studies have not found differences in the prevalence of AD between African Americans and whites.[24-25] Plausible explanations for a higher rate of AD among blacks are the community-based samples in studies finding differences (e.g., blacks are less likely to be institutionalized where rates of AD are much higher) as well as lower sensitivity of cognitive tests for identifying AD in blacks.[26] The study cited earlier showing an increase in prevalence of AD identified in Medicare claims records showed that the rate of increase was faster for blacks compared to whites.[15] This may suggest an increase in awareness of AD in the African American community, an increase in access to care, changes in coding rules that allow a diagnosis of AD with a history of stroke, or all of these.

What Treatment Options Are Available?

AD is non-reversible, and the current therapy available to directly address the disease is limited to: (1) pharmaceuticals

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that may slow the decline of cognitive function and (2) the development of approaches to best care for persons with AD who suffer from extreme cognitive decline and disability. Developing methods for early diagnosis of AD are of critical importance to provide maximum opportunities for both existing and any future therapies to have the best chance of success.

A recent review outlines the present pharmaceutical treatment options for AD that are currently in use.[1] These drugs are commonly used to treat the signs and symptoms of AD: Donepezil, Rivastigmine, and Galantamine (all Choinesterase inhibitors), and Memantine (a NMDA-receptor antagonist). Such treatment is currently the standard of care for the disease. Other pharmaceuticals are used to treat neuophychiatric symptoms and behavioral disturbances of the disease, such as depression, psychosis, and anxiety.[1] Development of new pharmaceutical agents is an area of intense interest for all parties—for physicians, patients, and families who want an effective therapy to address the underlying mechanisms of the disease or to better treat symptoms, and for pharmaceutical companies who understand the large market for persons with AD and dementia, generally. In short, there are few therapies available to address AD, and most efforts are spent trying to best manage symptoms, treat comorbid illness, and help families deal with the disability of their loved one.

"Twenty-five years from now, 35% of the state's population will be age 50 or older; hence dealing with AD will become an increasingly important issue in North Carolina."

There are hopes that future therapies will be more effective at either forestalling cognitive decline or perhaps even reversing dementia. For existing pharmaceutical therapies, as well as future ones, early diagnosis of AD seems to be a key to maximizing the benefit of both current and potential approaches. Conclusive diagnosis of AD is only possible through a post-mortem autopsy. Prospectively, the diagnosis of AD is made when persons meet standard criteria for the diagnosis and have no other plausible explanations for their observed dementia.[1] The primary advances in diagnosis over the past two decades have been (1) the adoption of standard criteria for diagnosis, (2) an understanding by the medical community and the population in general that dementia, and AD in particular, is a disease and not a normal part of the aging process, and (3) the development of more advanced imaging techniques that are useful for diagnosis. In particular, the decision of the Medicare program to finance the use of Magnetic Resonance Imaging (MRI) scans for diagnosing AD, and more recently covering PET Positron Emission Tomography (PET) scanning for the same purpose, may yield more precise and potentially earlier diagnoses of AD. However, it is important to note that the use of a PET scan is not generally considered to be necessary for the diagnosis of AD, and Medicare will only cover PET scans in complex cases where a cognitive decline is noted, but a diagnosis of AD can not otherwise be easily made. The development of new pharmaceuticals or other therapeutic approaches to either slow or reverse dementia associated with AD will increase pressure to diagnose the disease as early as possible, so new therapies and diagnostic procedures are likely to develop hand-in-hand.

There are non-medical treatment options designed to aid in the care of persons with AD, including placement of individuals in dementia care units that are long-term care facilities designed specifically to provide care for those suffering from AD and other dementias. This treatment is probably best understood as a means of dealing with the effects of AD in the most efficacious manner possible and doing so in a way that helps reduce the caregiving stress and burden on spouses and/or families of loved ones with AD. In reality, most persons with AD are living and being cared for in community settings. Families tend to seek institutional settings such as nursing homes/dementia care units for the care of their loved ones with AD when the difficulty, strain, and burden of caring for the patient in a community setting becomes too difficult. There are a variety of negative effects of caregiving for persons with AD that have been well-documented in the literature. A clearer understanding of these negative effects as well as the aging of the population with respect to the number of working-age persons for each person age 65 and over should lead to a societal discussion about the most appropriate manner in which to care for persons with AD and other sources of age-related disability.

Extent of Alzheimer's Disease in North Carolina

The population of North Carolina is rapidly growing, with tremendous increases among both working age persons as well as retirees. The state is getting older, like the rest of the United States; the North Carolina median age rose from 33.0 in 1990 to 35.3 in 2000, and will increase to 38 by the year 2030.[27] During the 1990s, the proportion of the North Carolina population at highest risk of AD, those 85 and older, increased by 53% (from 69,000 to 105,000 persons).[27] At present, 28% of North Carolinians are age 50 or older, which means that they are either at substantial risk of developing AD or will be at-risk within 10-15 years. Twenty-five years from now, 35% of the state's population will be age 50 or older; hence dealing with AD will become an increasingly important issue in North Carolina.[27] AD is the seventh leading cause of death in North Carolina at 27.7 per 100,000 (age-adjusted) population,[28] and was the primary cause of death in 4,996 deaths from 1999-2001.[27] The state's number of nursing home residents (all ages) per 1,000 persons age 85 and older in 2001 was 322.6, compared to 317.5 for the United States as a whole.[27]

Similarly, nursing home occupancy rates for North Carolina were 88% compared to 82.4% nationally.[27] As noted earlier, over half of nursing home residents suffer from AD or other dementias, but most persons with AD live in community settings.

Conceptualizing the Cost of Alzheimer's Disease

AD has a broad effect on American society, and discussion of the disease has ceased being only a clinical topic and become a part of the cultural dialogue of the United States. It is useful to distinguish three distinct perspectives of cost and burden when considering AD. Cost need not imply monetized cost estimates, but could. The first cost perspective is the private or individual level that encompasses the cost experienced by the person with AD. The second level is what can be called quasi-external costs, notably the costs borne by spouses and/or other family members who are engaged in caring for a person with AD. Taken together, the individual and the quasi-external costs could be viewed as a unified household perspective, but they are separately identified here because the preferences, potential costs, and wellbeing of all members of the household are not likely to be identical when choosing a particular way to care for a person with AD. Finally, there is the purely external cost, or the cost of AD to persons outside of the household. This perspective is largely comprised by the effect of AD on programs, such as Medicare and Medicaid, and any additional costs borne by others outside of the household experiencing AD, such as lost work productivity for companies whose employees are caring for a parent with AD. It is necessary to consider the private, quasi-external, and external perspectives to fully understand the social cost of AD on the larger society. Considering these different perspectives is useful because it illustrates that using one to the exclusion of the others provides an incomplete understanding of the cost of AD and may lead to suboptimal policy.

Private Costs of Alzheimer's Disease

AD most directly and profoundly affects persons who are stricken with the disease. Such persons have their lifespan shortened. Prior to death they suffer from a tremendous morbidity burden that greatly diminishes their quality of life. After onset of the disease, persons generally suffer from impaired memory, lose the ability to communicate via spoken language and otherwise, and become unable to complete executive functions. As the disease progresses they may suffer from sensory problems, lose their ability to walk normally, and may suffer from seizures later in the course of the disease. Higher-level functioning is lost as the clinical symptoms progress, resulting in the inability to complete Instrumental Activities of Daily Living (IADLs) such as driving, shopping, cooking, maintaining personal records, and the ability to appropriately take medicines. Further decline results in the loss of ability to complete Basic Activities of Daily Living (BADLs), such as dressing, bathing, going to the toilet, and eating. Behavioral disturbances, such as wandering, outbursts of anger, or an increase in socially inappropriate actions (e.g, disrobing in public places), can onset across different phases of the disease progression, and psychotic behavior and extreme agitation often come during later phases of the disease. The private costs of AD are profound, and the development of therapies, such as pharmaceuticals, aim to ease the burden of the disease on persons afflicted with AD.

Quasi-External Cost of Alzheimer's Disease

Quasi-external costs are those borne by persons other than the patient in either the immediate (spouse) or inter-generational household (e.g., adult children, siblings of the afflicted). The primary cost is the magnitude of informal caregiving that persons are likely to provide to a family member with AD. This care is not static, but increases steadily throughout the disease course. A past estimate of the cost of informal caregiving in the United States found that their costs ranged from $117-$292 billion (1998 dollars), depending upon the assumptions about the hourly price used in the calculation.[29] This estimate showed the cost of informal caregiving to be larger than the total spent on nursing homes in the same year, in spite of the fact that it represented a replacement-cost estimate (how much it would cost to replace informal care with paid care) and assigned a value of zero to the well-known negative effects of caregiving on the health, emotional, and financial status of caregivers. In short, the quasi-external costs of AD are staggering.

The informal caregiving cost estimate noted above was for all caregiving, not only that provided to persons with Alzheimer's disease. However, there is reason to expect that caring for persons with AD and other dementias is a large contributor to this total and is more burdensome on a per-case basis than caregiving for persons with other diseases and ailments. Most persons with AD are being cared for in non-institutional settings in the community. A recent annual estimate of the cost of providing care for a person with dementia was $18,395 in 1998.[30] The two largest sources of cost were caregiver time ($6,295/year) and lost earnings ($10,709/year) due to reductions in market work in order to provide care. A recent paper illustrated that Medicare-financed care represented less than half of the total cost of dementia care,[31] illustrating that ignoring the quasi-external perspective in favor of the external perspective only (e.g., cost to the Medicare program) gives a skewed view of the burden of the disease on society as a whole (i.e., the social cost of the disease).

The other major source of quasi-external costs are the physical, emotional, and financial harm that befalls caregivers of persons with AD. Caregiving for a person with dementia has been found to be more deleterious to the caregivers' health than is caregiving for a family member with cancer across a variety of domains, including stress, depression, isolation, and delay in the seeking of medical care by the caregiver him/herself.[32] More recent work has shown that dementia caregivers provide more care and suffer great self-reported strain, mental and physical problems, and family conflict linked to the care of their loved one than do persons caring for persons afflicted with other diseases.[30] Caregiving and perceived stress in this role has even been found to increase mortality among caregivers.[33] Such costs need not be monetized to demonstrate that the quasi-external cost of AD is immense.

Spouses and adult children typically suffer financial strain due to caregiving. This is shown through the reduction of market work, out-of-pocket payments for house modifications to aid with caregiving, and interruptions of the retirement savings of adult children. While some studies document the lost wages associated with caregiving as a cost of AD,[30] this review did not identify estimates of the effect of reduced contributions to retirement plans, and what effect such a reduction could ultimately have on either retirement decisions (timing) or the amount of retirement savings. This effect would most likely be seen through reduced private savings through vehicles such as 401-K or 403-B retirement plans. This issue could be of great consequence, since caregiving may interrupt the retirement savings of persons who are likely to be in their highest wage-earning years (50-somethings caring for their 70- and 80-something parents). Interruptions or decreases in retirement savings are not easily made up, even through accelerated contributions at a later date, given the effect of the compounding interest principle. Reduced retirement savings could also be viewed as an external cost to the Medicaid program as a person with reduced savings could be expected to "spend down" to Medicaid eligibility levels sooner than would a person with more retirement assets (see below).

Other quasi-external effects of AD are not as tangible, nor are they easily monetized. For example, the loss of grandchildren being able to interact with and learn from their grandparent with dementia is easily understood as a "cost" in the most general sense, but assigning an economic value to such a cost is difficult. AD robs younger members of the inter-generational household from being able to learn from the wisdom and experience of the older members.

External Costs of Alzheimer's Disease

External costs are those costs that are neither private nor quasi-external. These are costs borne by society, defined as persons outside of the inter-generational household. A very common perspective when considering the external cost of AD, is the impact of the disease on a program such as Medicare. Recent work shows that persons who are diagnosed with AD cost the Medicare program around 60% more per year compared to a similar beneficiary (in terms of age, gender, and disability level) who does not have such as diagnosis.[34] However, the time path of the cost effect is complex. Costs increase in the year that AD is first noted in Medicare claims. As the disease progresses, the cost effect reduces, eventually falling below average per-beneficiary costs, suggesting a reduced propensity to use Medicare-financed healthcare services at more advanced stages of the disease. Further, there is some evidence that the presence of AD may influence the manner in which an acute medical condition may be treated. For example, a heart attack may be treated less aggressively for a person with AD compared to one who does not have AD. Thus, a precise estimate of the effect of AD on the Medicare program would need to account for several types of effects: the costs of diagnosis that would be expected to increase costs; the morbidity burden associated with AD that would be expected to increase costs; the effect of disease stage on the propensity to use formal medical care, which likely declines as the disease progresses; and the fact that some illnesses may be treated less aggressively given the presence of AD, which would be expected to reduce costs. While it seems certain that the presence of AD results in higher Medicare program costs, the mechanisms underlying such increases are more difficult to measure precisely, and are best considered longitudinally and not in cross-section, as is most easily done. A future issue with respect to Medicare costs is the impact of the prescription drug plans developed through the Medicare Modernization Act of 2003, which will be in place in 2006. It is not clear if existing or future drugs designed to treat AD and/or symptoms of AD will be routinely included in plan formularies.

The Medicaid program serves as a de facto nursing home insurance scheme for the entire United States, with the deductible essentially being non-housing wealth. The Medicaid program pays for approximately 40% of the national nursing home bill.[35] And given that over half the persons living in nursing homes suffer from AD or a related form of dementia, it is clear that the effect of AD on state Medicaid programs is large. The Medicaid program is also involved in financing acute medical services, but for persons age 65 and over who are both Medicare and Medicaid beneficiaries ("dual eligibles"), the Medicare program is the primary payor for acute care. For this reason, the burden of AD on the acute-care expenditures of state Medicaid programs would be expected to be modest.

The effect of AD on Social Security is more ambiguous. Social Security is an inherently more simple program than Medicare in that it simply provides cash payments to a person age 65 and over and therefore doesn't have the uncertainty of medical innovations, the propensity to seek medical care, and the unit price of services that Medicare faces. A recent book on the cost of smoking to society points out that smokers actually cross-subsidize non-smokers with respect to Social Security in that they contribute through the payroll tax over the course of their life at similar rates to non-smokers, but die substantially earlier.[36] This means they take out less than they put into the Social Security system. A similar analysis could be undertaken for persons who later develop AD—comparing what those with AD contribute versus what they receive in benefits. But it seems that persons living to an older age and developing AD prior to death are precisely the type of persons who are being cross-subsidized by smokers and others who die either prior to retirement age or relatively soon after the receipt of Social Security retirement benefits (age 62 or 65 depending upon the choice of the individual). Thus, it seems that persons with AD are likely to be among the persons who will cost the Social Security program relatively more over the course of their lifetimes.

Social Cost and Next Steps

The social cost perspective takes account of all aspects of cost and burden of AD—private, quasi-external, and external. Excluding one type of cost will result in an incomplete understanding of the cost of AD to society and may result in an under-investment in strategies to address the cost of AD. A complete understanding of social costs can also help identify areas in which policy attention is warranted, but which may not often garner much attention. The point of this Issue Brief is not to produce an estimate of the social cost of AD, but instead to identify the different types of costs and policy considerations that emerge from doing so.

In the case of AD, both the private and external cost perspectives have generated much (warranted) attention. The burden suffered by individuals with AD is immense, and it is clearly a societal priority to develop improved means of treating AD and/or symptoms of the disease. Pharmaceutical companies and clinical researchers will continue to seek new treatments and more effective ways to diagnose AD earlier, which is likely a precursor to any effective treatment.

Likewise, the external cost perspective has received a great deal of attention in recent years as researchers and policy makers worry about the effect of AD on the future solvency of programs such as Medicare and Medicaid. Identifying the cost burden of AD on such programs is a legitimate endeavor, but it is not clear what such estimates can do other than underscore the seriousness of AD and its current and potential impact on the system. It is not clear that there are many left who need to be convinced. However, there is a need for conceptual clarity about what is being measured in such work. Are the costs of persons *with AD* of interest? Obviously, some of them also have heart disease and cancer as well. Or, is it more important to focus on the cost of *AD per se*? In other words, are we measuring the cost of treating a person with AD compared to what it would have been otherwise? While related, these two external cost perspectives are not identical, and they should be kept separate. The answer may not be that important, given that the Medicare program will have to finance acute care for such persons in any event.

The area in which there is too little policy concern is in identifying and responding to the quasi-external costs associated with AD. A body of research literature exists that documents the physical, emotional, and economic effects on a family caring for a person with AD, but there has not been a serious national or state discussion around what to do about it. This is an area needing focused discussion around the issue of how will persons with AD be cared for and whose responsibility will it be? While the hope for future pharmaceutical agents to address the processes of the disease itself is real, so is the fact that several million people are likely to live through and die with or from AD before such therapies are developed. Their families will be left primarily to deal with the effects of the disease on their loved ones. Therefore, a top priority should be to directly address the issue of informal caregiving and determine how society views it. Currently, we have made the policy decision by not addressing the issue head-on. As life expectancy has continued to rise and the proportion of the population that is retired compared to those who are working is also rising, we can no longer afford to avoid directly addressing this issue.

Policy Options: The Case of Germany and Japan

Two nations (Germany and Japan) have recently adopted long-term care financing strategies that are instructive for outlining some of the key issues related to how to care for persons with AD in the absence of any pharmaceutical or other therapy that drastically slows cognitive decline and/or improves functioning. It is important to note that the magnitude of the aging of the population is greater in both Germany and Japan than in the United States, so the situation we face is not unique. While the need to address population aging issues and long-term care is similar in Germany and Japan, their respective approaches are fairly different. Their differences provide food-for-thought for considering how AD might best be cared for in the United States context.

Germany[37] has developed a voucher-based approach whereby persons are eligible for a fixed subsidy based on their level of disability, regardless of age. The voucher amount is not expected to pay for the full cost of market-provided long-term care (such as a nursing home or home health), and families are responsible for the rest unless they are totally impoverished. The most innovative aspect of the German system is the ability for families to continue providing long-term care services in the community and to "cash out" their voucher for money to be used to defray the cost of caring for their loved one. The cash-out value is approximately two-thirds of the voucher amount, providing a cost-savings for government when families choose to provide care informally. The German approach to determining eligibility has been criticized as being too simplistic (it places people in very broad categories based on ADL limitations) and does not take direct account of the extent of cognition/dementia. It has generally been affirmed for identifying family-provided care as the preference of large segments of German society and moving through policy to make such care more sustainable—basically by identifying quasi-external costs as worthy of policy action.

The Japanese approach is quite different.[38] Whereas Germany has sought to continue giving emphasis to a system based on family-provided long-term care, Japan has moved to aggressively increase the supply of formally-provided long-term care services with the explicit purpose of reducing the reliance upon informal care. The political discussion of the Japanese long-term care system was euphemistically known as "the daughter-in-law bill." This highlights concern among political elites that gender equity issues were particularly acute in the area of long-term care, in the nation with the longest life expectancy in the world. The Japanese approach also differs from Germany in having a very detailed disability assessment approach that categorizes persons on numerous metrics, including the extent of dementia/cognition. Further, age is an explicit aspect of benefit determination, with those age 65+ presumed to qualify, but those age 40-64 are also able to qualify if they suffer disability due to an "age-related" condition.

Table 1.
Useful Information on Alzheimer's Disease and Long-Term Care for North Carolinians

Organization	Contact Information
Alzheimer's Association	800-272-3900 or www.alz.org (National) 800-888-6671 (North Carolina – Western/Piedmont Chapter) 800-228-8738 (North Carolina – Eastern North Carolina Chapter)
North Carolina Department of Insurance	http://www.ncdoi.com/
The Seniors' Health Insurance Information Program (SHIIP)	http://www.ncdoi.com/consumer/shiip/shiipwhat.asp 800-443-9354 (in state only) or 919 733-0111
North Carolina State Employees Health Plan Long-term Care Insurance Option	http://www.ncdoi.com/home/pdf/SHP_LTC.pdf
North Carolina Division on Aging	919-733-0440 or www.dhhs.state.nc.us/aging
Duke Alzheimer's Family Support Program	800-522-2451
North Carolina Area Agencies on Aging	www.dhhs.state.nc.us/aging/aaa/htm
North Carolina Regional Long-term Care Ombudsman	www.dhhs.state.nc.us/aging/ombud.htm

Adapted from Seniors' Health Insurance Information Program (SHIIP) materials.

The Policy Questions Ahead

These two approaches raise a series of questions that are useful for considering how to appropriately care for persons with AD. The questions are important even though it is unlikely that the United States would seriously consider a social insurance response to the provision of long-term care at any point in the foreseeable future.

First, given that family-provided care in the community is likely to remain the preference for many, is public policy intervention (e.g., public money) acceptable to defray the costs of such care?

Second, in determining eligibility of services/subsidies for long-term care for persons with AD, how will eligibility for services be determined? There is generally a trade-off between simple assessment (Germany), which is relatively cheap, and more precise assessment (Japan) that includes more data on a larger proportion of program costs on administration.

Third, what is of paramount importance in determining the best setting in which to care for a person with AD—the patient with AD or the caregiver(s)? This is another way of asking whether it is the role of the family to care for persons with AD or the family in conjunction with society as a whole.

There are certainly other questions that can be asked, but these are key ones to discuss and answer if the United States is going to more directly consider the quasi-external costs of AD.

What Policy Options Are Available for North Carolina?

Answering the questions posed above with respect to how to conceptualize the cost of AD and how such costs should be borne are prerequisites for good policy. A national discussion and approach are needed to prepare the United States for the coming increases in persons with AD, but this is likely to require a long-term discussion. At present, most acute care is financed by the Medicare program, and families provide most of the caregiving, with the Medicaid program financing nursing home stays of persons with AD after the point of personal spend down. Large-scale changes in this mix seem unlikely, and the development of a long-term care financing scheme based on social insurance principles similar to Germany or Japan's is not likely in the near future. Given this backdrop, North Carolina has two primary means of addressing the AD situation, long-term care insurance regulation and alterations of the state Medicaid program with respect to eligibility for nursing home and other services for persons with AD. Expanding Medicaid, while a possibility, seems unlikely given the fiscal situation of the state, so the remainder of this Issue Brief discusses long-term care insurance in North Carolina.

Long-term care insurance is often noted as a key to preparing for the aging of society and dealing with increased numbers of persons with AD and fewer workers to help support same. If North Carolina could develop policies that would lead to the expanded purchase of such insurance it would be helpful in dealing with AD. However, determining how to expand such coverage is not clear. Private long-term care insurance enrollment rates are very low, around 5% of the population.*

Insurance is commonly used to spread the risk of potentially large and catastrophic losses when the occurrence of loss is unpredictable, but plausible. If a potential loss is very small, individuals don't bother with insurance. If the likelihood of a loss is extremely small, then likewise, they do not bother with

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* Note: Among North Carolina's state employees and teachers, only 2,700 State Health Plan members subscribed to a long-term care group insurance plan offered to more than 550,000 plan members in 2004.

insurance. When potential losses are large and the likelihood of occurrence is more common, then a market for insurance is more likely to develop. Long-term care clearly fits the description of a potentially catastrophic cost that is fairly common, yet the market for private insurance is very small. Why is this the case? There are several possibilities.

The public may fully understand the risks associated with needing long-term care due to AD, and most may choose to self-insure via family caregiving, turning to Medicaid via spend down if necessary. Arguing against this conclusion is the myopia of many persons in thinking about long-term care.

Long-term care insurance may simply be too expensive for many persons, hence the low rates of coverage. It is also possible that many North Carolinians have not thought clearly about long-term care insurance (myopia), but would choose not to purchase it even if they did because of its cost. For example, the median wealth of households headed by persons age 70 and older across the nation in 1998 was around $35,000 according to the Asset and Health Dynamics among the Oldest Old (AHEAD) database, a nationally representative survey of elders. At such low rates of wealth (less than the cost of one year in a nursing home), long-term care insurance is neither affordable, nor reasonable, from a wealth-protection perspective. The North Carolina Department of Insurance consumer guidelines for the purchase of long-term care insurance advises persons with less than $100,000 of wealth (excluding their house, which is generally exempt from Medicaid spend down rules) against the purchase of such insurance. According to the AHEAD survey, persons at the 80th percentile of overall wealth had just $60,000 of non-housing wealth, on average, meaning that no more than 15% of the population might be expected to reasonably purchase long-term care insurance using the North Carolina Department of Insurance's conservative guidelines. Long-term care insurance can offer protection against catastrophic costs and can provide some control in where and how a person with AD receives care, but the vast majority of North Carolinians can't afford such coverage.

Long-term care insurance premiums are cheaper if purchased at a younger age. Persons who begin thinking about their need for long-term care in their 40s and 50s will therefore get a lower premium than will persons who purchase policies in later years. However, there is a subtle risk in purchasing long-term care insurance at younger ages due to the nature of the insurance products that are currently offered in the state of North Carolina (and in other states). Long-term care benefits are denominated in dollars per day, as opposed to care required, as is the case with major medical insurance. A 40-year-old purchasing a policy will most likely not use a long-term care insurance benefit for 30+ years. Even with a 5% annual inflation rider on a policy, which is the most common inflation protection chosen by consumers (policies sold in North Carolina must offer one of three types of inflation protection), the purchasing value of a policy will be substantially less than when enrollment occured if long-term care costs rise at just 5.1% annually for 30 or 40 years. Paradoxically, long-term care insurance purchased at younger ages provides lower premiums, more uncertainty with respect to what you are actually purchasing given the age at which most persons with AD need care, and perhaps a sense of unwarranted security.

There are at least two other motivations other than asset protection for purchasing long-term care insurance—control over some aspect of future care needs uncertainty and protecting family members from having to provide care. Long-term care insurance provides control over where long-term care is received and affords an individual the maximum amount of choice in receiving such care. In addition, long-term care insurance can prevent family members from having to provide care if needed. While many families may prefer to provide long-term care informally, others may explicitly not want to take this route for a variety of reasons, including the negative effect that caregiving has been shown to have on many caregivers. However, in order to act upon such motivations, an individual or family must have the financial resources necessary to afford such policies.

In the end, it is likely that only 15% or less of middle-aged or elderly persons in North Carolina might conceivably purchase long-term care insurance, based on wealth and income levels necessary to afford such a policy. The state Department of Insurance has some excellent materials on its Website, www.ncshiip.com, to guide consumers in considering whether or not to purchase long-term care insurance. The biggest advancement would be for more long-term care insurance policies to be denominated in terms of care provided, instead of dollars per day. In this way, the time/risk uncertainty involved with purchasing policies at younger ages when premiums are lower would be reduced.

AD is a large and growing concern for the people of North Carolina and the nation as the cost of this disease for society is enormous. Future advances in diagnosis and treatment are hoped for, but the fruition of same is uncertain. In the meantime, society must more clearly understand the costs of AD, and particularly the degree to which a large portion is borne by the intergenerational household of those affected with the disease. A societal discussion is needed to determine whether we will continue to let the epidemiology of the disease spread this part of the burden or whether society would be better served to develop a direct means of spreading these costs in a more systematic manner. Such discussions are needed every bit as much as research designed to develop new treatments for AD. State-level experimentation is often the preferred approach to tackling difficult policy issues. What will North Carolina do? **NCMJ**

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The Alzheimer's Association National Policy Agenda

Bonnie Hogue Duffy, MA

The evidence presented in Donald Taylor's Issue Brief is a compelling call for action.[1] The Alzheimer's Association has a plan that includes a major mobilization of people and significant new resources. The Association is prepared to lead the fight, but the nation needs the leadership of the President and the Congress as well. We call upon Congress and the Administration to take action in three key areas:

(1) Increase funding for Alzheimer's research at the National Institutes of Health (NIH) to $1 billion annually as quickly as possible;
(2) Protect Medicaid funding levels and improve quality of long-term care; and,
(3) Implement the new Medicare Modernization Act in ways that meet the needs of people with Alzheimer's disease and improve the Medicare program so that it better meets the needs of people with dementia and other chronic conditions.

Research Funding

In 1983, when President Ronald Reagan first designated November as National Alzheimer's Disease Month, the extent of the disease was not widely known. At that time, a definitive diagnosis could be confirmed only via an autopsy and there was no infrastructure for Alzheimer's research. Twenty years of investment in research through NIH has resulted in steady scientific progress and advances no one would have imagined in 1983. We are well into an era of discovery that has already brought us tangible benefits.

It is now possible to diagnose Alzheimer's with more than 90% accuracy. Understanding of the fundamental neurobiology of the disease and its impact on the brain is developing rapidly. Identification of potential points of therapeutic intervention has accelerated the search for new treatments. Several animal models mimicking some aspects of the disease are available to researchers, enabling scientists to narrow the targets for prevention and speed effective drugs to market. Five prescription medicines specifically approved to treat Alzheimer's are available in pharmacies. Three genes that cause rare, early-onset forms of the disease, and one risk gene for the more common, late-onset form, have been identified.

Current research is focused on the importance of identifying and treating Alzheimer's disease at much earlier stages, before the symptoms of the disease emerge. Additional strategies for slowing the progression of the disease process—to postpone onset of and hopefully prevent full-blown Alzheimer's—are under investigation. Advanced technologies, including neuroimaging techniques such as magnetic resonance imaging (MRI), functional MRI, and positron emission tomography (PET) are expanding possibilities for early detection and intervention.

The best treatment, for individuals, for the healthcare system and for the public health system, is prevention. If science could delay the onset of Alzheimer's by even five years, the number of individuals with the disease could be reduced by as much as 50% over time. The key to realizing a future without Alzheimer's disease is finding a way to prevent the disease. Scientists are closing in on this goal because of the past investment in research by the federal government, private funders like the Alzheimer's Association, and the pharmaceutical industry.

To ensure that rapid progress continues, additional resources are needed in all sectors, but especially at the NIH. If current federal funding for Alzheimer's research were increased to $1 billion annually, substantial progress could be made on the most promising leads in basic science, risk factors, early markers, and clinical trials to develop new treatments and prevention.

> *"If science could delay the onset of Alzheimer's by even five years, the number of individuals with the disease could be reduced by as much as 50% over time."*

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The National Institute on Aging (NIA) has undertaken two promising efforts, among many others, on genetics and imaging. While we maintain hope about our ability to slow the progression of and one day prevent Alzheimer's disease, we must also invest in research that will speed the discovery of risk-factor genes for late-onset Alzheimer's, the most common form of the disease. Discovery of risk-factor genes will help illuminate the underlying processes of Alzheimer's disease, open up novel areas of research, and identify new targets for drug therapy. NIA and the Alzheimer's Association are in the process of recruiting at least 1,000 families over the next three years to create the nation's largest repository of genetic material from families affected by late-onset Alzheimer's disease.

NIA, in partnership with the pharmaceutical industry, the Alzheimer's Association and the Food and Drug Administration (FDA), is also engaged in a new initiative using imaging technologies to monitor changes in the brain that indicate progression of Alzheimer's disease and to provide accurate, early diagnosis. We are hopeful that this initiative will lead to better diagnostic techniques. More importantly, the imaging initiative may help speed up the process of discovering new, more effective treatments and preventive agents for Alzheimer's disease by allowing scientists to detect the effects of interventions on brain function much more quickly than traditional clinical trials without the use of imaging.

> *"Twenty years of investment in research through NIH has resulted in steady scientific progress and advances no one would have imagined in 1983. We are well into an era of discovery that has already brought us tangible benefits."*

A significant, immediate investment in Alzheimer's research could save lives and money. Increasing funding for Alzheimer's research will increase the pace of discoveries that can delay the onset of the disease and slow its progression. If annual research funding of $1 billion for the next five years resulted in modest delays in onset and slowing of progression of AD by 2010, the return on investment in 2015 could be as high as $13 for each federal dollar spent on research. By 2025 the return could be as high as $28 to $1 and by 2050 it could be $100 to $1. Under this scenario, annual Medicare savings could reach $51 billion and saving in Medicaid spending on nursing home care could be $10 billion by 2015.[2]

Only Congress and the President, through a significant addition of new funding, can assure that we realize the opportunities in Alzheimer's research. Minimal increases in funding for the NIH are not enough to support additional clinical trials and maintain the momentum of basic scientific discovery. Inadequate funding increases mean that less money will be available to support new research grants and clinical trials, delaying scientific discoveries, and resulting in lost opportunities.

Medicare

Because of their impaired memory, judgment, and reasoning ability, Medicare beneficiaries with advanced Alzheimer's disease or other dementias cannot completely manage or direct their own care. As Alzheimer's progresses, individuals with the disease cannot follow the medication instructions or nutritional regimes prescribed by their doctors, nor can they recognize symptoms that their condition may be getting out of control. Individuals with dementia need ongoing care management to monitor their health status and prevent the acute care crises that are driving up Medicare costs today.

Alzheimer's disease is a major contributor to rising Medicare costs. Ninety-five percent of all beneficiaries with dementia have at least one other chronic health condition common in the elderly —30% have coronary heart disease, 28% have congestive heart failure, and 21% have diabetes. Medicare costs for beneficiaries with dementia and other chronic conditions such as coronary heart disease, congestive heart failure, or diabetes are twice as high as costs for beneficiaries with chronic conditions who do not have dementia.

One of the most effective ways to restructure Medicare in the short term is to establish a care coordination benefit targeted to individuals with complex chronic conditions, including Alzheimer's or other dementia. A Medicare chronic care benefit should include: payments to the beneficiary's primary healthcare provider for an initial assessment of health status; development of a coordinated care plan; and care management activities including coordination of clinical care across providers, medication management, multidisciplinary care conferences, and ongoing consultation with the beneficiary and his/her caregivers.

Care coordination is very different from disease management programs that focus on managing only one aspect of an individual's overall health status at a time. Care coordination focuses on managing an individual's care needs across various healthcare settings and among different providers to avoid adverse medical events exacerbated by the presence of multiple chronic conditions.

Passage of the *Medicare Prescription Drug & Modernization Act* will, for the first time, provide Medicare beneficiaries with Alzheimer's disease critically needed coverage for prescription drugs. This is an historic accomplishment that provides both up-front and catastrophic coverage of prescription drugs and offers subsidies to help protect low-income Medicare beneficiaries. The Alzheimer's Association believes that the addition of the prescription drug benefit moves the Medicare program in the right direction. The Alzheimer's Association, however, will be vigilant in overseeing the implementation of this new benefit in an effort to make sure this benefit meets the needs of people with Alzheimer's disease.

Medicaid

Medicaid is the single largest public payer for long-term care services in the United States and a last resort for persons with Alzheimer's who have no other way to pay for the help they need. Half of all Medicare beneficiaries with Alzheimer's also received Medicaid to help pay for long-term care, prescription drugs and other medical care because they have exhausted their own resources and qualify for assistance. In 2000, Medicaid spent an estimated $19 billion on nursing home care for people with Alzheimer's. Medicaid nursing home expenditures for persons with Alzheimer's are projected to rise to $118 billion by 2050—a more than six-fold increase over current spending.[2]

In the absence of a better national long-term care program, Congress and the President must preserve the long-term care safety net that Medicaid provides. This includes maintaining or improving the federal entitlement to benefits, and preserving existing nursing home quality standards as well as protections against spousal impoverishment. Reform proposals that cap Medicaid funding as a method of giving states more flexibility regarding benefits and services will leave many of society's most vulnerable citizens in jeopardy.

Conclusion

Without a cure, the number of Americans with Alzheimer's—4.5 million today—will increase to between 11.2 million and 16 million by 2050. Without a cure, the incalculable human costs will continue to rise—the pain of seeing loved ones suffer and the lost contributions of millions of older Americans who would otherwise enrich us as a people. The time to act is now.

There is real hope for a future without Alzheimer's disease. Greater understanding of the disease, improved care and treatment, and unprecedented scientific opportunities for delaying onset and preventing the disease can all lead to a future where Alzheimer's is just a memory. By investing in Alzheimer's research, President Bush and Congress can ensure that the scientific opportunities that lie before us are realized. And by improving the Medicare and Medicaid programs, Congress will help the 4.5 million people living with Alzheimer's get the care they need. **NCMJ**

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SPECIAL INTERVIEW

Alzheimer's and the Caregiver

Donald L. Madison, MD (with Myron H. Green)

Sadie Green's eyes are closed. She chews, swallows, and opens her mouth when her husband brings another forkful of syrup-soaked pancake near it. She chews each mouthful eagerly, the way anyone who likes pancakes and syrup would. But she doesn't otherwise respond; and her eyes stay closed, as they have for the better part of the past year.

She is 72 and has Alzheimer's disease, a malady named for the German psychiatrist, Alois Alzheimer, who in 1906 first described the characteristic changes in the brain tissue of a woman who had died of an unusual kind of mental illness.

Sadie also has Parkinson's disease, another "named for" malady, this one after the English general practitioner (and social reformer and political activist) James Parkinson. Parkinson described the disease in his "Essay on the Shaking Palsy" (1817), which is a model of the kind of detailed clinical description that made up so much of the medical literature of his time (and would for another 100 years).

Unlike Alzheimer, who observed a single patient's clinical course and later correlated it with the morbid anatomy of her brain, Parkinson relied on the clarity of his description of six clinical cases. And because his description seemed fresh and new to the medical profession, it commanded their attention. Sixty years later, the French neurologist Jean-Martin Charcot applied the name *la maladie de Parkinson*. And that is what we call it still today.

Parkinson said that the disease leaves the "senses and intellect... uninjured," even though some of his case histories revealed mental disturbance. (It is now believed that up to one-half of Parkinson's disease patients show mild to moderate dementia.) Perhaps Parkinson allowed this discrepancy to stand because he wished to emphasize that the dominant characteristic of the "Shaking Palsy" was the impairment of an involuntary function. Both Alzheimer's and Parkinson's result from degeneration of the brain—the cortex (the outermost region) and the sub-cortex. Alzheimer's is thought to affect the cortex primarily, and Parkinson's the sub-cortex primarily. But, since both diseases may affect both areas, it is usually presumed that the patient has Alzheimer's when the dominant symptoms represent defects of cognition; and when the dominant symptoms refer mainly to involuntary functions (but the patient at the same time shows defects of cognition), the diagnosis is Parkinson's Dementia.

"Presumed" is the key verb here; because both Alzheimer's and Parkinson's are presumptive diagnoses, which are confirmed only by examining the brain tissue in much the same way Dr. Alzheimer did in his laboratory in Munich. The recognizable behavior and clinical course of Alzheimer's are presumed to be accompanied by—and caused by—the characteristic amyloid plaques and neurofibrillary tangles in the cortex of the brain. But if they are not, it matters little to those who must provide the care. The criteria set down by those who first describe a disease, name it, or alter the understanding of it from later experience and investigation, are not so important to the "consumers" of the disease. Their experiences consist mainly of a gradual loss of function in the case of the patient, or in the case of the caregiver, of the work—the daily mundane routine—of nursing. Therefore, while the question of whether Sadie Green has Alzheimer's Disease or Parkinson's Dementia may be important to sticklers for correct clinical nomenclature and pathological criteria, it isn't nearly so important to Pete Green, her husband and caregiver. For once it is known that her illness is chronic, and that it is some variety of what used to be called "senile dementia" or "organic brain syndrome"—it doesn't matter much which variety it is—not to Pete, whose goal is to give comfort, not to cure.

Myron "Pete" Green grew up on the north side of Pittsburgh, the next to youngest of six children in a working class family. His parents did not name him "Pete." That familiar name was the result of a mispronunciation (by a toddler sibling) that stuck. Pete's mother kept house; his father worked for Jones and Laughlin Steel as a locomotive engineer on the company-owned "short line" that hauled steel between mills. (J&L operated on both sides of the Monongahela River in the south Pittsburgh area and a company railroad bridge spanned the River.) Following high school, Pete enrolled in the local north side college—Duquesne University—intending to

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work toward a business degree. Sadie also grew up on Pittsburgh's north side. The two met one rainy night in a north side restaurant, where Sadie's sister was working as a waitress. Pete remembers:

> I knew her sister well, because most of us guys loafed in this restaurant. And I just happened to come in that evening. And her sister said that she was glad that I'd showed up because her daughter had been out shopping with her sister (Sadie) when it started to rain very hard, and they were stuck in the restaurant and needed a ride home. That would have been in 1953. We were married two years later, in February of '55. She's two years older than I am.

After they married, Pete dropped out of school.

> I had to get a job. After the first child came I got a second job, working part-time. And then when the second child came, I was able to get a job with an insurance firm; and they would help pay for my education as an insurance sales agent if I would take advantage of it, which I did. Eventually, I went back to Duquesne, and it took me another year and a half, while at the same time working full-time selling insurance. I graduated from Duquesne, then, in 1964—finally. It took a while.

He continued in insurance sales, completed all of the training programs offered by the Underwriting Training Council, and spent the next 33 years with Western-Southern Life, a company headquartered in Cincinnati. At first, Pete sold what was called "industrial insurance-weekly premium" life insurance. This was a product designed mainly for lower-wage, working class families. It was, in fact, the principal product of the life insurance industry in both North America and Great Britain from the latter half of the nineteenth century, continuing up until World War II. Brigades of insurance salesmen once plied the streets of working class urban neighborhoods selling life insurance and collecting the weekly premium. Pete tells how he did it:

> I was out every day. They would supply you with an area that they called a 'debit.'

And this was an area you could draw on a map?

> Exactly. And they would give you a 'debit book' that was 'routed,' so that you would be able to go through it without doubling back too much.

Like a paper route?

> Yes, except that everybody's insurance premiums were not due at the same time. Some people paid weekly. 'Weekly premium' means that you could pay by the week if you wanted to. If I could convince them to pay by the month I could cut down on my travel time. One of the commissions on that was that if you sold one dollar of weekly premium you would make twenty dollars. So it looked quite enticing. You'd get out there and if you wrote five dollars of weekly premium in a day, you're making some money. But now, the company that I was with, they haven't exactly done away with the industrial insurance—they still carry it—but they don't market it any more. They honor the ones that are in force, but they don't collect at your house. They don't do that any more. And if you fail to pay your premium, well...

Pete was soon promoted to assistant manager at the same Pittsburgh office where he had begun as a salesman, with seven sales reps assigned to him. In 1966 he was promoted again, to district sales manager in Reston, Virginia; and in 1974 he was transferred, laterally, to be the district sales manager at one of the largest offices in the company, in Royal Oak, Michigan, just north of Detroit. Pete and Sadie lived in Michigan for 18 years; they raised their five children there. Then, in 1990, Pete took early retirement.

> ...for a couple of reasons. I had a little mini-stroke. What is that called? A TI or what is it?

TIA-transient ischemic attack.

> Yes. And that kind of bothered me. And then Sadie was having some problems at the time, not knowing what they were. And she was diagnosed wrong. When I would go to their help groups and I would hear what was going on, it wasn't at all like her. And I would tell her doctor that, and he would get mad at me and tell me that he was the doctor and he knew what he was doing. And so I listened to what he had to say.

As a young woman in Pittsburgh, Sadie did occasional modeling work. This portrait hangs in the Greens' living room.

After Pete retired the Greens stayed in Michigan two more years before moving to North Carolina. Some time earlier they had purchased a town house in Durham (near where Pete's brother was living) and rented it out. The plan was that when Pete retired they would move into that town house. They did so in 1992. None of the Greens' five children and 12 grandchildren live nearby. The children are all in Michigan or California. So after Pete and Sadie retired to North Carolina, they were alone and together, for better or worse. The couple didn't stay long in the town house.

> By the time we moved in Sadie was starting to get really ill. And it was a two-story town house, and a small one, and she would just not go upstairs. Well, one day we decided to take a little ride and drove down the road and came down through here. And the young couple that owned this house—they were the original owners—he was putting a sign out on the front lawn, 'For Sale by Owner.' So we came in, and my wife stood at the doorway—she didn't even go into the back or anywhere. She said, 'I want this house.' So she went out and took the sign out of the lawn and put it in the car. I said, 'I guess I've got a house.' That was 11 years ago. And I'm glad we bought this house, because it's all on one floor. It's a lot easier.

Newlyweds, 1955

I'm wondering... You said earlier that Sadie was having some problems back in Michigan, and that she saw a doctor. What was the reason she went to see the doctor then?

> She was having convulsions. She would get short of breath and start shaking, and sweating, and her pulse would race. And I took her to several doctors. And of course they would send her to another doctor. And we wound up with this one who said that he knew what was happening. He said she was manic-depressive. But I didn't think it was that. And he had her on some drugs; one was Paxil®—I think that's the name. Does that sound right?

Yes, it's a drug used to treat depression and anxiety attacks.

> But they had her on these drugs, and she was way out in left field. You would talk to her and she just wasn't there... just wasn't there. And she was like that for quite a while, until we moved down here. And I didn't know where to go, and so we went to Duke. And they had done all kinds of tests on her—sleep disorder, everything. And then she finally wound up at the Memory Disorder Clinic, with Dr. Donald Schmechel (Professor of Medicine and Neurology and Director of the Clinic). And he discovered through... It wasn't an X-ray; they put you through that machine?

MRI? (magnetic resonance imaging)

> MRI, that's it. And he showed me the picture of the back of her head. And there was a hole that had developed. And he said that she has Alzheimer's. He said, 'We can diagnose it as Alzheimer's, but we really don't know, because the only way we can find out for sure is... if and when she becomes deceased, if you donate the brain, we can dissect it and tell.' But he said that in his professional opinion she has it.

So she is presumably Alzheimer's.

> Exactly. And she has developed some Parkinson's now, too. That's the diagnosis that she has.

Pete says that after the move to Durham, when Sadie was taken off the earlier drugs:

> She could laugh, she could carry on a little bit of conversation with you, she would watch television, where before she'd be watching it but not really. And by this time she was losing her memory. That was already happening when we were in Michigan. She would forget where she put things.

I'm wondering if the convulsions stopped—either back in Michigan when she took that first drug, or after that?

> No, they never stopped. In fact, they were more severe. That's one reason why her doctor up there in Michigan and I... why I'd get a little upset with him. Because nothing was happening with that. But, Dr. Schmechel put her on Neurontin® (gabapentin) and then the convulsions subsided. They didn't stop right away, but they were less severe and less frequent. And now, the last convulsion she had was probably about three years ago.

And that's the only medication she's on now except for a beta-blocker—those two.

But since she doesn't talk anymore, I don't know when she's having pain. I called Dr. Sheline (Barbara Sheline, family physician on the Duke faculty) a few weeks ago because she was crying out in pain. Usually, I have no idea if she's in pain. But I've learned how to read her face. I look right here between her eyes, and if that forehead's kind of squished up, she's thinking something that's bothering her, or she's having some pain.

So now, you rely on yourself. And Dr. Sheline may call once in a while. How often?

Only when I call her. When I need her she'll come. When hospice discharged Sadie, Dr. Sheline told me to call her—a long time ago. She said, "Call me at home." She only lives ten minutes from here. But I always hesitated to do that, because I didn't want to take advantage of her. I just didn't feel that was proper for me to do.

Well, that's the straw she chose—to be called. She could have gone into dermatology. No one would call her then.

She could have. But, anyhow, I didn't want to call her. And things were going fine until several weeks ago, when Sadie was in pain, terrible pain, and I had no idea where it was at or anything. So I called Dr. Sheline. She came over Saturday morning. And she spent quite a while here. And she checked her all out. She said she had a slight bit of pneumonia in her right lung. And then we came in the living room here and talked for a while, and she said that her heart is relatively strong and her blood pressure is pretty good. And she said that when she does pass away it will probably be pneumonia. Because she's inactive.

How would you describe Sadie's condition at the time you bought this house, 11 years ago? I'm wondering if she required any care then?

She was able to walk, but she was very forgetful. Although if you had known her 11 years ago, you wouldn't know, unless you spent time here and then you would be able to detect some of the things that were going on... She looked normal, and walked normal, and talked to you. But, then she would forget something she had done 15 minutes before. Not always, but often. And she needed to be watched.

What do you mean?

To make sure that if she was going to the bathroom... I had to make sure that when she walked down the hall that she went to the bathroom, because if this chair was setting there, as she walked past the chair, she would sit down and go to the bathroom. So I had to keep my eye on her as to what she was doing and where she was going. And that would happen quite often. But as long as she was parked, she was fine.

What if you needed to go somewhere—to run an errand? Did you leave her here?

No, I'd take her with me. Well, she could be left here for a short period of time and not have too much of a problem. But then I'd have to stop and think: What if she lit the stove? And what if she did this, and what if she did that? So I'd take her with me.

Were there any times when you left her alone a little while, thinking she would be all right, but it turned out badly?

Sadie in the mid-1970s

Yes, once. I had a medical appointment over at Duke, and I had nobody to be with her. So I went over to get my X-ray or whatever they were going to do. And she stayed home. That's probably been nine years ago. I came home, and she wasn't here. I had been gone an hour, less than an hour. I looked in the showers; I looked under the beds; I looked everywhere. I couldn't find her. So I called the Sheriff. And the Sheriff said, 'Well, before you get really excited, take a walk through your subdivision while we get a car over there. See if you can find her.' Well, I was going to go that way, but I went this way, and I went around the back, to the town houses. And she was standing in the middle of the road. And all the neighbors were out working, so nobody was there to see her. And she was as red as fire. She was crying. She had wet herself. So I brought her back home, and changed her clothes for her, put her in bed, and put a cold washcloth on her head. What happened was she went out and sat on the front porch. And the door was not all the way open; it was

> halfway open. And a UPS truck came up the street for a delivery next door. And he seen her sitting on the porch, because nobody was home next door, and he asked her if she would take this package for them, which she did. And she told me this. She went to come back in the house, and when she opened the storm door the vacuum pulled the wooden door shut, and it was locked. But the back door was open. And she said, 'I just wanted to find you, so I went to look for you.' So I'm very fortunate that she turned this way into the cul-de-sac area, because if she had gone straight ahead that way, she would have been down on the main road where there is traffic. She may have been in trouble then. So that was about the last time she's been out of my sight.

And that is the only time she's been lost?

> Yes. But she's been confused many times. I had to put a rope... had to rope off the bedroom so that she wouldn't go past that rope, because she would sit on the edge of the bed and go to the bathroom. She wouldn't know where she was at.

As Sadie's condition deteriorated to the point where she was no longer responding, she was admitted to hospice. But hospice care comes with a term limit that is based on the expectation that the patient will die within a short time. Sadie did not die, however, and she was discharged last May. I asked Pete to describe the range of services that hospice provided.

> A nurse would come once a week to check the vitals. A nurse's aide would come once a day to give her a bath, even on the weekends. And the social worker would come maybe every six or seven weeks.

And since she's been discharged, have you done all of that yourself?

> Yes. Except that the two male nurses who are neighbors come in once and a while to check her blood pressure for me, and listen to her heart, when I ask them to. I keep charts on her—on everything I do, every day. I keep track of everything, and I can tell you... Here's where one of the nurses was over on July the fourth. Her blood pressure was 142 over 68. Her pulse was 60. 'Lung sounds...' I don't know what he put down here— 'coarse crackles.' So I keep track of everything. And I started doing that because when hospice came in the nurse would ask me some things. I'd have so many things going on... And I have so many things about Alzheimer's on my computer. Every time I find something new I put it in my favorite ones, and then I read all about it. I read how to turn her in bed and how to change the bedclothes and how to do all that. I read it and then I go in there and refresh my memory on a lot of that stuff. Of course, when hospice was in I watched them and what they did, too. So it taught me quite a bit.

But 11 years ago the care you were giving Sadie amounted mostly to keeping an eye out, watching when she got up to make sure she was headed to the right place, and so on. At some point the amount of care she required increased. I'm wondering what came next?

> Her inability to walk properly. She would trip over things... and fall. Finally, I got her one of those aluminum walkers. And she would walk with that. But then she would have difficulty with it because she would lean backwards instead of forwards, and she would fall backwards. And then, of course, after that I bought a wheelchair. That walking problem started maybe six, eight years ago, and she kept getting progressively worse. And so about five years ago I bought what they call a transport chair, with the smaller wheels on it—lightweight. I bought that. And then three years ago I had a ramp put out there on my back deck. I didn't want it in the front. And then I had a sidewalk put in.

So, up until five years ago she could still walk, although with difficulty. After that she could no longer walk and had to be transported in the chair. Could she tell you then when she needed to go to the bathroom?

> Yes, she would tell me, or I would know it was time. And I would take her in the back. In fact, I had the bathroom—the one in the room she's in, which is our master bedroom—it's her room now... the bathroom in there had a tub and a commode, and it was small. I had the wall knocked out and had the bathroom enlarged, had the tub ripped out, and put a shower in. And I bought a sliding bath chair. And I would set her in it, and I'd slide her into the shower, and then I'd get in the shower and wash her hair, and then slide her back out, dry her, and then bring her out here and put her in the chair, and she would sit there and either sleep or watch TV. But now I bathe her in bed. She doesn't get out of bed now. I stopped using the shower with her when I had my surgery (coronary bypass) two years ago, because they said I couldn't pick up anything over 30 pounds. I didn't have anybody here. Our youngest daughter came down and stayed for three months. She works at Home Depot, and she transferred down to this Home Depot in order to take care of Sadie. But she couldn't get her out of bed to put her into the shower.

Who would be here when you were in the hospital, or recuperating later, and your daughter was at work?

> When I was having my surgery I had my family down here. But it was when I was recuperating, after everybody left, and I hadn't reached room temperature... But

hospice was here then, and I was here, and I was able to call if I needed any help. I was able to feed her, and I was able to do little things—most things, except pick up heavy things. I was able to make her lunch and make her dinner, and my daughter was within calling distance at Home Depot. If I needed her she would come home.

But now, since May of this year (2004), when hospice discharged Sadie, you have been her sole caretaker?

Yes. I bathe her; I feed her; I change her clothes; I change the bed clothing on the bed. Everything that hospice did, I do now. Before that, when hospice came, I didn't bathe her in bed. Before she had to be bathed in bed I did bathe her, though.

Of all the caretaking tasks that you perform on a regular basis, which is your biggest challenge?

Bathing.

How long does it take?

Well, when I started I think it took all day.

Literally? All day?

No, I'm exaggerating. But it took quite a while, because I never did it before—at least an hour and a half, maybe two hours. And why it took so long was that she would become rigid, hold her arms down. And I would try to pull her arms up, and she would get mad, and then she'd holler. And I'm thinking, I'm hurting her. And it just became a hassle. But then, as I kept doing it and trying to schedule, I figured I didn't have to bathe her every day because she's not getting dirty. Hospice was doing it, and different ladies would come, and they were experienced in what they were doing. So I had to figure out what I was going to do, because I can't bathe her every day or I would have become a basket case myself. So I scheduled that I would bathe her every other day. But that wasn't working out either. I was falling short on laundry and... It just wasn't working for me. Now I have it down to where I bathe her on Monday morning and Saturday morning. That's when I bathe her. And I change the bed clothing—unless they get soiled—once a week. Because she sleeps on waterproof pads. I put them over the sheet, so the sheet does not get soiled, unless there's a leakage or something when I'm changing her and I happen to get some on her. Then I'll change the bed. I learned how to take a fitted sheet and hook the corner on the top, and hook the corner on the bottom, roll her over and stuff it under, roll her back and hook the other side. I'm an expert. And I haven't even been in the Army! I'm an expert at it. I can bathe her in bed. I can change the bed

clothing in bed. I can shampoo her hair in bed. Once every three weeks I put...she gets that cradle cap—like little babies do—and I put the cradle cap conditioning on, and I comb all the flakes out. So... I need care! I take good care of her, though.

When you were observing the hospice people bathe her, did she get rigid and cry out then during the bath?

I never really noticed that. But after I'd bathe her I would often sit down and think: How did they do it? I'm sure they had problems, though, because she still does that. I have to figure out how to get her arms and slowly move them down to her side, while I talk to her. 'I'm going to wash your tummy now, so you've got to keep your arms down here.' And as soon as I get them down and I turn around to get the washcloth, I see that arm coming back up again. She hears. And she understands. But it takes a while for a lot of things to register. I don't say it just once. I have to keep reminding her. And I have to say, 'OK, now, the washcloth is going to be warm, not hot.' This morning when I was bathing her I put a waterproof pad under her legs, and then I would take the pillow, flatten the bed, take the pillow out, and then I take another waterproof pad and roll the corner, roll it towards her. And she starts screaming. I don't know why. And her arm was up. She just got frightened, I think. I had to keep talking to her, and tell her, 'I'm not going to hurt you. I'm not hurting you. Everything's fine.' But that doesn't happen every time. But she does hear. That's why I refrain from talking about anything in reference to her in the bedroom. And when people are over, when neighbors are over, if they ask me a question that I think is not right for me to answer in front of her, I won't answer it then. I'll tell them in the other room.

When do you feed her?

> She has her breakfast in the morning. Then she has a snack in the afternoon. Then her dinner is about 5:30. Then in the evening about 8:30 I give her a Creamsicle. She loves Creamsicle. Then she's good for the night. I change her underwear first thing in the morning. Cause I don't want her lying in it until I get her breakfast, so I change her first thing in the morning. And then after I feed her breakfast, probably about an hour later, I go in and check her. And most of the time she needs to be changed then. Then I change her at dinnertime before I go to bed. And then every other day I have to give her a suppository. She'll have a bowel movement that'll be just a smudge. I buy the overnight fitted, throwaway underwear with the tapes on the sides. They're diapers. And that's what she wears. And, of course, she's on a waterproof pad, too, in case they leak. And I'm an expert at that, too. I can line it and roll her, and everything is exactly where I need it.

If you needed to go out for an hour or so this afternoon, what sort of arrangement could you make?

> I have a schedule. Mondays, I don't have nothing scheduled to do. It's a bath day. And I also have things to do around the house, maybe cut the grass or whatever. But today (Monday) I did go out. My neighbor, the nurse, came over and sat while I ran to the bank. And then I went to the drugstore to pick up her prescription and came right back. But that's only because my neighbor was home, and I was able to do that. Most Mondays I'm here all day doing what I have to do around the house. On Tuesday I have a sitter that comes in from 1:00 to 3:00 or maybe 3:30. And I run my errands at that time; and even if I don't have no errands, at least I can get out for a little while. I'm on the executive board of the Helping Hand of Chapel Hill, and this lady, she's been coming over here for the last two years on Tuesdays, she's like a member of the family, a very nice lady. And then on Wednesday I have the hospice volunteer from before hospice discharged Sadie. He's a retired professor from Duke, a wonderful elderly gentleman. But we knew him before, when we lived over in the town house. And it was amazing that he was with hospice when Sadie was in there. But he said that he wasn't going to stop coming here (after hospice discharged her); he was going to come on Wednesdays, because he just wants to do that. So he comes on Wednesday, gets here about 12:30, and I'm back here by 3:00 or 3:30. And Wednesday is doing some errands that I didn't have a chance to get to on Tuesday. And then Thursday is the most delightful day of the whole week. And that's grocery shopping—with all these elderly old ladies—at Harris Teeter. So I do my grocery shopping on Thursday. I have a sitter from UNC, a young lady who volunteers through the Helping Hand to sit while I go grocery shopping. And, of course, Friday I'm home all day, Saturday I'm home all day. Sunday I'm home all day—unless one of the neighbors stops in, and I may run down to the drugstore or something. Now, Sunday... there was a lady who was a nanny here in the neighborhood, and now she's... well, she's still a nanny. She's in her 70s, and she's been a very good friend of mine, and Sadie's, for about the last three or four years. She came here this past Sunday, and she fed Sadie for me while I went to the Wal-Mart—I had to pick up more diapers. So things like that will work out when I don't have anything scheduled. Somebody might stop by and tell me, 'If you have something to do, I have about an hour or so and...' We have a lot of friends here in the neighborhood. I was president of the homeowners' association here for seven years, so I know everybody.

Your past involvement in the neighborhood must make it easier for you to arrange this kind of help than it would for someone who wasn't that involved.

> That's true. And there's not a day that goes by that I don't have one or two neighbors who stop by.

Since May, when you've had to do all the bathing and bed changing and diaper changing and feeding—all of it yourself—have you noticed whether Sadie's condition has deteriorated further?

> It has. She shows more signs of something bothering her. And her eating habits have slowed way down. She doesn't eat as much. Although since Dr. Sheline was here a few weeks ago and put Sadie on some antibiotics for that pneumonia, her eating has picked up a wee bit. She's eating a little bit more than she did.
>
> This is a very difficult thing in life to do, to take care of somebody. And when this really got to the nitty-gritty of taking care of her, when I go back and think of the many developing problems that she's had over the years, it's a strange... I don't know whether it's strange, that's not the right word, but you find out that, number one, family backs away. Everybody wants to disappear. You might have one or two... But everybody backs away; they don't want the problem. And you get mad. You get mad at yourself. You get mad at God. You get mad at her. You know: 'Why are you doing this?' And I became confused. I didn't know what to do. I didn't know how to handle things. At least I thought I didn't. But when you finally accept—I'm just speaking for myself—when I finally accepted that this is the way she is, and she's going to need a lot of my help and attention; once I accepted that, what I do doesn't seem like nothing. Prior to that it was a lot of work. But I guess that's the way life is. Once you accept something it becomes a lot easier. **NCMJ**

COMMENTARY

Grieving the Living!

Linda E. Jordan, DMin, CT

Although the word "grief" is seldom used in the stories of families affected by Alzheimer's Disease (AD), it surely is woven into the entire fabric of the experience. Grief related to on-going AD is grief for the living, and it is often a disenfranchised grief. Our culture tends to devalue persons who grow to be nonproductive and dependent as is the case in AD; they are often stigmatized socially and marginalized relationally. The person who feels the pain of that devaluation and limbo status is the caregiver. In addition, the person with AD sometimes manifests unpredictable, inappropriate, and even indecent behaviors. These can be embarrassing to family members and intensify their pain and loss. Moreover, as long as the person with AD is alive, caregiver grief, though appropriate, is generally not recognized or sanctioned. The community is more likely to associate grief with a physical death. Yet, grieving the living is real; it is constant and complex; and it is important that caregivers receive help in managing it.

> *"...grieving the living is real; it is constant and complex; and it is important that caregivers receive help in managing it."*

When grief is acknowledged in AD, the concept most often used is *anticipatory grief*. Although this term has value, the losses incurred with AD are not just future; they are actual and profound in the present. Each pre-death loss in this progressive disease is compounded by all previous losses and introduces new tangible losses, as well as potential losses in the future.

In *Treatment of Complicated Grief* (1993), Therese Rando describes six grief processes that must be accomplished when loss occurs in order to integrate the loss successfully.[1] These processes are not linear, but are necessary tasks for the person in grief, and they can be useful to caregivers who experience pre-death losses. Being informed about these processes can assist healthcare providers in their care for family caregivers.

Acknowledging the Reality of the Loss

The goals of this process are to comprehend that the loss is permanent and irreversible and to understand the implications of that reality. For persons with AD, changes are often gradual, variable, and intermittent with good days and even lucid moments throughout, enabling caregivers to deny that loss is really happening. As the disorder progresses, it is natural for caregivers to want to believe that the deterioration is temporary and reversible, and it is complicated by the fact that the person is very present physically and frequently otherwise healthy. The death is psychological and is one which society does not tend to validate. Caregivers lose not only the person as they were prior to the disease, but also lose who they were with them. These secondary and symbolic losses, in addition to the physical ones, fluctuate and are re-experienced over and over again. Professionals can help by encouraging caregivers to identify the layers of loss, by confirming their grief, and by providing information that will help the caregiver assimilate the fact that the changes are real and permanent.

Experiencing the Pain

Healing can be accomplished only by contending with the emotional pain of a loss. Often caregivers of a person with AD are so consumed with the ever-growing list of caregiving tasks that they suppress their pain or do not take time to attend to it. Feelings such as anger, anxiety, and fatigue often go unexpressed when caregivers feel that they must maintain an atmosphere that is cheerful, calm, and optimistic. Unfortunately, our culture confuses care of self with selfishness, a position detrimental both to the caregiver and the person with AD.

Healthcare providers often try to rescue caregivers by trying to take away their pain instead of authenticating the gamut of strong and sometimes contradictory emotions. Providers will do well to remember that all emotions are energy in motion

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and can work for caregivers instead of against them. In addition, prescribing regular self-care for caregivers needs to be considered part of every treatment plan in AD. Most caregivers find family support programs reduce their isolation while enhancing their personal self-care strategies.

Reviewing and Remembering the Person and the Relationship Realistically

The goals of this process are to identify unfinished business, enable a good goodbye, and alter the bonds of the relationship. AD makes this, at best, a challenge, especially in the moderate and severe stages of the disease when the mental faculties needed for resolution are often missing. Yet, caregivers can accomplish the process independently of the person with AD, because it is about caregivers doing their own work—making their peace, finding forgiveness, and marking the significance of the relationship. It is important that caregivers be encouraged to tell the stories of the person and of the relationship—positive and negative. And it is important to recognize that conflicted relationships are nonetheless significant. Allan Gurganas, a North Carolina author, once told me, "Always remember that the story knows more than the storyteller." To tell the stories of the relationship can restore wholeness in the midst of brokenness. To tell the stories of the past informs the present and the future. In telling the stories, caregivers can find ways to alter the bonds of the relationship in ways that simultaneously allow them to stay connected and to let go.

Adjusting to the Environment Where the Person Is Missing

The usual goal of this process is to learn how to be in the world without a person who has died. However, the caregiver of a person with AD has to adjust to a new environment while the person is physically present and in need of emotional and physical care. Persons with AD never will be their "old selves" again; neither will the family unit. Caregivers are forced into additional roles and stresses that they did not choose and do not want. They have to revise their own identity, find different ways to define self-worth and pleasure, and learn new ways of thinking and relating to the person with AD. Adjusting to a new reality and relearning the world can be stressful; providers can patiently instill confidence in caregivers as they take these most difficult steps.

While counseling a husband whose wife had AD, I encouraged him to adjust to her new reality rather than trying to force her back into his reality—being with her mentally wherever she was. As he began to adjust to the new reality, he was able to sell their home of 40 years and move to a retirement facility where she had 24-hour care and he could still be near her while also having additional support for himself.

Revising the Assumptive World

Each of us has expectations of how things should be and should happen. When we adamantly declare that life is not fair, there is an assumption of what constitutes fairness, i.e., good things happen to good people. However, the goal of this process is to make sense of things NOW, not as we think they should be. When caregivers watch a vibrant personality disappear before their eyes, be unable to recall a rich life, and no longer recognize the familiar, they experience moments that do try their souls. Reeve Lindbergh, daughter of Ann Morrow Lindbergh, recounts a time when she shouted to her mother, who had AD, "Stop it. Don't abandon your principles... Don't be strange. Don't be weak..."[2]

This process of grief propels caregivers to re-define the values and core beliefs on which they can still base their lives. If they are religious, their faith can be a source of comfort and guidance as they encounter the mysteries of life and death. The essential movement is from "Why me?" to "What now?" Providers, without imposing their own values, can be instrumental in this transition. Again, Reeve Lindbergh's words are appropriate, "What we have is a day...We cannot make plans. We must live a border life and make concessions to both sides—a little life here, a little death there."[3]

Integrating the Loss and Reinvesting in a Meaningful Future

Throughout life, we are always integrating our losses—small and large. How we integrate these losses determines whether we move through life in despair or with gratitude. In the instance of AD, reinvestment means integrating not only what is lost, but also exploring what is still possible in the relationship. One woman with AD had played the piano for the children's department in her church for many years. When I entered her room one day she was singing a hymn so I joined her. She never changed her blank stare, but began singing in perfect alto harmony all the words of the hymn. I told her four adult daughters about this experience, and when they next visited, they spent almost an hour singing with their mother. In that brief time, they had part of their mother back and meaningful memories to recall in later years.

Additional Recommendations for Caregivers

Although the grief process in AD is complex, there are additional things that healthcare professionals can do to support caregivers of persons with AD and nurture their own emotional health and wellbeing.

One is *utilizing the health perspective*. It can be tempting to treat caregivers much like the person with AD—to foster dependency and to try to rescue them from pain. However, the health perspective recognizes that most people have the internal and external resources needed to integrate their losses into a meaningful future. Inherent health principles in framing this experience are: (1) pain and loss are normal, and grieving is a healthy way of taking care of ourselves; (2) each person has a unique style of doing grief work, and people have the right to interpret their loss and make choices that are right for them; (3) grief is a long process where small steps and partial accomplishments are enormous and should be affirmed; (4) grief is a healing process, not a disease. People have tremendous inner strengths to heal themselves if they are provided good information, a safe place to grieve, support for their journey, and reinforcement for their self-reliance.

Secondly, *creating a ritual* can be therapeutic. Society has not created rituals for pre-death grief, yet throughout history, rituals have helped families and nations mark numerous special events and sacred time. Rituals need not be equated with funerals and do not mean that the family is abandoning the person with AD. Instead, a family ceremony can be an intentional time designated for sharing present grief, remembering past joys, and strategizing future plans. Such an occasion can help family members address all of the six processes of grief discussed earlier and provide the momentum to reinvest in a new reality. Healthcare professionals can institute this practice as a standard of care and assist caregivers in designing an event that fits their needs. Families have an amazing capacity for creativity if given permission, assistance, and encouragement.

Finally, family caregivers can benefit from healthcare professionals directing them to *post-death bereavement services*. When physical death does occur in AD, often the grief reactions of survivors are again discounted because the disease has been so measured and the demands of caregiving have been considerable. Although death is frequently accompanied by a sense of relief, healthcare professionals tend to assume that the grief of AD is completed when the person dies; hence post-death grief is inadvertently disenfranchized. Not only is there the physical death of the person with AD to be dealt with, but there also can be the cumulative effects of a long-term and strenuous illness. Being knowledgeable about and supplying the family with information about specialized bereavement resources such as Duke Community Bereavement Services will be important in legitimizing post-death grief. In most communities, local hospices offer bereavement support to survivors whether or not they have been served by hospice.

Families are incredible. Ordinary people can face extraordinary hardships, and resilience is a more common outcome than defeat. Caregivers of persons with AD can be and have been examples of such invincible courage. **NCMJ**

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COMMENTARY

Family Care and Alzheimer's Disease

What Do We Know? What Can We Do?

Lisa P. Gwyther, MSW, LCSW

Alzheimer's Family Care: What Do We Know?

Alzheimer's family care is intense, personal, and unrelenting. It has been compared to running a marathon without ever seeing the finish line. Alzheimer's has forced long-term care services and policy to move from a narrow "aging" focus to a "family" focus that is more inclusive of the person with dementia as well. National public awareness campaigns have accelerated recent consumer trends. Families as consumers and surrogate decision makers for their impaired relatives are demanding earlier and more comprehensive diagnosis and treatment of Alzheimer's or a related disorder. This growing family recognition of Alzheimer's costs to multiple generations is becoming clear to the public in advance of business and policy recognition.

Family care definitions have also moved beyond blood and co-residence to be more inclusive of other informal or faith-based community support programs and working family members who frequently become long-distance care decision-makers and care managers.

> *"Not only do Alzheimer's families face personal fears and risks of heritability, but they also face documented risks to their physical and emotional health from providing care."*

Research estimates suggest that 30% of persons with moderate to severe dementia live alone in the community, often relying upon close supervision and direct help from family members, neighbors, or friends who live close-by.[1] Primary, secondary, and even tertiary family caregivers have been identified in studies of diverse ethnic and racial groups caring for persons with Alzheimer's.[2] In contrast to persistent myths of family abandonment, research consistently finds more Alzheimer's family care in hospitals and nursing homes than at any time in our history, with persistent documented negative effects on family caregiver mental health even after nursing home placement or death of the person with dementia[3,4] Although persons with Alzheimer's disease living alone or in nursing homes are more likely to be older women who have literally outlived all family support, 70% of nursing home residents have involved family caregivers and the majority of these residents have some form of dementia.

Even in the best of families, for whom Alzheimer's care is knowledgeably and willingly undertaken, and when there are personal testimonials about meaningful gratification in providing such care,[5] the "wear and tear" and prolonged strain of constant supervision have been shown to have negative consequences on health, family relationships, and future financial security of surviving family members. Research on Alzheimer's family care was the first to document the significant proportion of male (primarily husband caregivers) often overlooked in general studies of family caregiving as a predominantly women's issue.

We have long known that there is increased risk of late-onset Alzheimer's disease when one has two or more first degree relatives with Alzheimer's. Not only do Alzheimer's families face personal fears and risks of heritability, but they also face documented risks to their physical and emotional health from providing care. Providing more than nine hours of care per week for a relative with Alzheimer's disease has been associated with a two-fold increased risk relative to non-caregivers of coronary heart disease (CHD), hypertension, poor immune function, slow wound

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healing, low perceived health, depression and anxiety, exacerbation of chronic illness, and even premature death.[6]

Physicians also hear from anguished family members fretting from afar about relatives with dementia. One son laments,

> How can I know what's really going on? When I call, they say "we're fine," but I see changes. When I make suggestions to my sister, she reacts with "why don't you take them?" Crisis calls tear me up. I'm helpless, trapped, grieving. I catch myself relieved to be 3,000 miles away... and guilty about it.

Even families who have resources for extensive medical treatment and personalized home care still wonder, as Reeve Lindbergh did in caring for her mother, Anne Morrow Lindbergh, when she was dying with dementia,

> No matter how good the medical care, attention or money lavished on our beloved mother... we feel guilty because our presence doesn't seem to help... it is never enough.[7]

The Duke Aging Center's research on Alzheimer's family care documents that families make decisions about use of paid or voluntary services based on subjective perceptions of whether help from other family members or friends is "dependable, sufficient, or enough." Older spouses often "wait" for physician "prescriptions" for outside help, and they are frequently disappointed by cavalier recommendations to "look for nursing homes," which many families perceive as medical abandonment. Each family member has his/her own definition of what constitutes "dependable and sufficient quality care." This variability and complexity among family caregivers limits the effectiveness of Alzheimer's "disease management protocols" applied outside the context of family assessment. Practice guidelines for Alzheimer's disease management must consider care context as well as patient variables.

Alzheimer's Family Care Is Complex

Although no two family care situations will necessarily respond to a single, linear disease management algorithm or protocol, each family caregiver at some point will have to:

- Define and negotiate complex situations and decisions: Whose needs? How much help is adequate or enough? How long can we provide this level of help? How can we evaluate quality, safety, risks, cost, and benefit?
- Perform physically intimate tasks made more difficult because of resistance, fear, or misunderstanding by the person with dementia.
- Manage emotions and communication as the person with dementia becomes less able to manage his or her emotions and communication.
- Modify expectations of one's family, oneself as caregiver, the person with dementia, physician, and social support services.
- Capitalize on the person with dementia's intact remaining skills and abilities.

In the process of providing family care, individual family members may become the person with dementia's confidante, protector, enemy, constant companion, information seeker, care manager, consumer advocate, surrogate decision maker, and healthcare provider in no particular order.

High-Risk Family Care Profiles

There are known high-risk profiles for Alzheimer's family care that are not amenable to health or social interventions. Family caregivers who co-reside and provide a high or intense level of direct care or supervision, especially low-income or low-education female caregivers over 50 years old who perceive no choice in a decision to care, or frail older wives, are most vulnerable to negative outcomes from providing Alzheimer's family care. Studies further confirm modifiable risks associated with negative outcomes of Alzheimer's family care that are amenable to health and social support interventions: high depression and anxiety, impaired self-care and health behaviors, safety issues, inadequate social support (social isolation vs. engagement), and the challenging behaviors, personality, and communication changes of the person with Alzheimer's. Adult children who provide care out of financial necessity pose additional risks for the person with Alzheimer's from fraud, exploitation, abuse, or neglect. Often families providing care are at risk simply because they lack health literacy, knowledge of or access to information and support, or because they have personal health/mental health conditions that limit their capacity to provide quality care.

Box 1.
Just for Families: *Ten Things to Know*

1 The desire to avoid thinking about what you are facing is normal, but you can get beyond it.

2 The process of the disease is not completely predictable. Other things happen. Your family member will need more help over time, and you may be forced to make decisions that he/she will not like.

3 The person with AD can still, and needs to, do many things for you.

4 The person with AD is doing the best he/she can. Trying harder is frustrating and doesn't work.

5 You, not your relative, will have to change.

6 Your emotional relationship with each other will change despite your continued love and willingness to help.

7 Grief comes with this process of loss.

8 There is no single right or wrong place or time to care or care plan.

9 This is the rainy day for which you saved.

10 There is life beyond and after Alzheimer's care.

Personal and Social Costs of Alzheimer's Family Care

The most commonly cited personal costs of Alzheimer's care are feelings of being overwhelmed, alone, fatigued, depressed, anxious, angry, and suffering from exacerbated chronic conditions or stress-related illnesses. Often, families report the premature death of the primary spouse caregiver necessitates a sudden change in both the care location and primary caregiver, disrupting entire families. Further, families report social costs of Alzheimer's disease care as loss of valued friendships and community activities; family conflict and guilt; less personal time and privacy; and prolonged bereavement, loss, and sadness.

Box 2.
Nine Strategies for Alzheimer's Families

1 Being reasonable, rational, and logical will just get you into trouble.
2 People with dementia do not need to be grounded in reality.
3 You cannot be a perfect caregiver.
4 Making agreements with the person with dementia doesn't work.
5 Doctors need your input on what's really going on and what works.
6 You can't do it all. It's okay to get help before you are desperate.
7 It is easy to both overestimate and underestimate what your relative can do.
8 Tell, don't ask.
9 It is perfectly normal to wonder about the diagnosis when the person has moments of lucidity, insight, and good judgment.

Adapted from Family Caregiver Alliance Update, 21 (3):1. 2004.

Successful Coping with Alzheimer's Family Care

The Duke Aging Center's Alzheimer's caregiver studies provided early evidence of successful coping strategies of North Carolina families. The majority of North Carolina families reported reliance on a strong religious faith, belief system, or practice. In addition, caregivers who successfully modify expectations and re-appraise their efficacy ("good enough for now" solutions) report success in adapting over the disease trajectory. Other successful coping strategies include enhanced self-care and health behaviors, reducing rigid or inflexible behaviors, using humor, dependable family support, respite options, energy economies, forgiveness strategies, ingenuity, problem-solving, expressive, and advocacy outlets.

Key Decision Points for Physician Intervention: Transitions in Care

Transitions in illness symptoms and care are especially vulnerable times for persons with dementia and their family decision-makers. It is at these times that families are most likely to turn to physicians as gatekeepers. These transitions (see column to the right) in care highlight common hazards in family decision-making around Alzheimer's disease.

Families are often forced to make decisions in the face of an unrelenting series of crises without time to sort through conflicting perceptions and expectations. We know stressed individuals are at a disadvantage in decision-making and, for many families, Alzheimer's care is only one of a number of pressing family crises. Families may rigidly adhere to old promises that are no longer situationally relevant. Families may wait for the person with dementia to ask for help, chasing the ghost of the person as someone with intact judgment and executive function. Family decisions may await direction from a physician and often that direction is not framed in a way to facilitate a choice between equally unattractive options. Families may also delay acting on safety issues for fear of losing control of their relative's care to public or agency services. Finally, we know from clinical experience that families may delay decisions based solely on cost, on preserving assets for future generations, or from fear of the stigma and loss of privacy associated with the overwhelming disclosure required for eligibility and service determinations.

The following are examples of transition times where physicians can help families make difficult decisions and find ways to sustain their caregiving capacity:

- Diagnosis (reluctance to seek or accept early diagnosis by the person with dementia or family)
- Changes in driving (getting lost), handling money, taking medications, or alcohol use
- Decisions about the safety of living alone (fraud, neglect, exploitation—see Box 3)
- Decisions about hospitalization, surgery, diagnosis, and treatment of co-morbid conditions (Are symptoms and/or injuries attributable to dementia or signs of another acute illness, medical emergency, or delirium?)
- Decisions about the use of antipsychotics, antidepressants, anxiolytics, sedative hypnotics, and other psychiatric medications
- Changes in primary caregiver
- Need for constant supervision (respite options, in-home help, or day services).[8] See Box 3 for suggestions on how to determine need for constant supervision.
- Residential/assisted living care
- Skilled nursing facility care
- Palliative care and/or hospice care options

Physicians may use these transitions or decision points in care as opportunities to focus education on the most pressing family issues. The timing and "dosing" of information in a way that will not overwhelm patients and families may be just as important as the timing and dosing of medications.[9] Selecting educational strategies—brochures, websites, verbal directions, or referral to an Alzheimer's Association Helpline—should be done with sensitivity to literacy, culture, and capacity of the family caregiver. See examples of brief family caregiver reminders in Box 1 and Box 2. The geriatric prescribing axiom of "start low, go slow, and repeat often" is relevant to communication and family education around transitions in Alzheimer's care.

Box 3.
Considerations in Determining if a Relative is Safe Living Alone

1. Can the person use the telephone, read and send mail, manage their medication and money? Do they drink alcohol?
2. Is the person vulnerable to telephone, mail, or in-person fraud, scams, exploitation, neglect?
3. Can the person travel safely and at appropriate times outside home without getting lost?
4. Can the person maintain personal hygiene? Is the person continent?
5. Could the person be at risk for falls or other injuries. Are there guns or power tools, etc. in their home that might pose a risk?
6. Is the person at risk in their kitchen? Can they operate a stove safely, store food properly, recognize inedible food, etc.?
7. Is the person experiencing any weight loss or sleep disturbances?
8. Is discrete surveillance available from neighbors?

Key Messages for Alzheimer's Family Caregivers

- Be willing to listen to your relative, but understand that you cannot fix or do everything he or she may want or need. Know that it will not necessarily get easier, but things will change, and the experience will change your family forever.
- You are living with a situation you didn't create, and your relative doesn't like it any better than you do. Your choices may be limited by circumstances beyond your control. Seek options that are good enough for now.
- You can only do what seems best at the time. Identify what you can and will tolerate, set limits, and call in reinforcements. Doubts are inevitable.
- Find someone or a support group with whom you can be brutally honest, express your feelings to them, and move on.
- Solving problems is much easier than living with the solutions. It is tempting for distant relatives to second-guess or criticize. Hope for the best, but have contingency plans for the worst.
- It is not always possible to compare how one person handles things to how another relative would handle it if the positions were reversed.
- Your relative is not always unhappy or upset because of what you have done. He or she is living with unwanted dependency. Sick people often take out their frustration on close family members.
- Considering what is best for your family involves compromise among competing needs, loyalties, and commitments. Everyone may get some of what he or she needs. Think twice before giving up that job, club, or church group. Make realistic commitments and avoid making promises that include the words *always*, *forever*, or *never*.
- Find ways to let your relative help or give to you. He or she needs to feel purposeful, appreciated, and loved.
- Take time to celebrate small victories when things go well.

Primary Care and Family-Centered Dementia Care Models

The Alzheimer's Association has tested and disseminated family-centered models and tools for primary care diagnosis and management of persons with Alzheimer's, including guidelines for hospitalization and management of nursing home residents.[10] These collaborative models among physician group practices and Alzheimer's Association chapter services could be replicated in North Carolina.[11] North Carolina Alzheimer's Association chapters also have a national program workshop package available to help families communicate more effectively with physicians around dementia care. Linking health, aging, and social support services makes sense to consumers and health professionals, but the physician or healthcare provider is the lynchpin that makes or breaks seamless care delivery.

REACH (Resources for Enhancing Alzheimer's Caregiver Health)

A series of collaborative National Institute on Aging studies provides evidence-based direction for interventions to enhance Alzheimer's family care capacity and reduce negative consequences for caregiver health.[12] REACH tested interventions in settings ranging from primary care offices to telephone-based to in-home and group settings.

Original interventions targeted challenging behaviors, caregiver distress, delayed nursing home placement, and death. Interventions included cognitive and environmental strategies to reduce negative family appraisals of demands while enhancing the adaptive capacity of family caregivers. Other strategies targeted emotions or affective states of caregivers like depression, anger, and frustration. At six months, the studies reported clinically meaningful, site-specific positive outcomes such as decreases in depression, caregiver strain, and burden (especially among spousal caregivers); and increases in self care, social support, and efficacy in responding to challenging behaviors. When compared to the control group, persons with Alzheimer's whose caregivers received research interventions had significantly delayed nursing home placement, and their family caregivers suffered significantly less major depression.

REACH studies confirm the efficacy of multi-component interventions matched to individual caregiver risks. Multi-component interventions include a range of treatment modalities (like individual and family counseling, psychoeducational support

Duke University and Alzheimer's Families

"The docs back home don't know about this."

North Carolina responded to Alzheimer's families long before national attention focused on the public health and epidemic consequences of memory disorders on individuals, families and communities. Duke's Aging Center began its Alzheimer's Family Support Program in 1979 in response to urgent requests from families of persons with rare early-onset (i.e., before age 65) dementias taking part in the first federally-funded case control studies of Alzheimer's disease led by Duke University professor of neurology, Dr. Albert Heyman.[1] These families rarely knew of others their age in their communities coping with what was then commonly attributed to "senility or old age." These primarily middle-aged, well-educated couples were eager to meet and learn from each other and from "experts" while the national Alzheimer's Association was initiating its public awareness and support programs.

From Duke to Mobilizing Communities throughout North Carolina

These research subject families began attending a monthly "support group" at Duke in 1980. They connected with others at the monthly meetings, by writing letters or getting together socially outside of meetings. They urged Duke's Aging Center to publish a newsletter sharing their stories and tips, which the families named *The Caregiver*. Duke's *Caregiver* newsletter is now one of the oldest continuing newsletters for families and professionals caring for persons with Alzheimer's or a related dementia available by free subscription to North Carolina residents. The first-person narratives and tips in this newsletter addressed the isolation of these primarily rural families who lived at a distance from each other and Duke before there was e-mail, the Internet, cell phones or affordable long-distance telephone access. The original Duke support group has continued to meet monthly since 1979, now under the sponsorship of the Eastern North Carolina Alzheimer's Association.

In the early 1980s, North Carolina's Z. Smith Reynolds Foundation and Levi Strauss Foundation funded Duke's Aging Center to mobilize local informal support groups as sources of information and help closer to home. These groups are now part of two North Carolina Alzheimer's Associations sponsoring support groups across the entire state. Original subscribers to *The Caregiver* newsletter became mail survey research subjects for one of the first and most cited studies of Alzheimer's family care in the community.[2]

In 1984, the North Carolina Division of Aging (now the Division of Aging and Adult Services) contracted with Duke's Family Support Program to provide a toll-free telephone and mail clearinghouse for families and professionals caring for persons with memory disorders. The Duke contract covered state-level technical assistance, training, consultation, a newsletter and toll-free individualized telephone assistance. This annually renewed Program contract continues to serve as a state barometer of family needs, preferences, and gaps in health and social support services.

Subsequent studies at Duke and other universities have replicated and expanded original family care research findings. Duke Alzheimer's family care studies moved, along with federally funded cooperative studies, from measuring family stress and burden to interventions to mitigate negative consequences of caregiving on families. North Carolina now benefits from multi-site research findings offering an evidence base for clinically meaningful outcomes of family support strategies aimed at enhanced quality of family and community care for persons with Alzheimer's and related disorders.

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groups, self-care programs, and respite care) along with behavioral and skill-building techniques, which are available in standardized reproducible protocols and can be customized to caregiver risk profiles.

Future Responses to Alzheimer's Family Care

Evidence-based interventions for family caregivers are being translated into intervention protocols and packaged training materials that can be tested or evaluated in community settings. However, there remains a significant need to improve the quality of care in family settings through integration of health and social support services. This seamless, systematic, and more comprehensive support for families must focus on the vulnerable transition points in Alzheimer's care identified previously in this commentary.

Plans are in place to link this evidence-based research on family caregiver interventions to service delivery systems change in states (like North Carolina) that are participating in the Administration on Aging's Alzheimer's Disease Demonstration Grant to States Program (see Derence article on Project CARE).[13]

While we wait for state policy and service systems change, much can be done to assist physicians and community agencies to collaborate effectively in offering dementia-capable, family-centered care. **NCMJ**

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COMMENTARY

North Carolina's Support of Family Caregivers

Christine Urso, MSW

A significant number of adult North Carolinians are family caregivers. Many try to juggle the demands of children, grandchildren, and jobs, while taking care of their older relatives. By doing this, they often put their own health in jeopardy. According to the 2003 Behavioral Risk Factor Surveillance System Survey, one of every four adults in North Carolina provided regular care for an older adult within the past month.[1] Close to half reported that the person for whom they are caring has memory loss, confusion, or a disorder such as Alzheimer's disease (AD).

Although caregiving is a normative experience for families and plays an integral role in our long-term care system, it does not come without a price. Families providing care to a person with AD usually face a longer and much more difficult journey. As Dr. Taylor asserts in his issue brief,[2] our society must recognize the staggering quasi-external costs of caregiving (i.e., the deleterious effect on caregivers' immediate and retirement finances, physical and emotional health, family relationships, etc.) and examine the merits of using public dollars to help families care for loved ones at home. Taylor suggested that our inaction in support of caregivers speaks volumes.

The 2001 Report of the North Carolina Institute of Medicine's Task Force on Long-Term Care also called for action:

> The Office of Long-Term Care, within the Department of Health and Human Services, should assure that all policy and program development activities consider and respect the importance of family caregiving and examine how to further strengthen the capacity of families to perform their caregiving function.[3]

While North Carolina has begun to recognize and support the value of family caregivers, we are still in our infancy in developing the array of supports they need.

Because caregivers' needs change as the condition of their loved ones changes, a wide variety of supports must be available through the various stages and circumstances of the caregiving career. More importantly, there must be flexibility in the provision of these supports.

"While North Carolina has begun to recognize and support the value of family caregivers, we are still in our infancy in developing the array of supports they need."

What Is North Carolina Doing to Support Caregivers?

North Carolina first officially recognized the need to *support* caregivers of older adults in 1985[4] when the General Assembly passed respite care legislation and provided some funds to be administered through the (then) state Division of Aging. The statute identified the importance of counseling, support groups, training, access to services, assessment and care planning, and respite for the caregiver through in-home assistance and temporary out-of-home placement. This legislation targeted caregivers of persons age 60 and older, but was later revised to serve also people aged 60 and older who are providing care for an adult of any age. Although these funds helped raise awareness of caregivers' special needs, no concentrated, coordinated effort was implemented on behalf of family caregivers until the creation of the National Family Caregiver Support Program (NFCSP) in 2000.

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Figure 1.
North Carolina's Family Caregiver Support Program

Vision

Families will enter into caregiving with the knowledge and assurance that they can call upon the business, faith, and health and human service communities to assist with information, counseling, problem solving, respite, and formal services when needed.

Care Recipient and Caregiver Characteristics

- The average age of the person receiving care is 80, while more than half (53%) of caregivers are between ages 40 and 59.
- Nearly half of care recipients are cognitively impaired (44%).
- Seven in ten caregivers live with the care recipient.
- More than three-quarters of the caregivers are women (76%).
- Nearly half of the participants are caring for their parents (45%) and about a third (32%) for their spouse.
- Half of caregivers report their own health as 'fair' or 'poor,' as opposed to 'well.'

With the 2000 enactment of the Older Americans Act (OAA) Amendments, the NFCSP became the first federal program with a required focus on the caregiver. The NFCSP, Title III-E of the OAA, is intended to offer a "multifaceted system" of caregiver supports. The NFCSP must contribute to a seamless service delivery system, building on effective services, and developing new services where needed. The legislation allows five broad categories of supports, which correspond closely to those of North Carolina's 1985 Respite Act:

- Information
- Assistance with access to services
- Individual counseling, support groups, and caregiver training
- Respite care
- Supplemental services (on a limited basis) to complement the care provided by eligible caregivers[5]

The primary population served by the NFCSP are the family caregivers of persons aged 60 and older. Family is defined very broadly and includes adults in the immediate family as well as caregivers in the community who provide informal assistance. In many instances, these families are caring for older persons with AD or related dementia. The NFCSP also recognizes and supports grandparents and other relatives age 60 and older who are primary caregivers of minor children. See Figure 1 for further information on North Carolina's Family Caregiver Support Program (FCSP).

The OAA services, including the NFCSP, and state funds to serve community dwelling older adults are administered by the Division of Aging and Adult Services, within the North Carolina Department of Health and Human Services, through a network of 17 Area Agencies on Aging and hundreds of local providers. The services under its Home and Community Care Block Grant services include home-delivered meals, in-home aide, adult day services, and transportation. These services are available to any person aged 60 and older, although special effort is made to reach seniors who are socially and economically needy. Many of these services provide relief to family caregivers. At the end of 2004, more than 7,500 seniors were on a waiting list for services. In addition, services to at-risk adults of all ages are administered by Division of Aging and Adult Services through the county departments of social services. One of these services—Adult Protective Services—sheds additional light on the importance and stresses of caregiving. Among the Adult Protective Services-confirmed cases handled in 2003-2004, more than half (54%) involved self-neglect, 26% caregiver neglect, 12% exploitation, and 7% abuse.[6]

Challenges to Implementing a Caregiver Support Program

In implementing the NFCSP, the Division of Aging and Adult Services and the Area Agencies on Aging have had to tackle significant challenges. First, families providing care do not typically identify themselves as being "caregivers." They are just doing what comes naturally as a part of their familial responsibility. Their interest in the use of services is directly related to how their loved one will benefit.

From the program's inception in 2001, North Caroilina's version of the NFCSP has emphasized public awareness. Specifically, the program has attempted to reach caregivers and

Figure 2.
How Healthcare Professionals Can Assist Caregivers

Identify and recognize family caregivers.	25% of adult North Carolinians are caregivers of adults 60 and older.
Assess how the caregiver is coping.	Caregiver assessment forms in English or Spanish can be be downloaded at http://www.ama-assn.org/ama/upload/mm/36/caregivertooleng.pdf.
Provide information and education on the patient's disease process.	In addition to information that healthcare practitioners provide, caregivers can also refer to the Western and Eastern Alzheimer's Chapters and the Duke Family Support Program.
Encourage caregivers to be a partner in care.	Barring safety concerns, support families' decisions for where care will be provided, whether in an institution or at home.
Refer caregiver for support and further information.	Connect with the Family Caregiver Specialist at the Area Agency on Aging or contact the local Council or Department on Aging.

those who touch their lives, including employers, the faith community, and health and human service professionals. Because caregivers often do not self-identify, public awareness efforts remain critical. Caregivers need to know that they are not alone and that support services are available. Not only is public awareness key to reaching isolated caregivers, it also helps build partnerships and leverage resources.

The healthcare community has a vital role in this outreach and is viewed by the program as an important partner. Figure 2 outlines a view of some of the significant roles that healthcare professionals can assume in the lives of caregivers.

Caregivers often turn to healthcare professionals for information, and not surprisingly, this increases as the caregiver burden grows. Information is cited as the chief unmet need of caregivers in several surveys. The 2004 Caregiving in the United States Survey found that two-thirds of caregivers need more information on a variety of topics.[7] This figure jumps to three-fourths for those caring for persons with AD. Alzheimer's caregivers report a need for information on resources, help in navigating the system, and managing special behavioral challenges presented by their loved ones.

One successful effort that is helping physicians to better assist caregivers is *Making the Link: Connecting Caregivers with Services through Physicians*. This is a program of the National Association of Area Agencies on Aging and the United States Administration on Aging. Several of North Carolina's Area Agencies on Aging are using the tools of this program to raise awareness within the medical community about how caregiving can present its own health risks and to help physicians connect caregivers to local services when appropriate. In endorsing the program, the American Medical Association asserts, "an effective relationship model acknowledges the key linkage role of the primary care physician and recognizes that caregivers and patients form interdependent units. It also considers the caregiver as a partner with the physician in the care of the patient. The physician demonstrates concern for and carries out periodic assessment of the caregiver as well as the patient and validates the role of the caregiver."[8]

Hopefully soon, physicians and their patients will be better able to access information about community supports throughout North Carolina. A new initiative of the North Carolina Department of Health and Human Services will connect various community resource databases from across the state. This statewide database will be made available on the Internet to aid the location of supports for near-by or long-distance caregivers. Because of the myriad of services provided through a variety of public and private for-profit and not-for-profit agencies, caregivers need easier access to information about these services in making decisions about the care of their family members.

A second barrier to the program's implementation has been the limited federal funding made available, especially relative to need. North Carolina received $2.9 million in 2001 to start the Family Caregiver Support Program, and this increased to $3.7 million in 2004. These funds are minimal in comparison to the more than $868 million spent in North Carolina under Medicaid for nursing home care in 2003.[9] Without the ongoing support of families, the need and cost of facility care would surely rise. In introducing the NFCSP to states in early 2001, Edwin Walker, Director of Program Operations and Development at the United States Administration on Aging (AoA), offered these words of advice:

- The Caregiver program offers a chance to change the long-term care paradigm and correspondingly, the long-term care delivery system, to acknowledge the role of informal, unpaid services by caregivers.
- The focus is on the needs of the caregiver as opposed to the care recipient.
- We want to develop and implement multifaceted and coordinated systems of supports, not just services. The focus is on responding to diverse needs of today and building for tomorrow.
- Exercise caution—strategically plan a system of services, assess needs of caregivers, prioritize these needs, find and incorporate research and best practice—integrate, build on and enhance what exists when possible, including use of non-traditional partners as well as the current home and community-based care programs.
- Don't rush to provide services. Avoid the temptation to dump the money into existing respite services just to get it spent.
- AoA is going easy on regulations for the Caregiver program, preferring to allow flexible, innovative implementation at the local level. Don't push AoA to regulate or define things too quickly.
- Build broad-based coalitions that include non-traditional partners and find ways to maximize resources in comparison to need.
- Produce and document desired outcomes—build a foundation to justify the caregiver funding and advocate for additional funds.

Creating Partnerships

North Carolina heeded this advice and saw the need first to address a third challenge to the program's implementation, namely, the absence of a community infrastructure to focus on caregiver needs. The Division responded by creating the position of Family Caregiver Resource Specialist in each of the 17 Area Agencies on Aging located within regional Councils of Government across the state. These Resource Specialists are charged with building the multifaceted and well-coordinated system of supports that caregivers need. With limited public funds available, the specialists work to create partners and leverage resources whenever possible. Their success in this regard, along with the increasing number of local specialists, is largely responsible for the program's effectiveness to-date. With input from many different community agencies and groups and from caregivers themselves, these specialists have seeded numerous new and unique partnerships.

Strong partnerships with statewide organizations [i.e., North Carolina Cooperative Extension, Duke Family Support Program, AARP-NC, and The Carolinas Center for Hospice and End-of-Life Care] have provided significant support in the development and implementation of the Family Caregiver Support Program. For example, the North Carolina Cooperative Extension Aging Specialist and a social worker from the Duke Family Support Program became master trainers for a highly acclaimed caregiver curriculum the "Taking Care of You: Powerful Tools for Caregivers." With the assistance and financial support of AARP-NC, class leader workshops for this and other caregiving curricula were held across the state. Locally the Area Agencies on Aging, Cooperative Extension, AARP Health Specialists, and others now partner to deliver these workshops directly to caregivers across the state.

AARP-NC has further demonstrated its strong commitment to caregiving with two publications: the *Family Caregiving in North Carolina* guidebook and a *Grandparents Raising Grandchildren Guide*. These publications were developed with input from many participating partners. AARP-NC has also sponsored surveys and conferences aimed at helping businesses support caregivers in the workplace.

North Carolina is fortunate to have very strong professional and consumer resources focused specifically on AD. These resources have been instrumental to the implementation of the FCSP.

Since 1994, the General Assembly has invested in services for families affected by AD by helping fund programs of the Eastern North Carolina and Western North Carolina Chapters of the Alzheimer's Association. Their programs include support groups, caregiver workshops, maintaining a library of educational materials, toll-free help-lines, and many other services. Caregivers are learning first-hand about AD and strategies for managing challenging behaviors, and their association with others in similar situations helps reduce feelings of isolation. A calendar of events for the Eastern Chapter is found at http://www.alznc.org and for the Western Chapter at http://www.alz-nc.org. Since 2001, each of the two Chapters has received $75,000 in state funds, which has been critical to their operation.

Duke's Family Support Program, with an emphasis on dementia-specific supports, also receives state funds. Since 1984, the program has used its $50,000 to serve as a one-stop clearinghouse, crisis hotline, and technical assistance center for families and professionals caring for people with memory disorders. The state funding of the Alzheimer's Chapters and the Duke Family Support Program also has enabled North Carolina to leverage other resources. For example, it is helping provide the required matching funds for the federal Alzheimer's Demonstration Grant that the Division of Aging and Adult Services is currently administering and that is described in the commentary by Karisa Derence.[10]

The fact that North Carolina has chosen to support Alzheimer's-specific services is admirable among states. The fact that these funds have been stagnant is cause for reflection and concern. The number of family caregivers, including those of persons with AD, is growing dramatically with the aging of our state's population.

How Is the State Addressing Policy Issues?

Our nation, state, and local communities face a monumental challenge in meeting the long-term care needs of the aging population. As the state continues to move forward to meet the requirements of the United States Supreme Court's Olmstead decision for promoting the least restrictive care environment, family caregiving will inevitably play an even more critical role.

The North Carolina Department of Health and Human Services is the recipient of several grants through President Bush's *New Freedom Initiative*. These "systems change" grants through the Center for Medicare and Medicaid Services are charged with improving the infrastructure, availability, and

North Carolina Department of Health and Human Services:
Resources for Caregivers by Division

http://www.dhhs.state.nc.us/docs/division.htm

Division of Aging and Adult Services

Information and assistance, adult day services, in-home aide services, respite, caregiver support, transportation, home delivered meals, adult protective services, elder rights, long-term care ombudsman, guardianship, case and care management, adult placement services, Special Assistance In-Home Program (in selected counties),

Division of Services for the Blind

Adjustment to vision loss, counseling, information and instruction in basic living skills.

Division of Services for the Deaf and Hard of Hearing

Regional Resource Centers

Division of Medical Assistance

A Medicaid waiver program: Community Alternatives Program for Disabled Adults (CAP/DA)

Division of Mental Health, Developmental Disabilities and Substance Abuse Services

Area Programs

Division of Vocational Rehabilitation

North Carolina Assistive Technology Program quality of community services available to adults with disabilities. As envisioned, informed consumers will increasingly have the opportunity to direct their own plan and delivery of service supports. While these grants enhance work on systems change, demand for community services continues to exceed availability.

As society hears increasingly about the value of quality care in the setting of choice, government struggles with how to pay for this care for many of its citizens whose resources are inadequate or quickly diminish with the high cost of care. Government must operate under a responsive long-term care system where the caregiving contributions of families are valued and supported. Just as businesses are realizing the economic sense of responding to the interests and needs of working caregivers, support of caregivers is sound public policy.

This year (2005) the NFCSP comes up for reauthorization under the Older Americans Act. Also this year, the fifth White House Conference on Aging is scheduled, October 23-26, 2005. The previous conferences, held in 1961, 1971, 1981, and 1995, were significant in their policy recommendations to the President and Congress. They also assisted the public and private sectors in identifying emerging trends and preparing for current and future generations of older persons. One of many important issue areas will surely be health and long-term care and within this discussion, the importance of investing in family caregiving.

North Carolina's delegates to the White House Conference will be able to voice their opinions on the NFCSP and other public policy considerations, such as the proposed Ronald Reagan Alzheimer's Breakthrough Act of 2004. This bill would double funding for AD research at the National Institutes of Health (from $700 million to $1.4 billion); support a National Summit on Alzheimer's Disease; and increase the availability of services, such as respite care, home healthcare, counseling, and training. The bill also proposes to double funds for the NFCSP (from $125 million to $250 million) and the Alzheimer's Demonstration Grant Program (from $12 million to $25 million).

Both nationally and in North Carolina, we must follow the lead of the Task Force on Long-Term Care of the North Carolina Institute of Medicine, in finding "ways to invest in family caregiving so that it can be sustained as a primary resource for long-term care, reducing the risk for needing formal, publicly-financed services." **NCMJ**

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COMMENTARY

Dementia-Specific Respite:
The Key to Effective Caregiver Support

Karisa Derence, MA

Value of Informal Dementia Care

Most older adults, including those with dementia, prefer to remain at home and in the community for as long as possible. More than 70% of the 4.5 million Americans currently diagnosed with Alzheimer's disease live at home and are cared for by family and friends.[1] In order to ensure that individuals with dementia receive quality care in the environment of their choice, the support of informal caregiving is critical.[+] Extending the duration of home care is also an important health and quality of life issue. Adjusting to a new environment is particularly difficult for a person with Alzheimer's disease. The comfort and security of familiar surroundings and a stable routine can help alleviate the fear and anxiety often associated with progressive memory loss.

The value of informal caregiving extends beyond ensuring quality of life and freedom of choice. It has become "an essential element of our health and long-term care system."[2] The national cost of caring for people with Alzheimer's disease has reached at least $100 billion.[3] Unless an intervention or cure is found soon, Alzheimer's could bankrupt Medicare and Medicaid.[3] Even a one-month delay in nursing home placement is estimated to save the healthcare system $1 billion a year.[4] The contributions of family caregivers, worth $257 billion in unpaid services and support, are more than double the annual cost of home care ($32 billion) and nursing home care ($92 billion) combined.[1] This level of assistance simply cannot be replaced. The need to support and sustain family care at home will only intensify as our population ages.

> *"Unless an intervention or cure is found soon, Alzheimer's could bankrupt Medicare and Medicaid."*

Burden of Dementia Caregiving

The progressive and unpredictable nature of Alzheimer's disease poses enormous challenges to caregivers. People with Alzheimer's disease live an average of eight years after diagnosis but may survive for up to 20 years. They need help with most activities of daily living such as bathing, dressing, eating, and dealing with incontinence. Their level of care and ability to communicate can fluctuate from one day to the next and they may be resistant to personal care assistance. Behaviors such as wandering, hoarding, and perseveration further complicate care needs and create serious safety issues. Eventually, most individuals with Alzheimer's disease will need full-time care and continuous supervision.

A recent survey reported that among all caregivers, those caring for people with dementia experience a disproportionately heavy burden.[5] They spend more hours providing care over longer periods of time. More than half feel as if they are "on call" 24 hours a day and have to reduce or end employment to fulfill the demands of caregiving.[6-8] Dementia caregivers encounter more family conflict, personal stress, serious health problems, and a shorter life expectancy.[6,8,9] Many of these caregivers cope with immense grief and feelings of guilt, anxiety, and anger. Nearly half (43%) are clinically depressed.[10] The unique behavioral and communication challenges associated with dementia require specialized skills and make it even more difficult for the caregiver to get rest or help providing care.

Dementia caregivers are particularly vulnerable to severe burnout. Reaching this level of stress and fatigue places both the caregiver and the person with dementia at risk and is one of the most cited reasons for early institution-

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[+] In this commentary, the term "informal caregiver" is used interchangeably with "family caregiver" to include all types of unpaid primary caregivers: family members, friends, and/or neighbors. The term "Alzheimer's" is used interchangeably with "dementia" to include all types of progressive memory impairment or mental confusion.

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alization.[11] Caregivers need to adequately manage stress and have effective ways to relieve the tremendous burden of providing constant care. In doing so, family caregivers strengthen their ability to provide quality long-term care at home.

Respite* Options

Family caregivers identify respite care as one of their greatest needs.[12] Respite care offers relief for family, friends, and other informal caregivers so they can take a much needed break from their daily responsibilities while knowing their loved ones are in good care. Respite represents a continuum of services based on the individual needs of the caregiver and the person with dementia. There are many different ways respite can be provided (see Table 1):*

- In a home, community organization, or residential facility;
- For part of the day, evening, or overnight;
- By paid staff, volunteers, family, or friends;
- Occasionally or on a regular basis.

Dementia caregivers desperately need sufficient and regular amounts of respite, more than just temporary or short-term intervals. Respite support should be ongoing and is most helpful before the caregiver becomes exhausted, isolated, and overwhelmed. Families need to consider respite care before reaching a point of crisis. The unique circumstances of each family will help determine what type of support is most appropriate. The most successful and effective respite programs promote flexibility and consumer control, allowing caregivers to direct their own care.

Benefits of Respite Care

Respite care benefits both the primary caregiver and the individual with dementia. The person with dementia is provided with social stimulation and the opportunity to live in the community longer. Respite enhances quality of life, promotes better psychological health, and preserves family and caregiving relationships.

Respite care also mitigates the distress of caregiving and delays costly out-of-home placement.[12] Caregivers receive the kind of help that reduces the burden of dementia care and the likelihood of abuse and neglect. Without adequate support and timely respite, families often suffer economically and emotionally, and caregivers themselves face serious health and social consequences.

> *"Respite care also mitigates the distress of caregiving and delays costly out-of-home placement."*

Comprehensive Interventions

Respite care is most effective when enhanced with other caregiver-focused services such as individualized counseling, education, and ongoing support. Though essential, these services should not be used in isolation.[13] Flexible and comprehensive support programs maximize the benefits of caregiver interventions by effectively relieving caregiver depression and care-related stress over a long period of time.[10,13,14]

For many caregivers, respite is a gateway to more comprehensive care including training and emotional support.[15,16] Respite relief helps caregivers gain further perspective and make better decisions. Caregivers begin to take steps toward maintaining personal health and are often more willing to connect with peers and explore additional resource opportunities.

A Model Program

The North Carolina Alzheimer's Demonstration Program, Project CARE (Caregiver Alternatives to Running on Empty), uses a consumer-directed, family consultant model to provide comprehensive respite support to dementia caregivers. The goal of the program is to increase access, choice, use, and quality of respite care to underserved rural and minority communities. Through the integration of dementia-specific services, Project CARE intends to create a seamless, coordinated delivery system that is responsive to the needs, values, and preferences of Alzheimer's families.

Project CARE is funded through the federal Administration on Aging Alzheimer's Disease Demonstration Grants to States Program (ADDGS). The program is administered by the North Carolina Division of Aging and Adult Services and receives technical assistance from the Duke Aging Center Family Support Program. Operating within the community-based contexts of the Western Carolina Alzheimer's Association and the Mecklenburg County Department of Social Services, Project CARE Family Consultants visit the homes of referred Alzheimer's caregivers in crises. The consultants offer timely, individualized guidance, counseling, support, advocacy, and education for family caregivers. Their aim is to match families with the most appropriate and preferred local respite and community services tailored to the unique context of care and family needs. Families are able to choose among a full continuum of consumer-directed care options, including adult day services, group respite, private or agency in-home care, and overnight residential respite. There are three pilot sites set up to serve the following ten counties: Winston-Salem (Forsyth, Surry, and Stokes Counties); Asheville (Polk, Henderson, Transylvania, Rutherford, Madison, and McDowell Counties); and Charlotte (Mecklenburg County).

Project CARE Family Consultants employ a family-centered, home-based intervention. The North Carolina demonstration program emphasizes the use of home visits to accommodate caregiver time and energy limits. During home visits, the consultant:

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* Respite (res' pit) n. 1. a delay or postponement 2. an interval of temporary relief or rest.

Table 1.
Respite Options

Types	Provider	Services	Benefits/Cost
In-home Care	Employed privately, through a home health agency, or as part of a government program	1 Companion: help with supervision, recreational activities, and visiting. 2 Personal Care: assistance with bathing, dressing, incontinence care, and other activities of daily living. 3 Homemaker: help with housekeeping, shopping, and meal preparation. 4 Skilled nursing care: help with medication and other medical needs.	Person with dementia receives one-on-one attention within the comfort of their own home. Caregiver does not have to provide or arrange for transportation. Variety of service options and types of assistance. Moderate cost—dependent on level of care.
Adult Day Programs (or "community-based service")	State Certified Adult Day Care or Day Health Centers; Group Respite Programs	Daily activities may include music, exercise, social stimulation, and peer support. Staff are often highly interactive and, in some centers, consist of a social worker and recreation therapist. Adult Day Health Centers offer medical services administered by a registered or licensed nurse. Some centers have specialized Alzheimer's programs.	Participants have the opportunity to interact with others while being part of a structured environment. Most programs provide a meal and/or snacks. State certified centers are open a minimum of six hours per day for at least five days a week. Group respite programs are open a maximum of five hours per day, four days a week. Allows caregivers to continue working outside the home. More respite time available at a lower annual cost.
Residential Respite (or "institutional respite")	Nursing Homes, Residential Care Facilities, and Assisted Living Facilities	Provides overnight or short-term respite stays ranging from a few days to several weeks. Services include personal care assistance, meals, laundry, and therapeutic activities. Some facilities have special care units or programs for people with dementia.	Allows caregivers to take an extended break or vacation while the person with dementia stays in a safe, secure environment. Option for emergency situations such as an accident, illness, surgery, or long-distance trip. May be needed for crisis situations where there is a risk of abuse or neglect. High cost. Person with dementia may have difficulty adjusting to the new environment.
Informal Respite	Involves the help of family, friends, neighbors, church groups, or other volunteers who can share the responsibility of caregiving.	Range from companion services to personal care or household assistance. Some communities have organizations or support team networks that provide a stable source of volunteer caregiving services (e.g., Center for Volunteer Caregiving: www.volunteercaregiving.org; The Support Team Network: www.supportteam.org)	Provides emotional support for the caregiver and helps the person with dementia maintain a healthy level of social and recreational activity. Receive same benefits as non-medical in-home care at no cost. Not available in all communities. May not be as dependable as professional care. Some families feel they have less quality control when services are free. Can also be used to supplement formal care.

For more information, see the Respite Care Guide: How to Find What's Right for You (National Alzheimer's Association: www.alz.org), Community Care Options (Family Caregiver Alliance: www.caregiver.org) or Respite for Persons with Alzheimer's Disease or Related Disorders (ARCH National Respite Network and Resource Center: www.archrespite.com)

- assesses the family care environment,
- identifies the needs of both the caregiver and the person with dementia,
- facilitates discussion and mutual understanding among family members,
- connects the family with community resources, and
- ensures the provision of quality services.

The personalized approach of the Family Consultant fosters family trust, instills a variety of skills, and promotes self-care. Project CARE families learn the value of respite and are empowered to make self-directed, informed decisions about care.

Project CARE builds upon, enhances, and sustains existing home and community-based services. The Family Consultant uses local providers to deliver respite care and serves as a direct link to the expertise and resources of the Alzheimer's Association. Project CARE also opens doors to the Family Caregiver Support Program and other caregiver-focused initiatives creating a strong network of community support for Alzheimer's families. This comprehensive system builds the family's capacity to manage all the challenges inherent in caring for individuals with dementia.

Future Direction

Within the next ten years, as the first wave of baby boomers reach the age of greatest risk, the numbers of people affected by Alzheimer's disease will increase dramatically. In 2000, an estimated 132,329 older adults in North Carolina had mild, moderate, or severe Alzheimer's disease. This number is projected to rise to 253,176 by 2025—an increase of 91%.[17] It is critical that we prepare for this upcoming healthcare crisis by creating a sustainable, dementia-capable system of respite support for Alzheimer's families across the entire state.

The future of respite care in North Carolina is at a crossroads. The state Family Caregiver Support Program (FCSP) has insufficient funds to adequately serve all types of caregivers, and it does not contain a dementia-specific component. As we look to the future, federal and state policy makers would be well advised to build on the success of the FCSP and the Alzheimer's Disease Demonstration Project. North Carolina must integrate and fund dementia-specific respite as part of all future caregiver support programs. **NCMJ**

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North Carolina Alzheimer's and Dementia Web Resources

Diagnostic and Treatment Centers:

- Duke University Center for the Study of Aging and Human Development - Geriatric Evaluation and Treatment Clinic, Durham: www.geri.duke.edu/service/get.html 919-620-4070
- Duke University Joseph & Kathleen Bryan Alzheimer's Disease Research Center - Memory Disorders Clinic, Durham: http://adrc.mc.duke.edu/mdcfront.htm 919-668-7600 or 866-444-2373
- East Carolina University Brody School of Medicine - Geriatric Center, Greenville: www.ecu.edu/ecuphysicians/fpc/geriatric_center.htm 252-744-2045
- Memory Assessment Clinic and Eldercare Resource Center, Asheville: www.memorycare.org 828-771-2219
- Neurology Consultants of the Carolinas, Charlotte: www.neurology-consultants.com 704-927-7300
- University of North Carolina Memory and Cognitive Disorders Clinic - Department of Neurology, Chapel Hill: http://neuron.med.unc.edu/neurology/memcog.htm 919-966-5549
- University of North Carolina Program on Aging - Geriatric Evaluation Clinic, Chapel Hill: www.med.unc.edu/aging/clinical services_patient.htm 919-966-5945
- Wake Forest University Baptist Medical Center - J. Paul Sticht Center on Aging and Rehabilitation: Geriatric Consultation Clinic, Winston-Salem: http://www.wfubmc.edu/sticht/services/geriatric-asses.html 336-713-8543
- Veterans Health Administration Medical Center - Geriatric Research, Education and Clinical Center (GRECC), Durham: www1.va.gov/geriatricsshg/docs/ GRECC.doc 919-286-0411 ext. 6900

Alzheimer's and Dementia Support Services:

- Eastern North Carolina Alzheimer's Association Chapter: www.alznc.org 919-832-3732 24-HOUR HELPLINE 800-228-8738
- Western Carolina Alzheimer's Association Chapter: www.alz-nc.org 704-532-7392 24-HOUR HELPLINE 800-888-6671
- Duke Aging Center Family Support Program: www.duke familysupport.org 919-660-7510 or 800-672-4213

Family Caregiver Support and Community Education:

- AARP: www.aarp.org/states/nc
- Area Agencies on Aging: http://www.dhhs.state.nc.us/aging/aaa.htm
- North Carolina Division of Aging and Adult Services: www.dhhs.state.nc.us/aging
- North Carolina Family Caregiver Support Program: www.dhhs.state.nc.us/aging/fcaregr/fchome.htm
- North Carolina Caregiver Information: www.fullcirclecare.org
- North Carolina State Cooperative Extension: www.ces.ncsu.edu/depts/fcs/human/adult.html

Respite Care Information and Programs:

- ARCH National Respite Network and Resource Center: www.archrespite.org
- Easter Seals: www.easterseals.com
- Faith In Action: www.fiavolunteers.org
- North Carolina Information and Assistance Program: http://www.dhhs.state.nc.us/aging/services/iassist.htm
- North Carolina Adult Day Services Association: www.ncadsa.org
- Project Compassion: www.project-compassion.org
- Shepherd's Center of America: www.shepherdcenters.org
- The Brookdale Foundation: www.brookdalefoundation.org
- The Support Team Network: www.careteam.org

National Organizations, Programs, and Referral Sources:

- Alzheimer's Association (National Office): www.alz.org
- Alzheimer's Disease Education & Referral Center (ADEAR): www.alzheimers.org
- Alzheimer's Research Forum: www.alzforum.org/dis/abo
- American Association of Geriatric Psychiatry: www.aagpgpa.org
- American Health Assistance Foundation: www.ahaf.org
- Eldercare Locater: www.eldercare.gov
- eMedicine Consumer Health: www.emedicinehealth.com/articles/39500-1.asp
- Family Caregiver Alliance: www.caregiver.org
- Fisher Center for Alzheimer's Research Foundation: www.alzinfo.org
- Mayo Clinic's Alzheimer's Center: www.mayoclinic.com
- National Adult Day Services Association: www.nadsa.org
- National Association of Professional Geriatric Care Managers: www.caremanager.org
- National Family Caregivers Association: www.nfcacares.org
- National Institutes of Health:

  Senior Health: http://nihseniorhealth.gov/alzheimersdisease/toc.html

  National Institute on Aging: www.nia.nih.gov

  National Institute on Neurological Disorders & Stroke: www.ninds.nih.gov

    National Library of Medicine: Medline Plus - Alzheimer's Caregivers:: www.nlm.nih.gov/medlineplus/alzheimerscaregivers.html

    Alzheimer's Disease: www.nlm.nih.gov/medlineplus/alzheimersdisease.html

- Neuropathology - Dementia: www.uvm.edu/~jkessler/NP/neudemen.htm
- The Alzheimer's List Homepage: http://alzheimer.wustl.edu/adrc2/alzheimerlist
- United States Administration on Aging Alzheimer's Resource Room: www.aoa.gov/alz

COMMENTARY

Managing the Patient with Dementia in Primary Care

Sindy McCrystle, ANP-C, MSN, and Darlyne Menscer, MD

The primary healthcare provider can play an especially important role in the early detection, patient and family counseling, and medical care of the older adult with dementia or Alzheimer's disease (AD). The patient with such a diagnosis presents a unique set of challenges for the healthcare professional, whether physician, dentist, nurse practitioner, or physician assistant. Early on after such a diagnosis, the focal "client" becomes more than the patient alone, but must include consideration of the family or caregiver role(s) and the context within which the patient lives and receives care from loved ones or friends. Few of us, regardless of professional background, have received adequate training and experience in the management of the many dimensions of Alzheimer's disease and its manifestations to feel completely comfortable delving into the issues likely to be brought to our attention by family, friends, and even Alzheimer's patients themselves.

> *"Having an early definitive diagnosis and some understanding of the probable course of this disease can help families maximize quality time with loved ones and share periods of better health and lucidity with children, grandchildren and others."*

Establishing a Diagnosis of Alzheimer's Disease

It is important to diagnose AD as early as possible. Medications are available that can slow the progression of the disease, giving patients and their families precious time to make necessary adjustments and plans, as well as to forestall the urgency of nursing facility placement. Most importantly, as the disease progresses, there are important safety precautions that families with this information can use to lessen the likelihood of unfortunate circumstances or accidents in the home or in the larger community. Having an early definitive diagnosis and some understanding of the probable course of this disease can help families maximize quality time with loved ones and share periods of better health and lucidity with children, grandchildren, and others.

Despite the advantages of early diagnosis, it is quite common for clinicians to miss or misinterpret the signs of this disease and therefore be unable to assist with a more accurate and useful diagnosis early in the progression of the disease. Diagnosis is made even more complex by the fact that patients often work hard to disguise the symptoms that might signify the early stages of this disease. We have been made aware in our own practice of the extent to which some patients actually "rehearse" their likely interactions with their primary care physicians (such as reviewing the date, month, county of residence, names of the United States President and Vice President, and their own children) so as not to appear "forgetful" and to be judged to be as "normal" and "independent" as possible. Stories circulating among older adults about some who have come away from visits to their physicians with the admonition to give up their driver licenses and automobiles make many fear these visits. Whether imagined or real, any limitations on independence or any suggestion of the needs to live in a more dependant environment can be intimidating for a person with AD.

One strategy for minimizing the likelihood of obfuscation

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of these basic signs of dementia that has proven helpful to many clinicians is to ask that older patients be accompanied by family members (or close friends familiar with their everyday routines and living situations). Patients who naturally want to maintain their independence, dignity, and self-respect are uncomfortable with the discussion of problems with memory or functional activities of daily living. Even discussion of these issues with other family members in the presence of the patient can produce tensions between family members. But, every visit with a healthcare provider can be a valuable opportunity to note changes in one's physical, emotional, and functional status, as well as a chance to ask questions that might unveil new problems. Unusual scenarios recounted in these encounters can reveal patterns of behavior that signal the need for more careful diagnostic exploration (such as missed appointments, electricity or telephone service being cut off unexpectedly, problems with one's checking account and encounters with a local bank, repeated episodes of familiar cooking recipes not turning out well, leaving the burner of a stove on, or failure to remove a pot from the stove, etc.) are all valuable pieces of information that take a few minutes to garner in these visits, but are rarely shared by the patient visiting a clinic alone for a regular periodic encounter.

One of the most helpful aspects of medical care delivery systems for assuring that conditions of dementia or Alzheimer's disease are identified early is having every older adult served by a singular primary care provider who can follow the patient (and know the patient's family and living situation) over a sustained period of time. When multiple specialists are involved in the care of a single patient, each may be so focused on the specific clinical problem for which the patient has sought their care, and each may assume that the patient is being managed in a more comprehensive way by someone else, that no one actually "connects the dots" or synthesizes a complete picture of the individual's state of health. Diagnoses of dementia or Alzheimer's disease can take far longer when there is no single provider responsible for coordinating the care of the older adult. It is also important to use one pharmacy so that medications can be managed safely, even if multiple prescribers are involved. The pharmacist can be invaluable in detecting problems with multiple medications of the same class, too frequent refill requests, allergies, and identifying duplicate medications if generics and brand names are being used by different providers. Eliminating unnecassary polypharmacy is helpful.

Once the Diagnosis is Made: What Next?

At the point that a diagnosis can be established, the Alzheimer's patient and his/her family have a number of issues and challenges that require deliberate attention and often require the assistance of professionals in fields other than medicine or the health professions. Though it may not appear necessary at the time of an "early" diagnosis, care options for the future should be thought about and planned as early as possible. If the decision is made to continue living in one's residence, as is often the case for those whose diagnosis is made earlier, the presence of others who can offer social support is a consideration. The ability to drive, shop, cook, maintain household cleanliness and personal grooming, and participate in various aspects of social life (such as church attendance) become issues of importance to those with this diagnosis. Financial and legal planning are also important considerations. The management of personal banking and other financial matters is something that most families find difficult to discuss with a loved one who has an early diagnosis of dementia or Alzheimer's disease, but these matters become progressively more important as the disease develops. Advanced directives and healthcare power of attorney documents are the most important legal considerations, both of which need to be arranged while the individual is cognitively able to speak for him/herself, although these documents only become operative when the individual no longer has this cognitive capacity.

Physicians and other healthcare providers often do not see their role as very "direct" with regard to these issues, but asking the right questions and directing patients and their family members to appropriate community resources can be invaluable (many of whom are identified elsewhere in this issue of the *North Carolina Medical Journal*).

As the Disease Progresses, Caregiving Becomes Increasingly Important

In the United States, many families are smaller or more geographically distant with many more women working outside the home than in past generations. This can make caregiving options more difficult than in other countries or cultures. Adult grandchildren seem to be emerging as caregivers of AD patients. Their ability to drive and shop and cook can often be exchanged for free housing and other financial benefits. Late-life relocation can rob seniors of informal support systems such as a faith community, neighbors, civic clubs, and extended families. Long-distance caregiving can result in feelings of guilt among caregivers, especially family members. This is particularly relevant if the person with AD has been successfully hiding cognitive impairments. Many primary care practitioners have had several patients who have fallen and been unable to get up for several days, resulting in decubiti, fractures, and dehydration. Substance abuse, incontinence, or throw rugs are common causes. Simple solutions like Lifeline, telephone reassurance, or a neighbor checking on the individual can be helpful. Adding homemaking and personal care services, as the need becomes apparent, is also very useful and can extend the period of successful "aging in place."

The Importance of Routine Primary Care Visits

The routine clinical encounter with an older adult who has been diagnosed with AD should include consideration of changes in a number of dimensions of the illness experience and general life situation. It is important to assess patient function, safety, pain/comfort, and patient/caregiver coping at each of these visits. Changes involving incontinence, wandering, agitation, violence toward staff or caregiver, insomnia, active smoking, cooking, driving, guns in the home, or caregiving to young children or elder spouses when cognition in the AD person is moderately impaired can each trigger serious problems. Identifying problems in these areas and developing care plans can prevent untoward outcomes.

Unfortunately, aging in the later years often involves many losses. Loss of spouse, job, friends, driving, vision, or hearing are a few, and these can affect loss of pleasurable activities. Clinical depression is more pronounced than natural loss and is often missed in the ongoing assessment of the older adult with AD. These patients rarely present as sad or crying, but more commonly there is weight loss, isolation, and reports of "no energy" or "feeling empty." Treatment can be very effective, and patients often agree to try medications to increase appetite or boost their energy if not specifically identified as treatment for "depression."

Treating the Caregiver

For the caregiver, the first challenge is to accept that someone you care about has an incurable, progressive illness that is likely to last many years and make them very dependent with different personality traits. Role reversal is demanded with spouses becoming the parent and adult children "parenting" their parents as they become increasingly childlike and dependent.

> *"One of the most helpful aspects of medical care delivery systems for assuring that conditions of dementia or Alzheimer's disease are identified early is having every older adult served by a singular primary care provider who can follow the patient (and know the patient's family and living situation) over a sustained period of time."*

It can be uncomfortable and sometimes daunting to assume the role of disciplinarian, personal care attendant, and financial and legal planner. Decisions need to be made about how tasks that the person with AD can no longer handle will be managed by the caregiver. These include shopping, cooking, laundry, paying bills, preparing taxes, maintaining property, transportation, bathing, toileting, refilling prescriptions, making physician appointments and accompanying the person with AD, and offering socialization and religious fulfillment. Many families choose to take on these new responsibilities and assist the person with AD in their own home or have them move in with other family members. This often requires redistribution of other responsibilities to make time (i.e., part-time work rather than full-time work). Cost is also a consideration, as there is often an increased financial expense for food, gas, and prescriptions. According to the national Alzheimer's Association, more than seven out of ten people with AD live at home where family members and provide almost 75% of the care they receive. The average lifetime cost of care for an individual with Alzheimer's disease is $174,000. The average life expectancy after diagnosis of AD is eight years, but some individuals live as many as 20 years after initial symptoms occur.

Generational equity comes into play for many families. The tug of time and money being directed toward children and grandchildren versus aging parents and grandparents is a difficult one, especially for working families or those with multiple members with special needs. The allocation of resources is a personal one reflecting family and cultural values. Sometimes overlooked are the benefits that a person with AD can add to a family. Short-term memory may be impaired, but storytelling and reminiscence are often preserved until late stages. Physical abilities are also often quite intact, and there is usually absence of pain unless co-morbid conditions exist. There is time to reflect, to make wishes known, and to enjoy the love of family. If there has been a history of commitment to faith, it can often bring peace and contentment. Pets, children, and bright colors can bring joy. Simple tasks like folding laundry, setting the table, and watering plants can be helpful and add meaning to life. Since memory is impaired, individuals who previously suffered from anxiety are often quite calm and content as AD progresses.

The Decision about Institutional Care

For some families the choice of institutional placement and relocation is the optimal choice. This most often occurs at the point when family members are convinced that the patient can no longer be left alone. But, even when that choice is made, there are many necessary decisions that can be confusing to families and healthcare professionals. Nursing homes tend to embrace a "medical model" and allow persons with AD to have on-site assessment by professionals, including physicians. Assisted living facilities reflect more of a "hospitality model" and typically require that new residents be able to live with independence in most activities of daily living, but add on costs for additional services that might be required. Residents of assisted living facilities usually go to the physician's office for assessment, or, if urgent care is required after hours, to the emergency room. Retirement homes provide some transportation and food options, but no direct nursing or medical care. Continuing care retirement communities have the entire continuum from independent living to skilled nursing home care, making it possible for the individual resident to "age in place." The cost of this often includes a substantial up-front entrance fee, as well as an ongoing monthly charge. Dementia units are also available at some assisted living facilities and nursing homes. They vary widely and careful scrutiny of staffing, programs, and policies should be reviewed. Annual costs for these options vary from $15,000-$60,000 or more per year.

As healthcare providers, we often see how these choices bring out both the best and the worst in family relationships. While one family may benefit from the homecoming of a child who is temporarily out of work and unemployable as a primary caregiver for a parent with AD, another may experience considerable sibling disagreement over the decision to use what might otherwise be the children's inheritance as the source of funding for long-term institutional care. In our experience, the options available to Alzheimer's patients often reflect the resources, both personal and financial, they have "banked" before they became ill. The quality of the relationships they have with their children often affects how willing the children are, as adults, to sacrifice in their own lives in order to assist a parent.

There are no right or wrong decisions, but one's cultural, religious, and family values and background should be taken into account. Ideally the primary healthcare provider should work with the patient and family to connect with the many health and social services relevant to the patient's changing needs and enlist community and/or facility support systems as appropriate. If this is done, dignity, comfort, and quality of life can be preserved to the maximum extent possible, without the practice of futile medicine or caregiver burnout. Until reliable preventive measures or treatments for Alzheimer's disease are available, the provision of ongoing primary healthcare to patients and families experiencing the impact of this disease will remain a challenging problem for patients, their families, and their doctors. **NCMJ**

COMMENTARY

Alzheimer's Disease:
A Nursing Home Perspective

Ted W. Goins, Jr, and Lori R. Reid, BSW, CSW

Few would argue with Dorothy, "There's no place like home." We are all comfortable in our homes and lives, and want to keep it that way. Unfortunately, the ideal and the reality are often dissimilar. A person with Alzheimer's disease (AD) or dementia may no longer be safe living alone. Cooking, hygiene, and safety concerns collide with the desire to stay at home. A spouse or child may spend years caring for an Alzheimer's patient, often to their own detriment.

The sadness associated with caring for AD patients is overwhelming. Alzheimer's support groups are a necessity in providing caregivers the support and encouragement to continue. Family members constantly worry about early stage sufferers living alone. When will I receive a call that there has been a fire or an accident? How many times did mother get confused and call me in the middle of the night? Caregivers are exhausted from being awakened, worrying, chasing, cleaning, holding, and providing for every need.

> *"There comes a time when your local community nursing home is the best option. Your nursing home is salvation for the AD patient, caregiver, and the wider family."*

Professional Care

There comes a time when your local community nursing home is the best option. Your nursing home is salvation for the AD patient, caregiver, and the wider family. Many of North Carolina's 420[1] nursing homes are equipped to care for Alzheimer's patients, and some specialize in AD care. Most facilities are equipped to care for early stage residents, especially those who are not apt to wander. Wandering is as dangerous to the AD patient in a nursing home as it is to one at home. It is difficult to constantly watch any person in any setting.

Some nursing homes have specialized in AD care by creating special wings or units. An AD unit is usually a locked unit with programming specifically designed for AD residents, and has specially trained staff. Programming is important. AD residents need specialized approaches, care, and activities. Inviting an AD resident to sit and watch a movie for two hours or to work on a craft for an hour is counterproductive.

Successful programming may be unusual, but effective. After a retired mechanic was found under an overturned couch, he informed the staff he was changing the oil. The facility installed part of the front end of a car to keep the mechanic busy. Musical programs are well received. Residents may not remember many things, but they can belt out every word of "Amazing Grace." A resident may be quite confused, but that mouth pops open when the chaplain offers Communion, and they never seem to forget the Lord's Prayer.

Some facilities have created a "Snoozelin" room. Snoozelin, or Snoezelen, is a Dutch concept used with mentally disturbed children, and adapted for use with AD patients. A Snoozelin room contains light and sensory stimulation to improve the quality of life of residents. It might contain multi-color fiber optics, aromatherapy, music, cascading water,

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and more. Residents are encouraged to look, touch, and participate. The room is stimulating, satisfying, and tiring, thus reducing the tendency to wander.

"A 'dementia capable' staff is essential and should be the distinctive characteristic of an Alzheimer's care program."[2]

There must be appropriate numbers of staff who are appropriately trained to provide the best care to our loved ones. AD residents cannot be approached or cared for in the same way as other elders. The answer to the question, "Do you want a bath?" is always "no." The alternative may be, "How about helping me get cleaned up for dinner?" Leaning into the face of a combative resident can easily result in staff injury. It's important to know when and how to approach AD residents.

Special Alzheimer's units are becoming more prevalent. Many of these are wings of existing facilities that have been designed or converted for AD residents. While there are differing opinions on whether to lock a unit, or whether to admit AD residents into the general nursing home population, the prevailing opinion seems to be in favor of a locked unit specifically for AD. By the time AD residents are admitted to a nursing home, wandering is often a significant problem. Elopement, a resident wandering away, is a serious problem for a nursing home. The safety of the resident is at risk. Elopement is a major liability event. Elopement, even without harm, will result in serious punitive action due to the zero tolerance, perfection-based federal regulatory system. Locked units provide resident rooms, dining areas, activity space, and room to wander, while keeping the resident and the facility safe.

The use of physical and chemical restraints is a concern of residents, families, and healthcare facilities. Professional standards and federal requirements dictate that if residents must be restrained, that they be restrained in the least restrictive manner. Nursing home residents will fall. Helen Lach points out that healthcare facilities want to prevent falls, but this goal is not realistic. One-third of older adults living at home fall each year.[3]

Restraints can cause more harm than good. Residents can, and have, become entangled or even hung by their restraints or bed rails. Restraints can cause residents to become more agitated, combative, and likely to fall. Chemical restraints (drugs) can have serious side-effects including weakness and dizziness and can interact negatively with other medications.

Some nursing facilities have designated themselves as "restraint-free." All facilities are required to restrain in the least restrictive manner. Residents/families should discuss the issue with the nursing home to ensure a clear understanding. A proactive nursing home will be taking steps to minimize restraints and fall hazards. Restraints and falls can be minimized by proper exercise, supportive and nonskid shoes, elimination of tripping hazards, clean floors, appropriate medications, etc.

Choosing a Nursing Home

People should not wait to engage in the nursing home search until they need one. Your local nursing home is a wonderful community resource. Active involvement in its life and activities will help ensure the kind of place where you would want to live. If the local nursing home doesn't have an Alzheimer's unit, you may be able to assist in the creation of a unit, or expand the search to the nearest quality Alzheimer's facility. Choosing a facility is easy if it has been an ongoing part of your life. While there are various Internet and other resources to assist in selecting a nursing home, they are based on snapshots and subjective criteria. In the absence of active involvement, selecting a nursing home is best based on personal visits, interviews with staff, residents and families, and references from residents and their families. Residents and their families should expect:

- a safe, clean, and comfortable environment,
- friendly and well-trained staff with a customer service mentality,
- an attentive attending physician who visits when necessary and required,
- attractive and tasty meals,
- a home environment, even if the building is institutional in nature,
- regular involvement in the plan of care and care of the resident,
- stimulating activities, and
- appropriate medications.

Herb Shore was a founding member of the American Association of Homes and Services for the Aging. Mr. Shore was quoted during his eulogy as saying that "nursing home quality could be defined as a dry bed, warm toast, and a gracious 'Good Morning'." While this may appear simplistic, Mr. Shore covered the gamut in his definition of quality.

Residents and families must be realistic about long-term care, a subject that should be discussed at length on admission. The resident is being admitted to the nursing home because the family was not able to continue to keep the person at home, even with one or more caregivers involved, even with one-on-one care. Nursing homes are able to take advantage of economies of scale while making healthcare professionals directly available to residents. One-on-one care at home (or in a nursing home) could easily cost $87,600 per year, while the average annual cost of nursing home care in the United States is $42,000. Open and honest communication between facility and family will result in realistic expectations for everyone concerned.

The nursing home profession faces significant challenges for the future. The aging of America and the corresponding increase in the number of people suffering from Alzheimer's disease will overwhelm the current healthcare system in the United States. It is estimated that 4.5 million Americans have Alzheimer's disease. By 2050, the number of individuals with Alzheimer's disease could range from 11.3 to 16 million.[4]

The Challenge for Nursing Homes

The great "truth," "It's always about the money," has never been truer. We get what we pay for. Our society has shunned elders. Youth and beauty are in; aging is out. Many don't want to face the aging process, and society doesn't want to pay for it. As a result, Medicaid reimbursement, which pays for approximately 73% of nursing home care, is an under-funded and broken system. Twelve percent of North Carolina's nursing home residents are covered by Medicare.[1]

According to a recent Brown University study, 40% of African American nursing home residents live in low-tier facilities, compared to only 9% of whites.[5] Low-tier is defined as employing less staff, a high proportion of Medicaid-paid care, and having financial and management problems. Institutional racism pervades the Medicaid program. Different states fund Medicaid in different ways and at different levels, often poorly. The federal government must repair the Medicaid system to provide for today's and tomorrow's elders and to correct injustices against minorities and elders. Re-creation of the nursing home Medicaid program, similar to the federally-administered Medicare program, seems the most reasonable method of correcting inequities between states, institutional racism, and inadequate funding.

While the reimbursement system pays for "mediocrity," the regulatory system is based on criteria of "perfection." The federal system of regulation is expensive, punitive, and largely dysfunctional. Anything less than perfection during surprise nursing home inspections may be subject to severe penalty. A reasonable system of inspections and collaboration between residents, providers, and regulators could create a situation that provides a better home for every nursing home resident.

Nursing home financing cannot be left strictly to government. Every North Carolinian has the obligation to prepare for their own future, including healthcare. In light of the cost of long-term care and the likelihood of needing some form of care, long-term care insurance may be one of the soundest investments a person can make.

There is already a shortage of qualified, dedicated nurses, nursing assistants, and other workers in the nursing home profession. There is a projected shortage of almost 18,000 nurses by 2020.[6] The North Carolina Institute of Medicine Task Force on the North Carolina Nursing Workforce outlined a number of recommendations to combat the shortage, which should be addressed immediately.[6]

Future Models

Society's attitudes about nursing homes must change. Negativity about nursing homes hurts today's residents, and perpetuates negative stereotypes for future generations of people who may have to live there whether they want to or not. Our society has gotten even more mobile. Who will take care of you?

Nursing homes have to change too. The old institutional, hierarchical nursing home will not survive. Today's nursing homes are adopting quality improvement and innovation as their strategies. Nursing homes are adopting the quality of life improvements of the Eden Alternative and similar programs. Eden fights the old nursing home's ills of loneliness, helplessness, and boredom through resident-centered care, a team culture among staff, and even children, plants, and animals. Leaders are turning their facilities into homes!

Another quality improvement initiative, Wellspring, is to quality of care what Eden has been to quality of life. Using many of the same culture-changing techniques along with massive education at all levels, Wellspring improves the clinical care provided in nursing homes. Wellspring and Eden have seen the advantages of working together and have adopted the term "New Pathways" to reflect their work together. The five Lutheran Homes in North Carolina and the four Lutheran Homes in South Carolina have joined together to bring only the third Wellspring collaborative in the United States to the southeast. Medical Review of North Carolina is piloting a similar collaborative effort at this same time.

Culture change breeds more new ideas. The Eden Alternative and others have moved their emphasis from culture to physical facilities. Innovators are looking at new, less institutional buildings. The long, cinderblock hallways are being replaced with more homelike surroundings. Eden's Green House philosophy suggests six-to-ten-person (nursing) homes on the same campus or in the same neighborhood, using technology, and visiting nurses to perform needed functions.

There is no place like home, but for victims of Alzheimer's disease and many other elders, nursing homes are essential. Each of us should take the responsibility for creating a healthcare system that honors our elders. **NCMJ**

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COMMENTARY

Preparing Families to Make Informed Decisions about Long-Term Care

Sharon C. Wilder and Kathryn A. Lanier, MS

One of the roles of the Long-Term Care Ombudsman Program is to provide helpful information, make referrals to appropriate resources, and guide families through the process of locating a nursing facility that provides the services and care that meets their loved one's needs. In addition, once an individual becomes a resident in a long-term care facility, long-term care ombudsmen provide assistance to families experiencing difficulty either in communicating or problem-solving with the staff of a long-term care facility on behalf of their relative with Alzheimer's disease.

> *"Persons with Alzheimer's disease or a related dementia should always be included in the discussions about their future care to the extent they are able to participate."*

Families most often express concerns about protection of individual dignity, sufficient staff time to attend to personal hygiene, incontinence care, and adequate assistance with activities of daily living. Occasionally families share concerns when they think a facility staff member has failed to take the time to adequately assess why a resident with Alzheimer's disease may be exhibiting certain behaviors, particularly if the behaviors reflect aggressiveness or resistance to "hands-on" care.

Family members contact long-term care ombudsmen frequently for assistance when their loved one has experienced some type of acute episode that has resulted in their being advised to find placement in a skilled nursing facility. This article focuses on important issues families must work through to prepare themselves and their loved one for a smooth transition into the long-term care setting.

Where to Begin

For some families or spouses, there comes a time when they realize they can no longer adequately manage all of their relative's medical needs and activities of daily living in the home setting. Usually this awareness is triggered by rapidly escalating behavioral problems or medical emergencies that are occurring much too frequently. In such a situation, it would not be unusual for the family physician to be the one who first suggests that it may be time to begin planning for transitioning their loved one with Alzheimer's disease into a long-term care facility. It is very common for family members who are the primary caregivers to undertake this often daunting task during a time when they are emotionally and physically exhausted and don't know what steps to take to begin the process.

As the discussion is begun, family members need to obtain information about several important issues before they actively seek admission for their loved one. In some instances, there will be little or no time for planning because the older relative may already be in the hospital, and recommendations have been made by the physician for the hospital discharge planner to work with the family to find appropriate placement in a long-term care facility right away. In other situations, some advance planning can provide valuable information for a family or spouse beginning their search for a long-term care facility. Key planning issues include designation of a legal spokesperson for the older relative, consultation with the attending physician to obtain important information about the person's current medical status, and collection of information about the family member's assets and income that could be made available to pay for the costs of care in a long-term care facility. Persons with Alzheimer's disease or a related dementia should always be included in the discussions about their future care to the extent they are able to participate.

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Selecting a Spokesperson

Establishing legal authority is an important issue for many reasons, including the federal Health Insurance Portability and Accountability Act of 1996, Public Law 104-191, known as HIPAA. HIPAA laws have enhanced healthcare information security protections that prohibit healthcare providers from sharing any personal or medical information with others without appropriate written authorization from the individual or their legal representative.

When persons have Alzheimer's disease or a related dementia, it is important for their family caregivers to determine if their family member has chosen someone, usually an adult child or spouse, as the legal representative to act on their behalf, when they are no longer able to express their preferences or make decisions. If there is no legal representative, then an attorney experienced in elder law issues can be consulted to determine whether necessary legal documents, such as a durable power of attorney or a healthcare power of attorney, can be drawn up to reflect the relative's wishes. In situations where a family member has already experienced substantial declines in cognitive status without having designated a legal representative, the remaining option is for the family to petition the local Clerk of Superior Court to appoint a family member as the person's legal guardian.

Talking with the Physician

Physicians have an opportunity to empower the primary caregiver to assume a positive supportive role for the person with Alzheimer's disease, particularly as their relative gradually loses cognitive and verbal skills. In order to represent their loved one's wishes in care decisions, family members, or legal representatives need clear information about their relative's current medical condition, general medical history, currently prescribed medications, history of allergies, and the expected prognosis for each illness explained to them in laymen's terms. Accompanying their relative on a visit to their physician provides an opportunity for the family member and the physician to discuss recently observed changes in mental status, new safety issues in the home, or deteriorating health conditions. This thorough review of the loved one's current status will aid the physician in determining specific care needs and the care setting that can most appropriately provide the services needed. In some situations there may be an opportunity for the physician and family member to explore whether additional community resources, such as in-home services through the Community Alternatives Program for Disabled Adults (CAP-DA)* or respite services offered through the North Carolina Family Caregiver Program are options that may make it possible for their relative to continue living at home a little longer.

If the evaluation process results in a recommendation by the physician that the person with Alzheimer's disease has medical needs that require placement in a nursing facility, then the family member should ask whether the physician will continue to be the relative's attending physician after the move. If the community physician does not visit nursing facilities to treat patients, families need to know that they must find a new physician. Each long-term care facility can usually provide a list of physicians that a family may use to arrange coverage by a new attending physician for their relative's medical care while in the nursing facility.

Paying for Nursing Care

As stated earlier, primary caregivers or spouses will also need to collect and review financial documents and health insurance policies so that they have a clear understanding of their relative's assets, income, and any third-party health insurance, such as long-term care insurance, that may be available as a resource to pay for care provided by a nursing facility. Most people are not aware that Medicare Part A provides only a short-term skilled nursing benefit following a minimum three-day hospital stay. Often Medicare Part A coverage ends within two-to-three weeks or as soon as individuals achieve their maximum rehabilitation potential. At that point, long-term care expenses must either be covered by a person's personal assets, long-term care insurance benefits, other third-party insurance, or by applying for public financial assistance.

The state Medicaid Program is the primary provider of public financial assistance for nursing home care. The State County Special Assistance Program for Disabled Adults provides financial assistance to pay for assisted living level of care (also known as adult care). Both public programs are administered locally through county departments of social services and have stringent eligibility requirements. Some assisted living facilities and a few skilled nursing facilities admit only individuals who can pay privately for care. If a family member knows that it will be necessary to apply for Medicaid assistance in the near future, then he/she will need to investigate facilities that accept a mix of payment sources. This is important because, in a private facility, once their loved one becomes eligible for public assistance, they may be asked to move to another nursing home, which can be extremely traumatic for someone with Alzheimer's disease or a related dementia.

Looking for a Nursing Facility

When searching for a long-term care facility, geographic location is an important consideration for many families. A nursing facility close to work or home affords families opportunities to visit their loved one and ease in responding to situations as they arise. A second important consideration for families is selecting a facility that has a good performance record and can

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* The State County Special Assistance Program for Disabled Adults is administered locally through county departments of social services. In many counties there is a waiting list for these services.

meet their family member's medical and safety needs. Once several potential facilities have been identified, family members should obtain as much information as possible about each facility under consideration. Families can then compare the strengths and weaknesses of each facility before making a final decision. Important resources for specific information include:

- each nursing facility's most recent survey records and quality indicator scores are posted on the Medicare web site at www.medicare.gov/NHCompare/home.asp,
- public survey information is available through the North Carolina Division of Facility Services, Licensure and Certification Section,[2]
- other information is available through the local Regional Long-Term Care Ombudsman's Office,[3]
- personal visits to facilities under consideration are recommended, and
- each county department of social services collects public monitoring records, which are available for each licensed adult care home in that county.

Asking Important Questions

The placement process often triggers intensely mixed emotions for family members and can be a difficult period of transition for everyone. Because this situation is unlike anything that a family, particularly adult children, has ever experienced, they may have difficulty identifying the questions that need to be asked when meeting with the admissions staff in the facilities under consideration. Some of the crucial questions that need descriptive answers are:

> *"It is very common for family members who are the primary caregivers to undertake this often daunting task during a time when they are emotionally and physically exhausted and don't know what steps to take to begin the process."*

- What is the organization's philosophy regarding the treatment and care of individuals with dementia?
- Does your facility have a Special Care Unit?
- What factors determine whether someone should be placed in a Special Care Unit?
- What services are provided?
- How is the Special Care Unit staffed?
- What is the background and training of the individuals who work in the Unit?
- What steps are taken by the facility to ensure the autonomy of each resident?
- What happens when the type of care needed or payment sources change?
- What are the facility's visitation policies?
- How does the facility ensure good communication with family members about service provision issues?
- How are individual resident or family concerns and grievances handled internally by facility staff?
- Is this information provided in writing?

Additional resources for guidance about important questions that need to be asked or assistance in developing a checklist that can be used during facility visits are available on numerous web sites such as www.aarp.org, www.medicare.gov, and www.myziva.net.

After the Move

After moving a loved one into a nursing facility, it is not uncommon for family caregivers to experience an array of mixed feelings such as guilt and relief. They may experience lingering concerns that facility staff will not be able to care for their loved one like they did at home. Sometimes a family member or spouse may worry that their loved one will be frightened because he/she cannot understand where he/she is and will not recognize the staff as caregivers. Other family members may be uncomfortable initially with the idea that their loved one is confined behind locked doors or wearing a monitoring device.

Daily routines in a long-term care setting are very different from those one is accustomed to in a private home. Such a change in setting can be very disconcerting, especially for the person with Alzheimer's disease. The most significant changes in the daily routine generally will revolve around the new resident's wake/sleep cycles, eating habits, and bathing routines. It is important for both family members and facility staff to allow the newly admitted resident some time to adjust from having been the center of attention in the home, to now being one of several people depending on staff for care and personal attention. Another important adjustment that may surface is the issue of sharing personal living accommodations with a stranger in a space much smaller than their bedroom at home. In terms of new residents becoming more comfortable in their new surroundings, it is essential that families make an effort to provide staff with personal information about their family member. They can also informally share information with the direct care staff, such as the best way to approach the person, the name their relative responds to, situations that are frightening to them, favorite foods, foods they will not eat, allergies, activities that interest their relative, and a host of other intrinsic characteristics that make their loved one "unique."

This transitional phase is also an ideal time for families to explain to the facility staff, including the resident's new attending physician, how they can be contacted and what types of information or notifications they wish to receive regarding changes in their loved one's health status or problems encountered during daily care. The legal representative for the resident should provide neatly printed or typed instructions including all telephone numbers to be placed in the front of their relative's medical chart along with a copy of their durable power of attorney, healthcare power of attorney or guardianship documents. This information should also be placed on file with the facility social worker and passed on verbally to nursing staff on duty during visits with the resident.

It is important that residents and family members quickly learn to whom questions or issues of concern should be addressed. Once they have identified the appropriate staff members, the next step would be to determine the best way of conveying information. The most effective method is to speak directly with staff about a specific issue or concern and then follow up the conversation in writing. Communication should always be courteous and respectful and focused on specific issues in order to achieve a satisfactory outcome. Many times, situations that initially need minimal attention or intervention turn into matters of seemingly great magnitude as a result of poor communication. It is crucial for residents and family members to know about the facility's internal grievance procedures and the process by which concerns that have been expressed are addressed by facility management. All long-term care facilities have a responsibility to ensure staff familiarity with the facility's policies and procedures for communicating with a resident, resident's family or legal representative, especially in the event of acute changes in condition, accidents, or injuries. When all parties use this frame of reference, then the lines of communication will remain open. Well established communication systems within the facility can help alleviate misunderstandings and reduce a family's anxiety about their loved one's care.

If/when these channels do not produce the desired results, then other avenues of assistance should be sought out to address the issues, such as contacting an objective third-party, like a local long-term care ombudsman. The Long-Term Care Ombudsman Program's mission is to protect residents' rights, welfare, safety, and improve the quality of care and life for residents in long-term care facilities. When complaints are received by or on behalf of residents, long-term care ombudsmen offer an informal grievance resolution process as a tool to resolve issues in a manner that is mutually acceptable to the involved parties.

The North Carolina Division of Aging and Adult Services has several resources available to families on its web site at http://www.dhhs.state.nc.us/aging/ombud/ombtools.htm.

One document "Nursing Home Concerns" details which staff member(s) to direct questions or concerns to based on the nature of the issue(s). A second document "Puzzle Solved" gives suggestions on steps to take to ensure messages are conveyed effectively. **NCMJ**

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Dementia Care:
An Outpatient, Community-based, Multi-Disciplinary Approach

Virginia H. Templeton, MD

Many believe our ability to remember is a fundamental part of what makes us human and consider with dread the thought of dementia. Thomas Jefferson said, "Bodily decay is gloomy in prospect, but of all human contemplations, the most abhorrent is body without mind." When I first decided to work in the field of dementia, most of my peers did not understand. Dementia is a devastating disease with no cure and few viable treatment options at this point in history. My training as a family physician emphasizes prevention and health, but with dementia the terms of care change dramatically. Besides the bleak state of medical interventions, the issues are largely social and the reimbursement minimal. I was asked, "Won't you be depressed?" "How can you make a living?" "What can you actually do to help these families?" It was a big personal gamble in many ways, but I have always been interested in neurology and in how illness affects families and thought: what more family-centered disease is there than dementia? When I was offered a position at the Memory Assessment Clinic and Eldercare Resource Center in Asheville, I didn't exactly jump at the opportunity, but I decided to take the risk.

History of the Program

The Memory Assessment Clinic (MAC) was established by Margaret A. Noel, MD, a fellowship-trained geriatrician, who has worked in western North Carolina for the past 15 years. When first in practice, she set up a general geriatric care clinic ensconced within the hospital system in Asheville, North Carolina, and found that the majority of patients came with their families for evaluations of cognitive impairment. Initially, the hospital was able to underwrite the expense of the program, but when re-imbursement changed in the 1990s and funding was limited, the program was unable to sustain its cost and had to close. Because of her work, Dr. Noel knew the extensive needs of the geriatric community in the region and, with the support of a local retirement community that provided space at minimal cost, she established MAC as a nonprofit, charitable organization. By collaborating with the Alzheimer's Association and other community agencies, MAC became a part of Asheville's medical community and is now a valuable community resource for dementia care.

The Need

After joining MAC in 2002, I learned more fully about the impact of aging in our community and began to understand the array of issues that comes with a diagnosis of dementia. As is true for the rest of the country, the aging population in North Carolina is on the rise. According to the United States Bureau of the Census, close to 35 million Americans are now more than 65 years of age (up by 12% from 1990) of whom nearly one million live in North Carolina (up by 20.5% from 1990).[1] While this increase in life span is a huge success for public health efforts, healthier living, and medical advances, it also contributes to the creation of a population at great risk for developing dementia. It is thought that approximately 50% of those who reach 85 years of age will show signs of dementia,[2] so as our population ages, there is a concomitant increase in the incidence of dementia. In North Carolina, the Alzheimer's Association estimates that 132,329 residents have Alzheimer's disease, of whom 77,023 (58.2%) live in one of the 49 counties in the western portion of the state,[3] making it a major health issue for our region.

Dementia is a disease that not only affects the patient, but those around them as well. Caregivers for people with dementia learn to handle finances, manage medications, cook, clean, and provide transportation. Eventually they may also help with bathing, toileting, and feeding, and monitor for wandering. Individuals are often stretched far beyond what they thought they could do. In an editorial in the *Annals of Internal Medicine*, Kenneth Covinsky aptly states that "...a diagnosis of dementia is a sentinel event that signifies progressive loss of independence and increasing demands on caregivers."[4] Families struggle with taking a car from their loved one who relies on it for groceries, medications, and attending church. Removing guns from the home of a paranoid spouse or parent may protect lives, but may

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also trigger angry outbursts and affect relationships. Taking responsibility for these important safety issues is necessary, but for many caregivers is done at the expense of their own careers and educations and causes substantial financial and personal loss. As Covinsky points out, because those with dementia are not eligible for palliative services through Medicare until much later in their disease course, the burden of care at earlier stages falls on families.[4] It is no surprise that in a recent report released by the Alzheimer's Association and the National Alliance for Caregiving, "Americans are as afraid of becoming an Alzheimer's caregiver as they are of getting the disease itself."[5]

> *"In caring for people with dementia, I feel I have found a truly family-centered practice very much in keeping with the goals I had going into medicine."*

Our Model

The model of care utilized by MAC attempts to respond to the needs of patients and caregivers by providing the time necessary for accurate medical assessment and treatment, support and care management, and education about the disease process. There is also a commitment to educating the lay and professional communities in the region about healthy aging, dementia prevention, and dementia care.

In the clinic, each team has a physician and a care manager who is trained in nursing or social work. The model is similar to those in memory clinics established in academic centers, but is unusual and challenging outside such a system. In essence, MAC is a community-based, family support program integrated within a medical practice. Patients come to MAC by physician referral at a variety of stages of illness. For those who request enrollment, but have no primary care physician, a list of local physicians accepting new patients is provided so they can undergo initial evaluation and laboratory tests to ensure referral to the program is appropriate. Collaboration with primary care physicians is essential to facilitate routine monitoring and treatment of health problems that may impact cognitive function, such as diabetes, hypertension, hyperlipidemia, and others. MAC physicians serve in a consultative role and focus on the dementia, alone, and are often involved for the duration of the disease process, depending on family needs. Because those with dementia cannot always provide an accurate history and caregivers may not feel comfortable contradicting them, primary care physicians face a task that is not always feasible in a 15-minute office visit; HIPAA rules may limit their interactions with caregivers unless explicit permission is obtained from the patient. MAC is structured so that caregivers and patients each have time alone with the physician to discuss concerns; initial evaluations last from three to four hours with follow-up visits taking an hour. The time MAC has dedicated for physicians to spend with caregivers provides additional history that helps facilitate an accurate diagnosis, opportunity for developing realistic management plans, and a chance to educate caregivers about dementia and its expected progression. The time also allows physicians to address complicated emotional issues that can arise with care-giving. Some find themselves in the position of caring for a previously abusive parent; others are losing a treasured partner and need help finding appropriate ways of dealing with complex feelings. While to some providers, the time may seem luxurious or inefficient, in practice, it feels like a vital part of providing the best care for those suffering with dementia.

In addition to physician services, MAC employs nursing and social work staff who are the program's care managers and provide a wide range of information needed by caregivers. This interdisciplinary approach is a basic necessity for any dementia program to help families deal with such issues as incontinence, insomnia, paranoia, wandering, grief, and more. It may extend the time patients can be cared for in their homes and, if placement becomes necessary, ease the transition. Collaboration with other local service organizations such as the Alzheimer's Association, adult daycare programs, Mountain Area Health Education Center, the Council on Aging, and others is also a fundamental part of care provided.

Funding

The model of care utilized at MAC is costly and could not exist without substantial community support. While insurance companies pay for physician-patient time, they do not cover staff time spent with families for counseling, education, or creation of management plans. To deal with this dilemma, MAC asks each family to pay a yearly enrollment fee ($385), which covers caregiver time spent with the physician, care management, and other support services. The fee is waived for those unable to pay and charitable funds are raised to pay for the remaining expenses of the program. While this is an unusual arrangement for a medical office, extensive efforts are put into explaining the fees to those enrolling, and to-date the organization has been well-received. In our 2003 Caregiver Survey, 87% of responding caregivers (N=121 of 194 surveys sent) felt the caregiver fee was reasonable for the time and service provided through the program; 99% of caregivers and 98% of responding physicians (N=37 of 114 surveys sent) either agreed or strongly agreed that the program should continue to provide these services.[6]

With a commitment to prioritizing time with families, MAC has the challenge of achieving sustainability, which is difficult for all nonprofit organizations. Alternative approaches to funding have been explored, but all have substantial drawbacks. One option would be to house the program under the umbrella of a larger institution such as a university, medical school, or hospital that could cover the financial gap, but if there came a time when the institution could no longer underwrite the expense of the program, it could be dropped or demands made that the model of care be compromised. Families may also be willing to pay in full for the services provided; however, this limits care provision to the wealthy and leaves out a large number who need and deserve the services as well.

Conclusion

During medical training, I learned to maximize the 10-15 minutes I had with each patient. I often found myself choosing which problems to discuss, knowing important issues were being postponed, but hoping we could address them at the next visit. With dementia, this approach is not only inadequate, it is dangerous. Particularly at early stages of disease when diagnosis is difficult, vulnerability is at a peak—medications may be missed or overtaken, dangerous drivers remain on the road, and life savings may be spent or squandered. Without a diagnosis, it may be unclear to families that intervention is necessary. Experience has shown that good care for people with dementia needs to include extensive education, counseling, and support of caregivers and partnerships with community organizations. Time with caregivers is an essential part of providing this care and requires a medical system that values interactions with caregivers, not just in theory, but in practice. MAC is a difficult program to replicate because its structure is not financially viable without considerable community support. The model is an excellent one to provide the best possible care to those with dementia and their caregivers, but it requires community investment and the commitment of individuals who believe in its worth. In our part of the state, where many older adults choose to retire, the degree of community support for MAC has been remarkable and speaks to the need for such a program in this area.

In caring for people with dementia, I feel I have found a truly family-centered practice very much in keeping with the goals I had going into medicine. While a cure remains elusive, the science around this disease is exploding and exciting to be a part of. I confess I occasionally moonlight in an emergency room and relish the moments of actually fixing a problem, but at this point would not trade the complexity of dealing with dementia as a professional focus of my practice. For me, in addition to the joy I find in learning ever more about our brains and how they work, there is great satisfaction in seeing families rise to the challenge of dementia, reach in their hearts and find creative solutions to complicated dilemmas. In a most unexpected way, I have found my path as a true family physician through care of those with dementia. As Jane Austin wrote, "There seems something more speakingly incomprehensible in the powers, the failures, the inequalities of memory, than in any other of our intelligences." **NCMJ**

Acknowledgements

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COMMENTARY

Alzheimer's Disease, Family Caregivers, and *Faith in Action* in North Carolina

Catherine O. Ahrendsen and Teepa Snow, MS, OTR/L, FAOTA

More than 70% of all dementia care is provided by a family member in the home setting, according to a survey conducted by the national office of the Alzheimer's Association. For many caregivers, the journey is an isolated one, particularly when there are no local relatives to take a shift or lend a hand. The call to duty rings seven days a week and caregivers have little or no time to tend to their own needs. Many are unaware that programs such as *Faith in Action* can offer respite and emotional support to those caring for loved ones.

Faith in Action, a national initiative of The Robert Wood Johnson Foundation, was launched in 1984, and there are 804 local programs across the United States including Puerto Rico and Guam; 355 serve Alzheimer's patients. Twelve of the 32 *Faith in Action* programs in North Carolina provide non-medical assistance to Alzheimer's patients and respite for their caregivers. *Faith in Action* programs organize volunteers from faith congregations and the community-at-large to provide non-medical assistance to their neighbors in need. While programs vary geographically, they share the commonality of the five building blocks that define a *Faith in Action* program. The programs must be (1) interfaith, (2) volunteer, (3) focus on caregiving, (4) provide assistance in the care receiver's home, and (5) serve individuals who have long-term healthcare needs. *Faith in Action* programs operate under the slogan, "A Neighbor's Independence Depends on You."

> "*Faith in Action programs operate under the slogan, 'A Neighbor's Independence Depends on You.'*"

According to Larry Weisberg, the director of communications at the *Faith in Action* national office (affiliated with Wake Forest University School of Medicine in Winston-Salem, North Carolina), programs receive start-up grants from the Robert Wood Johnson Foundation. After the initial funding of $150,000 to 25 grantees in 1984 and $25,000-$35,000 to grantees funded since 1994, *Faith in Action* programs depend on donations from individuals, businesses, and other organizations, and grants to continue to provide services. Programs unable to continue operations beyond the 30-month grant period cited lack of funding as the principal reason for closing, rather than lack of need or lack of volunteer participation.

A survey commissioned by The Robert Wood Johnson Foundation in 2001 profiled *Faith in Action* programs receiving grants from 1993 to 1999. The typical *Faith in Action* program operates with a $70,000 annual budget. Eighty percent of coalition members are faith congregations, and the remaining are from the community-at-large and include civic organizations, businesses, and healthcare agencies. More than 90% of programs provide basic services, such as home visits, telephone reassurance calls, transportation, shopping, and help with household chores. More than 70% care for ill and disabled care receivers, providing respite and hospice care. Volunteers typically serve two to three hours per week and 60% of *Faith in Action* volunteers stay with the program more than 12 months.

One role of the *Faith in Action* national office is to help the programs "share best practices," according to Weisberg. Technical assistance is provided on volunteer recruitment, coalition building, fund raising and other aspects of organizational development. Volunteer screening and training is the responsibility of the individual programs.

On a national level, *Faith in Action* has established a partnership with the American Association for Retired Persons (AARP). As part of its community service initiative in North Carolina,

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Teepa Snow, MS, OTR/L, FAOTA, is the Director for Educational Programs at the Eastern North Carolina Chapter of the Alzheimer's Association. She can be reached at tsnow@alznc.org or 400 Oberlin Rd., Suite 220, Raleigh, NC 27605-1351. Telephone: 919-832-3732 or toll free 800-228-8738.

Box 1. Why Do They Do That? – Cursing and Swearing

Two major causes

Language and speech destruction and preservation

- Alzheimers' patients have trouble finding the right words, saying what they mean, understanding exactly what you mean, and making you understand. As the disease progresses the person has more and more trouble using words. The speech gets vague and lacks specifics, making it very difficult to understand. Eventually the person may be able to use only one or two phrases or words for all communication. Ultimately, very few words are available. He or she may either speak very little or speak in a 'word salad' making 'no sense,' but keeping some of the rhythms and patterns of speech.
- While the formal language center is damaged early, there are other parts of the brain that are preserved. The first is singing and music. This is why the person can sing all the verses of familiar hymns, or songs, but can't complete a sentence. The second skill is automatic social language and phrases. Things like, "How are you?" "Fine." The third preserved 'skill' has to do with forbidden words and phrases. Swear words are ones that you learned early in life and then stored in the 'don't use these!' areas of your brain, and you learned to use other substitute words. Phrases such as "shoot," "gosh," and "darn" became your substituted words when you felt the need to use the spontaneous 'forbidden words.'

Loss of impulse control

- The front of your brain allows you to control your impulses. It causes you to consider the consequences of your words or actions before acting and deciding whether to say it or not based on the possible or probable outcomes. In a healthy person, this part of the brain keeps you from saying something you might regret and from using the words you are not supposed to use in polite company.
- With the start of Alzheimer's disease, the frontal part of the brain is damaged and then destroyed. The person with Alzheimer's lacks impulse control. If he/she thinks it, he/she will say or act on it. Therefore, Alzheimer's patients may swear and use words that make us uncomfortable or may be completely out of character for that individual. It is critical to realize and remember that persons with Alzheimer's are doing the best they can. They have dementia; it is not a choice they are making.

What Should We Do?

- Always use the positive physical approach when you are helping a person with Alzheimer's disease. Make sure the person is aware of your presence before you begin speaking.
- If a swear word or forbidden word is used, recognize that the person may be frustrated or upset about something.
- If possible, back off a little and give some extra space and time.
- Use empathy and make one of the following statements...
  - "(Name), it looks like you are getting frustrated with this..." (then wait for a response or agreement or disagreement from the person)
  - "It sounds like you are not very happy right now..."
  - "It seems like you are having some trouble..."
- Always remember: You are not this person's 'mother' and you cannot teach impulse control. The brain is dying, and the person is doing his or her best under the circumstances.
- Stop and take stock. Maybe you both need a break before you continue.

AARP recruits members to serve as volunteers with selected *Faith in Action* programs. Eight North Carolina programs are involved in the partnership: A Helping Hand in Chapel Hill, Care Partners in Greensboro, Center for Volunteer Caregiving in Cary/Raleigh, *Faith in Action* at Work in Burlington, Greene County Interfaith Volunteers in Snow Hill, Care Partners of Mountain Area Hospice in Asheville, Project Compassion in Chapel Hill, and Shepherd's Center of Kernersville. Other *Faith in Action* sites include the following Hospice programs: Center of Living Home Health & Hospice in Asheboro, Hospice of Mitchell County, Hospice of Rutherford County, and Lower Cape Fear Hospice, and LifeCare Center in New Hanover County.

AARP training available to *Faith in Action* sites includes community service programs such as End-of-Life issues, Caregiving, Health and Wellness, Benefits Check-up, Driver Safety, Tax Aide, pharmaceutical affordability, Social Security, and Safe Mobility for at-risk drivers. Some *Faith in Action* program directors have become certified class leaders to conduct "AARP Powerful Tools of Caregiving" workshops. The six-week course focuses on self-care for the primary caregivers of persons with severe progressive and chronic illnesses, such as Alzheimer's, Parkinson's, and stroke. Caregivers learn coping strategies/techniques and are provided with a 'tool box' of resources including publications and information on support groups.

Some *Faith in Action* programs partner with the local Area Agency on Aging to provide in-home respite care. A provision of the Older Americans Act, amended in 2000, provides funding for the National Family Caregiver Support Program in North Carolina. This program offers family caregivers a source of information about local resources and offerings, including respite, which may help them provide care for a loved one.

Working with people who have any form of dementia, especially Alzheimer's disease, requires specialized training for the provision of safe and effective service. *Faith in Action* programs and other nonprofit agencies serving the elderly recognize the need to offer additional training to these special volunteers. A

Box 2. Positive Physical Approach

- Approach from the FRONT - let the person know you are coming
- Go SLOW - reaction times slow as we age - it takes longer for information to register
- Get to the SIDE - be supportive NOT confrontational
- Get LOW - don't use your height to intimidate
- Offer HAND - let the person with Alzheimer's start the interaction
- Call NAME - the name that person PREFERS
- THEN wait.

- Start Message
    - Give basic information - "It's time to..."
    - Give simple choices - this or that (orange juice or milk) (eat or go to the bathroom first)
    - Give single step directions - break down the task (to get up, lean forward, pull your feet in)
    - Ask the person to HELP you - it feels better to give than to receive!
    - Ask the person if he or she will at least TRY. Sometimes people will try, even if they don't think they can.
    - DON'T Ask, "Are you ready?" or "Do you want to...?"

- WAIT for a response (silently count to 10)
  IF **NO** response, ask again

  IF Responding...
    - Give positive STROKES - Feedback
    - "Good job!"
    - "Yes!"
    - "That's it"
    - Smile, nod
    - Hug, stroke, or rub

basic understanding of typical behaviors, common symptoms, and realistic expectations for responses and abilities is critical when developing relationships and offering help and support in these situations. Providing respite volunteers with the essential skills needed to interact and respond to Alzheimer's patients can mean the difference between a valuable, long-term, reliable resource for a caregiver and a one-time disaster for everyone involved. One recommended volunteer training program has been developed by and is provided by the Alzheimer's Association-Eastern North Carolina Chapter. This workshop averages four or five hours and provides the latest information about the various dementias as well as addressing misconceptions and myths associated with Alzheimer's disease. Volunteers are given tools to respond to challenging behaviors by learning more about the disease and participating in hands-on demonstrations and role playing. Faith community volunteers learn that they have the potential to be the bridge between the patient and the family, as well as a vital connector to the larger community.

Role playing and demonstration of behaviors and responses is used extensively in the Eastern Chapter's training of *Faith in Action* volunteers in North Carolina. These interactive and experiential techniques are particularly helpful in teaching volunteers how to cope with challenging behaviors. Lead trainers demonstrate characteristics and behaviors of a person with dementia. As the trainer approaches, showing impaired speech, memory, understanding, and impulse control, volunteers in training initially watch and react with nervousness, discomfort, and ineffective but typical responses. A very common issue and concern of potential volunteers is the frequent and unexpected use of profanity and vulgar phrases or words by the patients. Many *Faith in Action* volunteers benefit from a clear and simple explanation of this phenomenon, moving it from a 'bad behavior' to one of the very frustrating yet typical symptoms of this disease (see Box 1 for more information). As training progresses, volunteers begin to use the strategies provided and gain skill and confidence in their abilities to make a difference in interactions and client outcomes. By the end of the session, volunteers are able to approach (see Box 2), interact with, respond to, and meet the needs of the person with dementia in a more effective and consistent manner. Long-term feedback from volunteers and family members has indicated that this preparation makes a great difference in the ability of the volunteers to help both the person with Alzheimer's disease and the caregiver.

Weary caregivers need respite. Medicare and private insurance providers rarely fund such services, yet the use of respite can delay or prevent institutional placement for many elders with cognitive losses. *Faith in Action* programs can provide a valuable resource to community-based dementia patients and their families. These volunteers offer an expanded 'labor pool' that is committed to service. Dementia-specific training and education supports these volunteers and promotes the safety and well-being of all parties involved. Healthcare providers, physicians, physician assistants, nurse practitioners, and other providers can be valuable advocates and information sources for family members and people with dementia. They can encourage the use of respite and reinforce the need for primary caregivers of dementia patients to seek out respite volunteers, which allow them to rest, de-stress, and take care of themselves. A referral to one of the cited resources can show caregivers where to turn for assistance. Increasing public awareness of local resources and supporting these volunteer-based programs will help create an expanding network essential to baby-boomers who become part of the care pool. **NCMJ**

Community Resources

***Faith in Action* National Office**
877-324-8411
www.faithinaction.org

Alzheimer's Association - Eastern NC Chapter
800-228-8738
www.alznc.org

Alzheimer's Association - Western Carolina Chapter
704-532-7392
www.alz-nc.org

AARP North Carolina
866-389-5650
www.ncaarp.org

COMMENTARY

Dementia-Responsive Acute Care at Mission Hospitals in Asheville, North Carolina

Nancy Smith-Hunnicutt

In 2002, Mission Hospitals and the Western Carolina Chapter of the Alzheimer's Association received a grant from The Duke Endowment to develop an education-based program to improve care for hospitalized elders with dementia. The grant funds have supported an ongoing hospital initiative called "Dementia Responsive Care." This commentary describes the problem the hospital and chapter are trying to address through the initiative and the specific interventions that have been put in place.

Overview of the Problem

At-risk elders are the greatest consumers of healthcare. This is particularly true in western North Carolina, which is one of the fastest growing retirement areas in the country. Estimates provided by the National Alzheimer's Association indicate that 10% of the population over the age of 65, and almost 50% of the population over 85, have Alzheimer's disease, the most common type of dementia. People with Alzheimer's disease live three to 20 years from the time of diagnosis and often have concurrent chronic diseases that require hospitalization.

Currently, the overall hospital experience presents significant health risks for the patient with dementia. Lack of information regarding cognitive impairment and behavioral issues create serious problems for accurate patient assessment and treatment. Dementia is rarely a primary or even secondary diagnosis upon admission to the hospital. These already-compromised patients, often with multiple chronic conditions, physiologic impairments, numerous medications, and decreased functional reserve, are particularly vulnerable to the adverse affects of hospitalization common to geriatric patients. The hospital experience itself, with unfamiliar environments, changing caregivers, and invasive medical interventions, compromises patients with dementia even further. Research has shown that persons with dementia leave the hospital with more functional limitations than they had prior to admission, have a longer than average stay in the hospital (approximately four days longer), and are more frequently readmitted within 31 days of discharge.[1] Staff difficulty in understanding challenging patient behaviors and limited communication with both patient and family exacerbates complications such as delirium, malnourishment, skin breakdown, decreased mobility, and falling.

Mission Hospitals

Mission Hospitals is an 735-bed regional referral center and Level II Trauma Center for the western North Carolina region and sections of several surrounding states. Because of its location in a rapidly growing retirement area, the hospital has a high proportion of elder patients, including patients living with dementia. Although Mission Hospitals is not a teaching hospital, it does have family practice residents from the local Area Health

> *"Research has shown that persons with dementia leave the hospital with more functional limitations than they had prior to admission, have a longer than average stay in the hospital (approximately four days longer), and are more frequently readmitted within 31 days of discharge."[1]*

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Education Center completing rotations within the health system. Currently, specialized geriatric efforts within the hospital include: the Geriatric Resource Nurse Program based on the Nursing Improving Care for Health System Elders (NICHE)[*] Geriatric Trained Providers, Geriatric Clinical Nurse Specialist Consult Services, Palliative Care Consultation Team,[+] Senior Medications Assistance Program, and a community-based Elder Clinic. The Dementia Responsive Care initiative builds on these geriatric programs and services.

Objectives of the Dementia Responsive Care Initiative

The problems and issues to be addressed by the Dementia Responsive Care initiative are encountered in three distinct groups: the patients, the hospital staff, and the family caregivers. Objectives are to:

- identify patients with dementia at the time of admission;
- increase staff knowledge of acute care for persons with dementia, including assessing for delirium, dementia, depression, pain and common geriatric syndromes;
- preserve function: prevent/reduce functional and cognitive decline during hospitalization;
- implement interdisciplinary best practices in care of patients with dementia, including nonpharmacologic and environmental interventions; and
- increase involvement and support of family caregivers.

Many of Mission Hospitals' existing programs and services have helped to improve care for patients with dementia and especially to increase family caregiver participation in care activities. In addition to the aforementioned geriatric efforts, there are targeted initiatives on pain management, restraints, falls, patient and family-centered care, an Ethics Committee focus on older adult issues, and a study on artificial nutrition and hydration in end-stage dementia. The chronic and terminal nature of dementia requires staff and caregivers to join together as partners in care planning and delivery.

Interventions

Utilize the expertise of Geriatric Resource Nurses as a resource for bedside nurses and other disciplines caring for patients with dementia. Dementia Responsive Care (DRC) builds on a successful geriatric nursing initiative already in place at Mission Hospitals and other hospitals in the country, the Geriatric Resource Nurse Model. The Geriatric Resource Nurse model (GRN) develops unit-based nurses to provide excellent bedside geriatric nursing care and to be a resource to other staff on the unit. Mission Hospitals currently has 50 Geriatric Resource Nurses practicing on 14 units throughout the hospital. GRNs carry a usual caseload of patients while serving as a unit resource on geriatric best practices. Like the Geriatric Resource Nurse model, Dementia Responsive Care relies on assessment, education, and resource identification to help provide comprehensive care to patients with dementia.

Educate staff on the unique needs of patients with dementia. The curriculum for the multidisciplinary education and training is built around the following assumptions:

- It is essential to address common geriatric syndromes in addition to treating admitting diagnoses. Modules were developed to define a process that looks at the person in terms of risk stratification based on their signs and symptoms, admitting diagnosis, chronic illness profile, and history for the presence of common geriatric syndromes.
- The best history gathering and assessment is holistic and reflects a consistent framework for driving the plan of care.
- Elders are best compared to their own baseline when developing a plan of care for hospitalization. Central to the design of the initiative is the tenet that family caregivers be directly involved in care planning for the patient.
- To assess functional status only is not enough. Effective care planning addresses safety and risk factors while promoting and preserving independence and social function.
- It is critical for persons with dementia to be given the opportunity to practice preserved function while hospitalized. This requires interdisciplinary communication and care planning.
- Patient comfort and avoidance/easing of suffering is of paramount importance.
- Preferences regarding intensity of care, palliative care, and end-of-life considerations are appropriate items for discussion during each hospitalization and should build on earlier dialogues.

Provide a system for addressing the individual needs of each patient with dementia and involve family caregivers in the hospital care of their loved one.

Information about patients with dementia for the hospital team. Upon admission, caregivers are given the brochure *Hospitalization Happens—a Guide to Hospital Visits for Your Loved One with Memory Disorders* (http://www.dhhs.state.nc.us/aging/alzbroch.htm)[#] and are asked to complete a short form that provides a snapshot of the patient just prior to the onset of the acute episode. Caregivers are asked to provide vital information and insight into the patient by

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[*] NICHE - Nurses Improving Care for Health System Elders, a national initiative funded by John A. Hartford Foundation, a program of the Hartford Institute for Geriatric Nursing at New York University.

[+] Palliative Care Consultative Team, a collaborative program of Care Partners Mountain Area Hospice and Mission Hospitals.

[#] This brochure was supported by a grant from the Administration on Aging to the North Carolina Division of Aging as a product of the federal/state Alzheimer's Services Demonstration. Available at: www.dhhs.state.nc.us/aging.

identifying the patient's strengths, interests, habits, daily routines, nonverbal communications regarding pain and other needs, and non-pharmacologic methods for addressing anxiety and agitation. This form, *Personalized Care for Our Elder Patients*, is returned to the nurse at the time of admission, and the information is incorporated into the patient's plan of care and becomes a part of the medical record. Caregiver input and ongoing involvement are critical to providing dementia-responsive care. Persons with dementia must be given the opportunity to practice preserved function while hospitalized, and hospital staff need information from family caregivers to provide optimum care. Physical, functional, and psychosocial deterioration is best minimized through an awareness of the common risks of hospitalization for elders with dementia.

Information about dementia for family caregivers. Caregivers are provided information and education regarding dementia, community resources and support, and a referral to the Alzheimer's Association early in the hospitalization. Discussions with family members regarding disease progression, tube feeding in patients with dementia, advance care directives, palliative care, and end-of-life care are held during every admission. Caregivers are given additional information and the hospital referrals necessary to make informed decisions.

Information about patients from nursing homes. Nursing homes are provided with *Personalized Care for Our Elder Patients* forms and asked to fax completed forms to the hospital following transfer of a patient. Hospital staff are encouraged to talk with the long-term care provider to establish functional status prior to the acute episode and to receive patient-specific information pertinent to caring for the patient.

Information about dementia via Mission Hospital's Intranet-patient/family education literature. Educational materials written at sixth grade reading level are available for downloading on all units throughout the hospital. Additional materials are available from case managers and discharge planners on each unit.

Education and training for family caregivers. Education and training can enhance caregiver confidence in providing care. The caregiver is given strategies for communication, personal care assistance, and preventing and understanding difficult behaviors. Confidence and enhanced caregiving skills strengthen the caregiver's ability to provide care for the person with dementia.

Partner with the Alzheimer's Association to educate and support family caregivers regarding dementia and community resources.

When a loved one is hospitalized, the heavily stressed caregiver must cope with new and often complex medical challenges. The caregiver may be required to make critical decisions based on limited information with little support. The caregiver also suffers the added burden of the patient's increased confusion. Upon discharge, a new challenge arises, as the patient, most likely, will have declined considerably during hospitalization and is now more dependent on the caregiver for care. Family members often have become isolated during the course of their caregiving and have little knowledge of available community resources or how to go about accessing resources.

Caregivers of patients with dementia are given information on services available through the local chapter of the Alzheimer's Association, such as Safe Return, caregiver support and education, and respite coordination, as well as other resources available in the community. Additional resources in the community include the Memory Assessment Clinic & Eldercare Resource Center, adult day programs, legal services, in-home aid, respite care, and meal delivery. Connection with community resources can enhance quality of life for both the caregiver and the person being cared for, and provide appropriate supports as the disease progresses.

Evaluation Plans

This is an interim report, provided pre-evaluation. Dementia Responsive Care was piloted on two adult medicine units and is currently being implemented throughout the hospital. Evaluation of clinical, educational, and system outcomes is underway and will be completed in summer 2005. **NCMJ**

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Remembering “Bud” Busse

(1917-2004)

Dan G. Blazer MD, PhD

Ewald W. “Bud” Busse, MD, DSc, died on Sunday, March 7, 2004, and North Carolina lost a quadruple threat—an outstanding investigator, administrator, teacher, and clinician. The JP Gibbons Professor of Psychiatry Emeritus at Duke University Medical Center, Dr. Busse was 86 years old at the time of his death. Bud Busse held many positions of importance at Duke and in North Carolina, serving from 1953-1974 as Chair of the Department of Psychiatry and from 1974-1982 as Associate Provost and Dean of Medical Education. He served as the President and Chief Executive Officer of the North Carolina Institute of Medicine from 1987-1994. Yet, the offices do not define the man. Bud defined each position with his unique style and creativity.

Bud was a gracious yet intimidating man. Quadruple threats are intimidating in large part because they innovate—weave their talents together in ways that people more narrowly focused cannot conceive. The metaphor derives from triple threat football players some years back, specifically single-wing tailbacks. These players could run, pass, and kick (and I suppose they were quadruple threats because they played defense as well). When I was growing up in Nashville, Tennessee, a diehard Vanderbilt fan, I dreaded the annual game with Tennessee. The Vols were a hated rival, and they always featured a player in their single wing formation (few teams were using the single wing after the mid 1950s) who possessed a collection of talents that seemed inevitably to coalesce into a unique and game winning play I had not seen before. For example, one year Vandy had Tennessee pinned at their own ten-yard line on third down. The tailback ran back, faked a pass, and quick kicked the ball 80 yards. I could not imagine that play before I saw it, a play both innovative and intimidating. Vandy (as usual) could not recover and Tennessee won the game. Bud frequently won victories in ways most could not imagine.

Bud was first and foremost a scientist. During his early research career, he discovered a distinctive spike on electroencephalographic (EEG) tracings in the temporal lobe associated with aging.[1] Though he never established the origin of that spike, nor its physiological relevance to aging, this finding lead Bud down two paths that ran counter to prevailing trends in American medicine, especially psychiatry—biological psychiatry and gerontology. At a time that psychiatry was dominated by psychoanalysis, except in the most backward of state hospitals, Bud grounded his understanding of human behavior in the basic biology of the brain. To put it another way, Bud was a pioneer neuroscientist in psychiatry. At a time when aging was considered closely linked (if not identical) to disease, Bud pursued an understanding of aging as a normal part of the life cycle.[2]

To investigate this “radical” view, he established the Center for the Study of Aging and Human Development at Duke in 1954. The core research project at the center was a biopsychosocial[3] study of elderly community volunteers evaluated on a regular basis for 20 years. The initial and follow-up evaluations included biological measures (such as blood studies and encephalographic studies), psychological tests (such as portions of classic intelligence tests), and extensive exploration of the social environment in which these elders lived (such as family structure and community involvement). This longitudinal, biopsychosocial exploration of normal aging, intuitive today, was a far-reaching paradigm shift and remains the pillar of modern gerontology. Much of the current excitement about “successful aging” is built on the foundation of aging as normal, not a disease state.[4]

Bud asked questions. He never stopped asking questions! Over the decades that I knew him, I never ceased to be amazed at the questions he asked. He would call my office. After a few pleasantries, he asked if I had seen a recent article (I answered

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in the negative more often than not because he was on top of the literature like a leopard pouncing on a zebra, devouring it as soon as it was in sight). What did I think about…? About two weeks prior to his death I visited him. He pointed to two books at his bedside. The first was *The Da Vinci Code* by Dan Brown,[5] a novel that raises many questions about something most of us have taken for granted—the Last Supper painting by Da Vinci. The second was *Doubt: A History* by Jennifer Hecht,[6] a book documenting the importance of doubt, not a vindictive and overly critical debunking of established truths, but rather an honest questioning of what we all-too-often take for granted. I have no idea if he read *Doubt*. If he did, he would have liked it.

Bud's administrative style was also unique for his era. At a time when the disciplines of medicine were differentiating and dividing themselves, we never quite knew whether Bud was a psychiatrist or a neurologist (of course, he was both). At a time when the chair of a clinical department was "the Professor," establishing his (at the time they were virtually all men) reputation by pronouncing an answer to every clinical question, Bud asked questions. At a time when clinical departments exemplified a particular ideological bent (Freud, Sullivan, Kaplan, Kraepelin), Duke's department was eclectic (the first time I ever heard the word eclectic was during my interviews for residency at Duke). The department had ties to a psychoanalytic institute, supported a strong program in social psychiatry, and was engaged in basic neurobiological research. At a time when investigators tended to work in isolation, either with their case reports or their test tubes, Duke investigators worked in interdisciplinary teams. Therefore we should not be surprised that Bud founded the longest standing aging center in North America, if not the world, established the first fellowship training in geriatric psychiatry in the United States, facilitated a clinical faculty that was so integrated into the medical center that at one time fully one third of all patients admitted to Duke Hospital were seen by psychiatry in consultation, and grew a department whose budget exceeded the budget of entire medical schools in the south.

Bud took that style of leadership worldwide in his service to the scientific and professional community during his professional career. His various positions of leadership include: President, American Psychiatric Association (1971-1972); President, Gerontological Society of America (1967-1968); President, American Geriatrics Society (1975-1976); President, Southern Psychiatric Association (1975-1976); President, International Association of Gerontology (1983-1984); and President, North Carolina Neuropsychiatric Association (1957). He also served as Chairman of the Veterans's Administration Committee of Geriatrics and Gerontology (1981-1985); Secretary-Treasurer of the American Board of Psychiatry and Neurology (1967-1969); Chairman of the Residency Review Committee for Psychiatry and Neurology of the American Medical Association (1968-1969); Member of the National Council on Aging at the National Institute on Aging (1979-1983); and member of the President's Biomedical Research Panel (1975-1976).

Bud was an excellent lecturer, yet, I believe he saw less value in such public dissertations of one's knowledge than from a well-written book. He learned from books and he taught by writing books. Bud and his colleagues authored or edited many books, including *Behavior and Adaptation in Later Life*[7] and *The Handbook of Geriatric Psychiatry*.[8] These two volumes exemplify Bud's philosophy of teaching. He believed in a well-written, carefully reasoned, exhaustively researched presentation of a topic. The lecture format did not permit filling in all the gaps. Every argument must be complete. All arguments must eventually come together. He especially admired the work of EO Wilson, who presented such a comprehensive argument in *Consilience: The Unity of Knowledge*.[9]

Bud's clinical talents were well exhibited in his willingness to pragmatically tackle some of the most difficult clinical problems. At a time when psychiatrists theorized about "hypochondriacs," yet provided virtually no practical advice to primary care physicians who encountered these very difficult patients, he provided practical guidance for treating patients with multiple physical complaints of unknown origin, such as: (1) never try to explain to the patient that his or her symptoms are not caused by an illness; (2) limit time seen with patients to 15-20 minutes; (3) do not venture a diagnosis or prognosis; and (4) do something that assures the patient that an effort is being made.[10] These practical suggestions hold today as much as they did 50 years ago and busy practitioners would do well to follow Bud's keen clinical insights.

Prior to his long tenure at Duke, Bud received his bachelor's degree from Westminster College in Fulton Missouri, which awarded him an honorary DSc degree in 1960. He received his MD degree from Washington University in St. Louis in 1942 and interned at the St. Louis City Hospital and his training in psychiatry at the University of Colorado from 1946-1948. During his medical school and internship, Bud acquired an expertise in electroencephalography. Between his internship and residency he served as a Major, MC, AUS in the United States Army and this expertise (rare at the time) was utilized during his military career.

While at the University of Colorado, Bud nourished his interest in aging. He came from a long-lived and healthy family, so a fascination with longevity came naturally. Upon arrival at Duke, he immediately set out to create an interdisciplinary center for aging studies and became the founding director of the Duke Center on Aging and Human Development in 1957. The university received a grant from National Institutes of Health that supported the building of research facilities (a building that today carries Bud's name). Yet, the Aging Center was far more than simply a building. Bud gathered a group of scientists that ranged from the most basic biologists to economists. That interdisciplinary team designed the Duke longitudinal studies. For many years, these investigators met at Bud's home, sharing their findings and discussing this new horizon. These were halcyon days for aging research.

Bud received many honors during his career, including election to the Institute of Medicine of the National Academies; The Edward Allen Award from the American Geriatrics Society; the William Menninger Award from the American College of

Physicians; the Brookdale Foundation Award from the Gerontological Society of America; the Salmon Award from the New York Academy of Medicine; and the Jack Weinberg Award from the American Psychiatric Association. He was a member of the Rotary Club in Durham during most of his career in North Carolina, serving as president in 1972-73.

I was a psychiatric resident at Duke in 1973, the 20th year of Bud's tenure as chair of the Department of Psychiatry. Dignitaries throughout the country attended a symposium in his honor, including eight sitting chairs of psychiatry directly mentored by Bud. After listening to accolade after accolade, Bud rose to speak and he said something that startled me! "You may have noticed that I have rather large ears." Yes, I had noticed, yet Bud was an intimidating man. I never dared to mention it to anyone and had never heard anyone say a word about his ears. "I have been conscious of my ears since I was a child, and that is why I was intrigued by Rudyard Kipling's story 'The Elephant's Child' in *Just So Stories*.[11] As we may remember from our own childhood reading, the elephant child was brimming with curiosity, and never stopped asking questions. One question that was avoided by parents and friends alike was, "What does the crocodile eat for dinner?" "Don't ask," was the answer. Finally the elephant child approached the crocodile and asked his question. The crocodile answered by reaching out and grabbing the elephant child's nose, trying to pull the child into the water for dinner. The child survived, but with a greatly extended nose, and perhaps less curiosity.

Bud then quoted the poem that follows the story:

I keep six honest serving men
(They taught me all I knew);
Their names are What and Why and When
And How and Where and Who.
I send them over land and sea,
I send them east and west;
But after they have worked for me,
I give them all a rest…
I know a person small —
She keeps ten million serving-men,
Who get no rest at all!
She send 'em abroad on her own affairs,
From the second she opens her eyes —
One million Hows, two million Wheres,
And seven million Whys!

Bud Busse was a man of seven million Whys! **NCMJ**

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Running the Numbers

A Periodic Feature to Inform North Carolina Healthcare Professionals
About Current Topics in Health Statistics

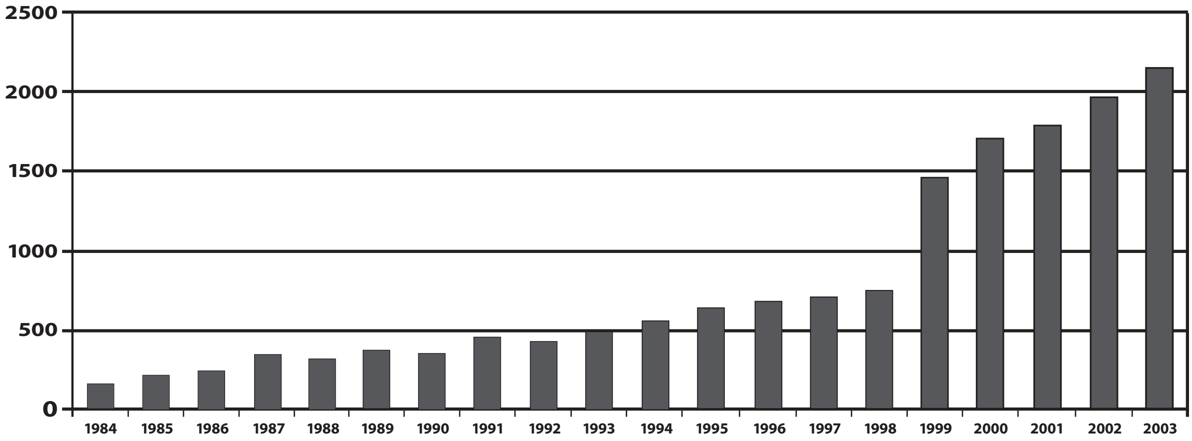
From the State Center for Health Statistics, North Carolina Department of Health and Human Services
www.schs.state.nc.us/SCHS

Deaths and Hospitalizations from Alzheimer's Disease in North Carolina

Alzheimer's disease was the seventh leading cause of death in North Carolina in 2003, ranking behind heart disease, cancer, stroke, chronic lung disease, diabetes, and non-motor-vehicle injuries. In 2003, 2,143 death certificates of North Carolina residents showed Alzheimer's disease as the primary cause of death. Alzheimer's disease was the fifth leading cause of death in 2003 among persons ages 65 and older (all but 19 of the total Alzheimer's deaths occurred in this age group) and the fifth leading cause of death among females (1,557 deaths compared to 586 for males). In addition to the 2,143 deaths in 2003 with Alzheimer's disease as the primary cause of death, there were 1,110 deaths with another primary cause, but with Alzheimer's disease listed as a condition contributing to the death.

Over the past 20 years, there has been a large increase in the number of deaths in North Carolina from Alzheimer's disease. The chart below shows the trend, based on primary cause of death. There is a large jump in the number of Alzheimer's disease deaths in1999, due mainly to the change from the ninth to the tenth revision of the International Classification of Diseases (ICD) mortality coding system. Nearly all deaths that were attributed to "pre-senile dementia" under the ninth revision of the ICD were coded as Alzheimer's disease under ICD-10. In 1998 (the year before implementation of ICD-10) there were 748 deaths attributed to Alzheimer's disease and 481 more attributed to pre-senile dementia.

Number of Deaths from Alzheimer's Disease in North Carolina, 1984-2003



In 2002, there were 1,481 hospitalizations of North Carolina residents with Alzheimer's disease listed as the primary cause of admission. Of these hospitalizations, 906 were for females and 575 for males; 39 were for persons under age 65, 236 ages 65-74, 743 ages 75-84, and 463 ages 85 and older. The total hospital charges for these 1,481 hospitalizations were $15,628,000, or $10,552 per hospitalization. The North Carolina hospitalization database still uses the ICD-9 for diagnosis coding, but only another 21 hospitalizations in 2002 had pre-senile dementia listed as the primary cause of admission.

Contributed by Paul A. Buescher, PhD
State Center for Health Statistics, North Carolina Division of Public Health

Reader's Forum

A Letter *from* The Editor:

To Our Readers:

In a January 27, 2005 *New York Times* article remarking on an exchange among residents of a Bronx neighborhood, which was previously published in a community newspaper, Alan Feuer had this to say:

> In the great combustion engine of democracy, the letter to the editor is probably the smallest working part.
>
> There is the vote, which sparks the pistons, and the campaign contribution, which greases sticky gears. Then there is the letter to the editor, which acts much like a valve. It allows a citizen to pour out powerful emotions and, often, to vent spleen.

While the Editors of the *North Carolina Medical Journal* have not gone seeking "spleen venting" letters or commentaries from our readers, we have constantly invited letters and other communications addressing the themes covered in the Journal. Like the situation in the Bronx, we consider our "Readers Forum" to be an important part of the Journal and hope that more of you will offer (publishable) comments in response to the issue coverage we are working hard to provide to interested healthcare professionals and other stakeholders every other month.

We hope you will let us know what you think and add to the conversation that we hope will enliven these pages.

Gordon H. DeFriese, PhD
Editor-in-Chief and Publisher
Durham, NC

Quality of Care and Performance Improvement

To The Editor:

I enjoyed your recent issue of the *North Carolina Medical Journal* on "Quality of Care and Performance Improvement." It reminded me of our experience developing and implementing the American College of Radiology (ACR) Mammography Accreditation Program (MAP).[1] This ultimately led to federal legislation and the Mammography Quality Standards Act (MQSA) in 1992. Congress then charged the Food and Drug Administration (FDA) to develop and implement regulations, and there have been additions and amendments on several occasions since that time.

More than 20 years ago I chaired the Mammography Committee of the ACR. We became progressively concerned regarding the uneven quality and accuracy of mammography throughout the United States. We developed the ACR/MAP, which officially began in August, 1987. It was voluntary and directly addressed image quality and radiation dose by means of a four-phased process:

- First, there was a comprehensive questionnaire concerning personnel (radiologists, technologists, and medical physicists); equipment; technique; quality control practices; patient information; and reporting and follow-up procedures. If any part of this survey did not meet acceptable standards, it must be corrected before proceeding to the next phase.
- Second, there was actual testing of the entire mammography imaging process (equipment, technique, receptors, processing, image quality, and radiation dose). Again, any failure must be corrected before proceeding.
- Third, there was peer review and evaluation of clinical mammograms. Again, failure required correction.
- Finally, quality control practices and records for the immediate previous 30-day period were evaluated.

Each site received a detailed report including a pass or fail result and suggestions, especially for correction of the latter. Accreditation was for three years and required annual updates.

The MAP only indirectly addressed the quality and accuracy of interpretation of the mammograms by assessing the radiologist's training, American Board of Radiology certification, experience, and continuing medical education. It recognized the need for a patient tracking system for data collection including follow-up information for results and accuracy determinations.

Some measures of the MAP's success are its endorsement and support by the American Cancer Society, the Center for Disease Control, the National Cancer Institute, and others. It led to the Mammography Quality Standards Act (MQSA) with oversight by the FDA and is mandated by law with potential penalties.

It has resulted in significant improvement in image quality. But there are some things we did not foresee. Mammography has become the most regulated and is one of the most litigious procedures in all of medicine. MQSA/FDA has increased costs significantly without appropriate increased reimbursement, especially for screening mammography, which may have led to a "loss-leader" mentality. It has not directly addressed the accuracy of interpretation issue, and comparisons with results in Europe (United Kingdom and Sweden), where mammography is done at centralized specialized facilities, suggest a need for this.

The ACR Mammography Accreditation Program is a success story as far as it goes. But there are lessons to be learned within the program and by those who entertain similar ideas.

Robert McLelland, MD, FACR
Department of Radiology
University of North Carolina School of Medicine
Chapel Hill, NC

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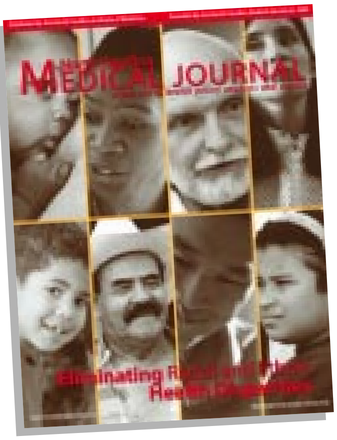
Eliminating Racial and Ethnic Health Diparities



To The Editor:

Kudos to you and your contributing authors for your November/December 2004 issue on "eliminating racial and ethnic health disparities." The issue should serve as a model for other states as they consider and confront the issue of health disparities. It serves as a challenge and a guide for action. Thank you for continuing to identify and discuss the important question of "who is left out?"—a question that should drive our priorities and our actions.

William L. Beery, MPH
Vice President
Group Health Community Foundation
Seattle, WA

To The Editor:

Today I enjoyed another copy of the *North Carolina Medical Journal*; as usual, several items stick with the reader. I shall mention a few.

I always enjoy reading a "grass roots" letter, as written by Dr. Peters of Winston-Salem, North Carolina. His view point is as he reports, from the "trenches." He mentions a number of the burdens that the clinician encounters daily-all true. One of his items is: "fewer physicians in practice;" so, in spite of the increasing numbers of visas being issued to foreign physicians, I assume he's relating to North Carolina's population growth of approximately two million souls since the days the East Carolina University (ECU) Medical School was conceived. I also understand (although I don't know the numbers) that the other three North Carolina medical schools have reduced their admissions in the intervening time. I recall the struggles encountered in trying to get the ECU medical school (the Brody School of Medicine) through the North Carolina General Assembly—most of it due to the vigorous opposition of our state's then three existing medical schools. Now, considering the increase in North Carolina's population and the strong movement toward specialization in our state, we are experiencing a shortage, perhaps as serious as was being experienced then. This is especially true if it is a member of your family facing the difficulties experienced by persons who are unable to get an appointment (and even less likely, a prompt appointment) and the difficulty physicians have in obtaining prompt referrals. Of course, the emergency department is not the panacea of all these problems; although, it appears that many want to hide the problem behind that veil.

I was particularly taken with the page called "Running the Numbers." This information is somewhat startling in its revelation of data on the health (in certain situations, not all) of North Carolinians. It starts out to tell the health story of North Carolina's American Indians, but it ends up relating a more telling story in its comparisons with "white" and "African American" groups. It is something every person, not just physicians, should be aware of.

John R. Gamble, Jr., MD
Lincolnton, NC

(Editorial note: Dr. Gamble is a former member of the NC House of Representatives)

The North Carolina Institute of Medicine

Since January 2002,
Publisher of The *North Carolina Medical Journal*

In 1983 the North Carolina General Assembly chartered the North Carolina Institute of Medicine as an independent, nonprofit organization to serve as a non-political source of analysis and advice on issues of relevance to the health of North Carolina's population. The Institute is a convenor of persons and organizations with health-relevant expertise, a provider of carefully conducted studies of complex and often controversial health and healthcare issues, and a source of advice regarding available options for problem solution. The principal mode of addressing such issues is through the convening of task forces consisting of some of the state's leading professionals, policy makers and interest group representatives to undertake detailed analyses of the various dimensions of such issues and to identify a range of possible options for addressing them.

Members of the North Carolina Institute of Medicine are appointed for five-year terms by the Governor, and each task force convened by the Institute typically includes at least one-third of its membership from among the appointed members. Topics to be addressed through task force efforts are chosen following requests from the Governor, the General Assembly or agencies of state government. In some cases, topics are selected on the basis of requests from a number of stakeholder organizations across the state where this type of analytical process is considered to have potential value.

The North Carolina Institute of Medicine assumed the role of publisher of the *North Carolina Medical Journal* in January 2002 through an agreement with the North Carolina Medical Society, which founded the Journal in 1845. The Institute views the *North Carolina Medical Journal* as an extension of its mission. The Journal provides a forum for stakeholders, healthcare professionals, and policy makers and shapers to study and discuss the most salient health policy issues facing our state. Like many states, North Carolina is grappling with issues such as an increasing number of uninsured, the unmet health needs of the growing Latino population, a critical shortage of nursing personnel, the health risks of tobacco and obesity, rising prescription drugs costs, mental health system reform, the increasing societal burden of chronic illness care, the threat of bioterrorism and the necessity of assuring adequate public health preparedness—all in the midst of an economic downturn. Each of these issues presents unique challenges to healthcare providers and state policy makers. Yet, a fully implemented task force to consider each of these sets of issues is not feasible. The Journal makes it possible to present an organized and balanced overview of some of these issues, six times per year, and allows interested persons the opportunity to engage in the ongoing discussion of these issues throughout the year. The Institute hopes that our readers of the *Journal* will, in this way, become involved in the continuing debate about the most promising avenues for assuring the highest standards of health and healthcare for all North Carolinians.

health policy

North Carolina Institute of Medicine

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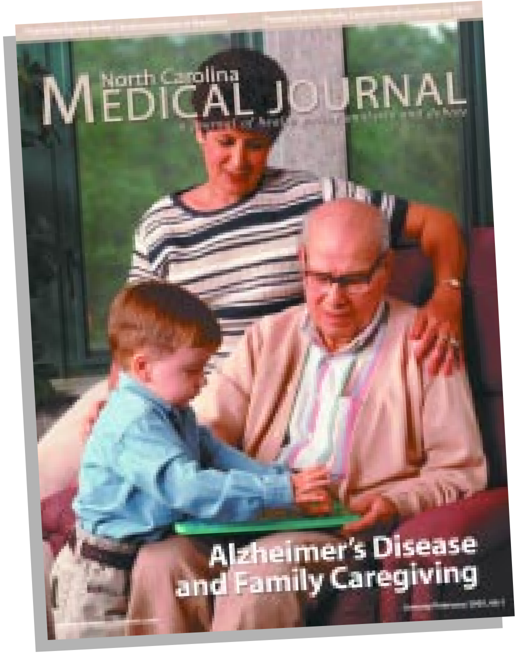
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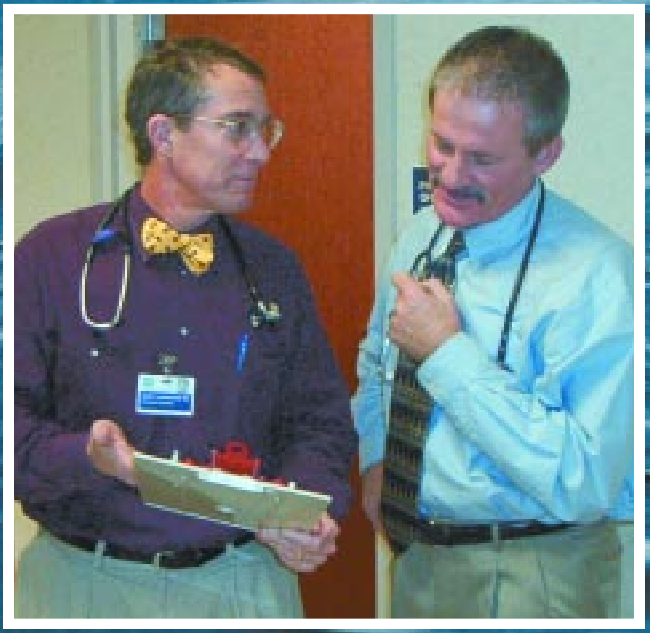

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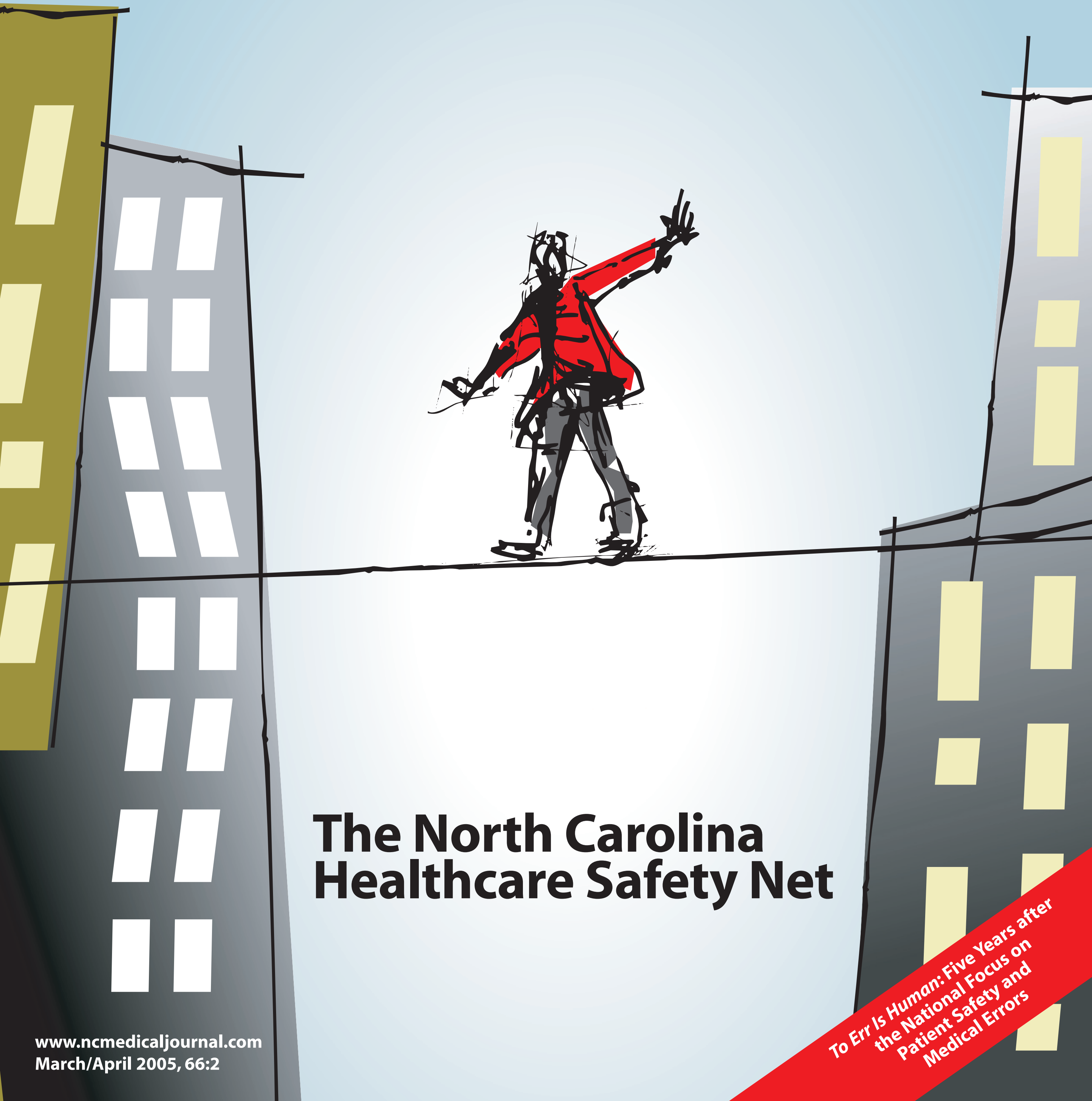

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SPECIAL ARTICLE

This paper is derived from the author's keynote presentation to the "Patient Safety Symposium" sponsored by the North Carolina Foundation for Nursing Excellence. January 20-21, 2005

Patient Safety:
Rejecting the Status Quo

Arthur A. Levin, MPH

A little over five years ago, the National Academy of Science's Institute of Medicine (IOM) released its groundbreaking report on medical errors *To Err Is Human.*[1] The report, a product of more than a year's work by the Committee on the Quality of Health Care in America—on which I had the privilege to serve—was a startling indictment of the unsafe state of hospital care prevalent in the United States.

As this report was released there was an enormous media response, especially to the body count of patients that the IOM attributed to safety lapses (44,000 to 98,000 deaths in America's hospitals each year). The range of estimated fatalities meant that medical error was the fourth or eighth leading cause of death in the United States, and even more alarmingly, many of these deaths were said to be preventable.

Reaction to the IOM's *To Err Is Human*

To Err Is Human caused a firestorm of reaction, some of which was highly critical of specific conclusions or recommendations made by the committee. While few denied that there were safety problems, many took issue with either the IOM's assessment of the dimension of the problem or to its specific recommendations—especially those that proposed mandated changes in the ways that hospitals and health professionals went about providing care and how they were held accountable for the safety of patients.

There was, in general, an expression of gratitude for the IOM's leadership in bringing the problem to the forefront of national consciousness, and while many went back to business as usual, many other providers, professionals, and policy makers rolled up their sleeves to try to do something about the safety problem.

President Clinton pulled together an interagency task force to tackle safety within the federal healthcare system. Congress, heeding one of the IOM's principal recommendations, budgeted an extra $50 million to the Agency for Health Care Research and Quality (AHRQ) to be used to improve patient safety throughout the healthcare system.

That same year, a group of large employers formed the Leapfrog Group to discuss how they could work collectively to influence healthcare quality and affordability. The group promised (and threatened) to use their combined financial leverage to drive the system toward improved safety and better quality outcomes.

Hospitals began to plan for computerized physician-order entry systems (CPOE), bar coding, and the use of clinical pharmacists on rounds to reduce medication errors. Operative sites were to be marked for identification (or, was it the "non-operative" site that was to be marked?), and operating room "time-outs" were instituted to ensure that the right patient was getting the right operation for the right site. Three decades or more of plans for converting from paper to electronic medical records, digitizing films and test results, and other ways of sharing critical patient information in real time were dusted off. Joint Commission on Accreditation of Healthcare Organizations (JCAHO) quickly developed accreditation standards that focused on patient safety, and the American Medical Association (AMA) founded the National Patient Safety Foundation. Legislatures in more than a dozen states began considering legislation aimed at attacking the patient safety crisis.

So, from early 2000, it appeared, at least to some observers, that patient safety was an issue whose time had come, and that perhaps the IOM's challenge to healthcare providers and professionals—to work toward a 50% reduction in medical errors by the end of 2004—was a real possibility.

Quagmire

But, there were some divisions that had begun to erode any unified sense of purpose and almost immediately began to slow forward motion. For example, there was a lot of push-back on the estimates of 44,000-98,000 patient deaths each year that the IOM said were linked to medical errors in hospitals. These estimates, which were based on two different studies by Harvard researchers,[2,3] were being challenged as vastly overblown. Critics agreed that there was a patient safety problem,

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but it was far less lethal than *To Err Is Human* claimed. And, they argued, "error" was a subjective, imprecise event that defied simple definition (i.e., many deaths attributed to error were more likely due to other factors outside of the control of providers and professionals). Thus, a protracted debate ensued about the lethality of medical errors in hospitals and, of course, some provider and professional associations (perhaps embarrassed by the sorry state of patient safety) seized on these critiques to argue that patients were not nearly as much in harm's way as the IOM report claimed, and that they (providers and professionals) had the situation well in hand.

I would have hoped that the numbers distraction would have evaporated more quickly, but it did not. As recently as last year the medical society of my home state, New York, characterized the IOM estimate as having been "discredited" by critics such as Troy Brennan, MD, JD, MPH, a physician, health services researcher, and lawyer from Harvard who is also, paradoxically, a co-author of both of the large studies of hospital patient errors that the IOM relied upon in its report. Brennan, however, while preaching caution, still believes the human toll of medical error is substantial:

> "Whenever you extrapolate from relatively small samples, you have concerns about the statistical precision of the estimates… although we don't know exactly how many people die from medical errors, there is no doubt it's at least 50,000 per year in hospitals and many additional outpatients."[4]

Focusing on Systems and Assuring Professional Compentency

One very key IOM recommendation disappeared from the radar screen almost instantly. It was a recommendation for establishing state-based, mandatory reporting systems for medical errors that caused serious patient harm. Even more contentious was the committee's belief that some of the information collected by states should be publicly disclosable. The IOM committee actually had the temerity to suggest that the healthcare system should be held publicly accountable for its safety performance.

In my mind this was not a radical suggestion. After all, industrial plants post the days without an employee work-related accident in plain view—why shouldn't hospitals and doctors? I debated two successive presidents of the AMA over this issue, and, arguably, their position against mandated reporting of serious harm and any public disclosure of that harm, has for the most part carried the day.

A good part of the IOM's message was that, even more important than individual behavior, there is a lack of effective systems to prevent the epidemic of medical mistakes. The very title of the report, *To Err Is Human*, was, after all, recognition that human error is almost inevitable, especially in complex, constantly evolving environments like healthcare. And so, the essential task, the IOM concluded, is to build systems that are sensitive enough to recognize the conditions that are antecedent to error and that are adept at preventing patient harm from actually occurring. This "de-individualized" approach was seen as transformational—a turning away from a tradition of blame and shame and mostly punitive approaches to error prevention that had so clearly failed in the past. Needless to say this move from a focus on individual provider or professional responsibility to a "systems approach" was *welcomed* by the "players" in hospital care—perhaps *embraced* would be a better description. For the most part, I agree that a systems approach has great merit (the recommendations of an IOM committee are the result of a consensus process), but I worry about the wisdom of a too enthusiastic rush to dismiss the importance of a professional's competency in the patient safety equation.

Ironically, it was the "it's the system approach" permeating the IOM report that may have helped doom the recommendation that there be mandatory reporting of serious error accompanied by some public disclosure. That theme was fodder for critics of an error-reporting mandate to characterize it as antithetical to a non-punitive, systems-based approach to safety improvement. This partly explains why that essential IOM recommendation dropped off the table. Another reason for the disappearance of reporting mandates from ensuing discussion was that many who wanted meaningful improvement in safety and quality to move forward rapidly worried that such efforts would fail to gain traction if there was a fractious break with providers and professionals over a requirement to report harm.

The airline industry's approach to error became the role model for the patient safety movement. Of course, the fact that pilots happen to be the first to hit the ground when serious errors are committed in the cockpit, does not detract from the industry's seriousness of purpose in its safety efforts. Nor that serious harm to pilots and crew, their passengers, and their aircraft is always announced in a very public manner. It is also well-established public policy to invest almost unlimited resources in a painstaking forensic analysis of the causes of any flight failure that is performed by an independent, highly skilled agency. And the lessons learned from the root cause analysis often are used to mandate airline safety improvements. This is not at all analogous to how attempts to understand what went wrong play out in a highly secretive, mutually protective healthcare system, a system that is comfortable with having mistakes remain ambiguous in origin and that historically lacks a culture of safety. The airline analogy also fails to consider that, unlike healthcare professionals (who are more often than not licensed in perpetuity), cockpit crew licensees are tested for competency routinely throughout their careers and in addition, are required to prove competency as they take any different responsibilities, either as to aircraft or crew position.

In healthcare, except for the hit-or-miss, often misdirected employee firing, loss or reduction of credential or privileges, monetary fine, lawsuit or action against a license, there is really no program in place that demands understanding and accountability for unsafe practices.

I did then, and still, take issue with two reasons often used to bolster the benefits of voluntarism and anonymity in reporting: that it produces more and better quality reporting. I think there is little or no evidence to support these claims and, in fact, we seem to have some evidence quite to the contrary. For example, New York State's hospital incident reporting system, known as NYPORTS, which was cited as an example of mandated reporting by the IOM, receives many times more reports of events that meet a sentinel event definition than the total number reported to JCAHO by hospitals across the country. And, the Food and Drug Administration's (FDA) MedWatch system for collecting adverse drug reactions (ADRs) is estimated to receive only from one-to-ten percent of the number of ADRs that actually occur. Even though the FDA has no interest in or any authority to punish those professionals or organizations that report an ADR, there is still vast under-reporting.

Providers have less of a problem with the other half of the IOM reporting recommendation—one that called for a national *voluntary* system of *anonymous* reports of so-called near misses that occur in hospitals. The model for this system has usually been the NASA-run "incident" reporting system used in the airline industry. That system collects anonymous narrative reports of "incidents," which, in airline talk, are "near misses." The reports are reviewed by retired pilots and controllers to spot important lessons to be learned; and these, in turn, are published so as to improve performance.

But, to-date no such voluntary system exists. Bills purportedly addressing this omission passed in both the houses of Congress last session, but failed to reach a conference to settle differences between them. These bills miss the mark and would mainly serve only to protect hospital patient errors, even those causing serious harm, from any outside discovery. The proposals, rather than build on existing organizations such as the federally funded Quality Improvement Organizations (QIOs), would create a new type of entity, Patient Safety Organizations (PSO), to collect, protect and analyze the safety information that hospitals voluntarily submit. The bills set no data standards, no criteria for judging the success of the PSOs in improving patient safety, allow hospitals to opt out of reporting safety data, and add yet even more expense to a healthcare system steadily marching toward 1.8 trillion dollars in annual costs.

Another key IOM recommendation, one that addressed new responsibilities for licensing and credentialing agencies and organizations in assuring professional competency and knowledge of patient safety practices, went almost unnoticed. But, the concept of periodic, routine competency assessment is gaining traction, especially among medical specialty societies.

This encouraging development can inform the work of other health professions and those providers that credential or privilege professionals. It would seem logical to assume that routine assessment of professional competency could have a substantial positive impact on patient safety and healthcare quality. And by making it routine, it becomes a *systems approach*, not a punitive one.

Why am I spending so much time on the past when what's really important is to understand where we are today? An appreciation of the history of professional and provider reactions to the IOM errors report (what was accepted and what was not) helps us understand how we arrived where we are today.

The Situation Today

Three years after the IOM report was published, author and journalist Michael Millenson had this to say in the March/April 2003 issue of *Health Affairs*:

"…the silence within much of the healthcare community about the true dimensions of the crisis caused by poor quality has changed only modestly over time. Many continue to avert their eyes."[5] Millenson, author of *Demanding Medical Excellence; Doctors and Accountability in the Information Age* went on to say:

"There is a world of difference between calling for a revolution and actually leading one. (And, yes, the latter is far riskier to one's professional well-being.) That difference is why the quality improvement movement, it pains me to say, remains essentially a sideshow for most providers and most of the public."[5]

Millenson's words ring as true today as they did in 2003. There is a profoundly disappointing lack of urgency and unified sense of national purpose to support immediate, forceful steps to significantly reduce and eventually eliminate preventable patient harm.

Consider this: if medical errors kill approximately 50,000 patients each year in hospitals alone, then as many as 250,000 patients may have died since the IOM report was published—a greater toll of human lives than that of the recent tragic December 20, 2004 tsunami. One essential difference, however, is that lethal patient error is not a natural disaster for which we have had little or no warning and no way to prevent.

According to a Kaiser Family Foundation poll released in November 2004, four in ten people surveyed believe the quality of care has gotten worse in the last five years.[6] One in three report that they, or a family member, have experienced a medical error at some point in their lives, and for one in five Americans, the error had "serious health consequences" such as death (8%), long-term disability (11%), or severe pain (16%).[6] Remember the immediate, visceral provider and professional opposition to IOM's recommendation of mandatory, publicly reported error tracking systems? Perhaps not surprisingly, nine out of ten of those surveyed said that reporting of serious medical errors should be required, and two out of three wanted this information to be public.

Patient Body Counts Move Public Policy

Patient "body counts" make providers and professionals uncomfortable, but they are necessary to move public policy in the right direction and to have it stay the course. Talking about preventable death puts a face on what is otherwise a "wonkish" debate and is a necessary element in convincing policy makers and the public that improvements in patient safety are critically needed.

Remember the $50-60 million dollars that Congress was providing to AHRQ for patient safety? Without commenting on whether it was money well spent or the miserliness of allocating only $50 million for safety in a 1.5 trillion dollar healthcare economy, the fact is that the money now competes with other needs [e.g., health information technology initiatives (IT)]. The shift of AHRQ funding from "safety" to "IT" tells me that without a body count to vividly remind us of the magnitude of havoc created by unsafe healthcare; adequate, sustained support for improvement is unlikely.

Upon discovering the lack of attention paid to the considerable human costs of preventable harm that occurs in our healthcare system, Millenson describes himself as at first stunned, then depressed, and finally outraged. That outrage is the appropriate response to the lack of progress toward saving lives evident at the five year anniversary of *To Err Is Human*.

The fall 2004 issue of *Health Affairs* published an article by Robert Wachter,[7] which was commissioned by the Commonwealth Fund for a quality improvement colloquium and marked the fifth anniversary of *To Err Is Human* in November 2004. Dr. Watcher's assessment is that the healthcare system deserves only a "C+" over-all grade for the progress it has stimulated in addressing patient safety. That's not great news, considering the costs of not getting an "A." As if a C+ grade is not bad enough, this report card's grading is highly subjective. The reality is—a reality confirmed by all those attending the November quality colloquium—that we do not have an effective safety data collection system to track medical errors (beyond internal systems in place in many hospitals) and; therefore, cannot say whether things are better, the same, or worse than five years ago. How is this state of affairs acceptable when tens of thousands of lives are at stake, and how did it happen? Remember that the IOM recommendation about tracking medical errors causing serious harm was abandoned not very long after it was made.

For the record, it has not been abandoned everywhere. Some states have subsequently legislated reporting and public disclosure. Minnesota, for example, has just published a report on hospital errors that is the result of a law passed in 2003.[8] Because we have no baseline medical error rate and no way to count errors across systems, we cannot measure the progress made overall in meeting the IOM's error reduction challenge.

In *his* answer to the question "Are we making progress?" Wachter writes: "after hearing of yet another sentinel event in their institutions, every patient safety leader I know laments how little headway we've made in the last five years." He goes on to say "… signs of progress are unmistakable." He illustrates this assessment by telling us that when he asked 400 hospitalists (i.e., physicians who spend the bulk of their practice caring for inpatients) for their views about progress in improving patient safety, 45% of them said things were better than five years ago, 38% said they were the same, and 17% said things had gotten worse.[6] Wachter admits this is only anecdotal evidence, but, inexplicably, he finds it "instructive and reassuring." My problem is two fold: (1) it is not credible evidence because we do not have a valid tracking system; and (2) even anecdotally, more than half of those asked said there has been no progress.

These anecdotal responses of the hospitalists are alarmingly *instructive* and certainly not reassuring. Consider the apparent disconnect of the majority of the hospitalists' somewhat-rosy view that things were better, or at least no worse, with the considerably more pessimistic view of the public surveyed by the Kaiser Family Foundation—that the system is no safer or less safe than five years ago.

Bob Wachter is certainly one of the best in the patient safety and quality improvement movement, but he, like most healthcare professionals, is probably troubled by the truth—that tens of thousands of patients continue to die because healthcare, and all its constituent parts and players, have not applied forceful enough pressure to stop the bleeding caused by safety lapses.

That said, it would be unfair not to point out the hard work that is being done by many around the country to make patients safer every day and the great successes in improving safety that have been achieved through dedicated hard work in individual hospitals, clinics, delivery systems, and other settings. That's the "good news." Patient safety does not have to be an intractable or inevitable problem in healthcare. Providers and professionals do care, and they are able to substantially reduce patient harm if and when they put their shoulders to it. On the other hand, the fact that the healthcare field often knows what to do, what will work (either gleaned from first-hand experience or the lessons provided by others) and still it isn't done consistently or at all (think: hand washing) adds to the frustration of those who believe patient safety has not been made the national priority it should be.

The failure of the healthcare system and policy makers to squarely address the crisis in patient safety and, thus, to allow tens of thousands of preventable deaths each year should be viewed as morally unacceptable public policy. It must be a violation of the ethical standards of every healing profession to be knowingly involved in the delivery of substandard, dangerous care. This should not imply that healthcare workers, as individuals, make conscious decisions to harm patients. Rather, the point is that considerable threat to patient well-being occurs in everyday practice, and these dangers are well known to all the players.

The timidity with which we (those who make public policy or, like myself, try to influence it) have approached providers and professionals alike, to beg, cajole, and entice a meaningful, unwavering devotion to fixing our patient safety crisis must change. Keeping patients safe can no longer be just one more request made of a healthcare provider or professional to improve care. It must become the pass/fail condition of continuing to practice and to serve patients.

A Positive Step

I would be remiss if I did not end on a more positive note. It is my opportunity to issue you a challenge to make things better—to provide a "how to do better" along with my outrage about what has not happened five years after *To Err Is Human*. So, I would like to call to your attention to a courageous and critically important initiative just begun by Dr. Donald Berwick and the Institute for Healthcare Improvement (IHI) —the campaign to save 100,000 lives.

I call it "courageous" because, for the first time, someone of great influence in the safety and quality movement is willing to mention the body count, albeit in a positive framework of prospectively saving lives. I call the campaign critically important because, if successful, it could actually save tens of thousands of lives in a relatively short period of time, and wouldn't that be a wonderful turn of events? It's also important because, by joining, healthcare providers and professionals admit both ownership of the tragic error problem and the ownership of working toward hopeful solutions.

The campaign aims to enlist at least 1,500 hospitals across the United States to commit to six key evidence-based, safety and quality improvements that have the potential to save 100,000 lives over the next 18 months—and beyond. These key improvements are:

(1) *Rapid response teams* (RRTs). These are teams that can respond, assess, and take action quickly at the first sign of a patient's decline. RRTs were pioneered in Australia, and studies have reported they can reduce hospital mortality rates by 27%.

(2) *Prevention of central line-associated bloodstream infections*. While not rocket science, this safety intervention can be almost 100% effective. The bundle consists of five steps; hand hygiene, barrier precautions, proper skin antisepsis, proper site care, and no routine replacement. All five, the "bundle," must be delivered to be optimally effective.

(3) *Prevention of surgical site infections*. Again, there is emphasis on the use of well-understood processes of good care, which include the appropriate selection, timing, and duration of antimicrobial prophylaxis; glucose control; proper surgical site hair removal technique; and other basic prevention strategies. These strategies can cut surgical site infections in half.

(4) *Prevention of adverse drug events*. Implementation of proven safety measures (e.g., standardizing and implementing core medication processes in high-risk areas) and learning from many successful examples of what works from innovating hospitals around the country prove it is possible to reduce fatal adverse drug events and even to eliminate them.

(5) *Improved care for acute myocardial infarction (AMI) patients*. The so-called AMI "bundle" of five specific interventions: beta blockers at admission, aspirin at admission, an ACE inhibitor, reperfusion, and beta-blockers at discharge has been shown to reduce AMI mortality by 40%.

(6) *Prevention of ventilator-associated pneumonia* (VAP). The ventilator "bundle:" elevation of the patient's head by 30 degrees, peptic ulcer prophylaxis, deep venous thrombosis (DVT) prophylaxis, "sedation vacations," and strict hand-washing can eliminate cases of VAP altogether.

I think this initiative is worth your careful consideration as a very public way to show that your organization or your profession: (1) recognizes that there has been and will continue to be a significant loss of life as long as healthcare is not safe care; (2) recognizes that much has been learned about how to do things safer and better and these procedures have been tested in settings not unlike your own; (3) makes a public commitment to refocusing current work on patient safety in ways that will demonstrably and almost immediately begin to save lives; and (4) willingly agrees to having progress tracked and fed back to your organization or profession for comparative purposes (although at this point not publicly disclosed).

Berwick concluded his announcement of the 100,000 lives campaign in December 2004 with these words:

"…the patients whose lives we save can never be known, and though they are unknown, we will know that mothers and fathers are at graduations and weddings they would have missed, and that grandchildren will know grandparents they might never have known, and holidays will be taken, and work completed, and books read, and symphonies heard and gardens tended, that without our work, would have never have been….the point is, lets get started…"

I hope that Berwick's words help to inspire you to make patient safety the priority that those who come to you for care deserve. As we remarked in *To Err Is Human*: "The status quo is no longer acceptable and cannot be tolerated any longer." **NCMJ**

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ARTICLE

Improving Diabetes Care among Low-Income North Carolinians:

Project IDEAL

Ronny A. Bell, PhD, MS, Fabian Camacho, MS, Vanessa T. Duren-Winfield, MS, Denise E. Bonds, MD, Roger T. Anderson, PhD, Joseph C. Konen, MD, MSPH, and David C. Goff, Jr., MD, PhD

Abstract

Objectives: *Many barriers exist in implementing evidence-based guidelines for diabetes care, particularly for low-income patients. To address this, the North Carolina Project IDEAL (Improving Diabetes Education, Access to Care, and Living) Diabetes Initiative was created.*

Study Design/Setting: *Fourteen programs representing different types of agencies and intervention strategies across the state participated in the initiative.*

Data Collection: *Separate random samples of medical charts of participating patients were reviewed at baseline (n=429) and three-year follow-up (n=656) to assess changes in six process (assessment of hemoglobin A1c, cholesterol, blood pressure, and urinary protein; conduction of foot and retina examination) and three outcome (glycemia, blood pressure, and lipid control) measures. Four national guidelines (DQIP, HEDIS, NCEP and ADA) were used as benchmarks.*

Results: *Large increases were observed for some measures (hemoglobin A1c control and testing, LDL-cholesterol testing), while modest increases were observed for others (dilated eye exam, blood pressure testing, and control).*

Conclusions/Relevance: *Project IDEAL was successful in improving access to high-quality diabetes care for low-income patients. Additional effort is needed to address specific areas of concern, particularly retinopathy screening.*

Key Words: *Quality of care, DQIP, HEDIS, NCEP, low-socioeconomic status.*

Introduction

As with the rest of the nation, diabetes mellitus is a tremendous public health burden in North Carolina. Over 500,000 North Carolinians have diabetes, and about one-third of them have not been diagnosed. Diabetes is the seventh leading cause of death in the state and accounts for about 14% of all hospitalizations at a cost of about $1.5 billion.[1] Persons with diabetes in North Carolina have an 80% greater rate of death from stroke, more than twice the rate of death from coronary heart disease, and three times the rate of death from hypertensive heart disease, compared to those without diabetes.[2] North Carolina ranks in the top 25% of all states in diabetes mortality. The burden of diabetes in North Carolina is highest or higher, whichever is true, among the state's sizeable population of older adults, ethnic minorities, and persons of lower-socioeconomic status.

Evidence clearly suggests that the implementation of evidence-based guidelines for treatment of persons with diabetes can greatly reduce the risk of chronic complications associated with diabetes,[3,4] and these guidelines are readily available. However, across a number of different patient populations, there is low adherence to these guidelines, generally as a result of patient- and

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provider-oriented barriers.[5] Patients may have limited time or transportation to visit their doctor, while providers may be constrained by time or by challenges in communicating prevention strategies to patients. Thus, there is a need to implement unique and creative approaches to address these barriers to reduce the burden of diabetes.

This report describes a unique community-based initiative implemented in North Carolina designed to improve the quality of care and quality of life of many of the state's vulnerable diabetes population. Included in this report are results that describe improvements in the quality of care provided to patients of programs participating in the initiative.

Methods

The Project IDEAL Diabetes Initiative

Beginning in May 1999, The Kate B. Reynolds Charitable Trust funded 14 programs across North Carolina under the Project IDEAL (Improving Diabetes Education, Access to care and Living) Diabetes Initiative that proposed to enhance the delivery of healthcare services to and the quality of life of underserved North Carolinians with or at risk for diabetes mellitus. Organizations that received funding included public and private, non-profit, healthcare organizations that served populations with a substantial burden of diabetes and had evidence of collaboration among community organizations as well as demonstrated sustainability and local commitment. The range of funds provided to the programs during the three years was $160,000-$275,000.

The Kate B. Reynolds Charitable Trust contracted with the Wake Forest University School of Medicine (WFUSM) Department of Public Health Sciences to develop, administer, and evaluate the initiative. An advisory committee consisting of representatives of state, federal, and private public healthcare agencies was convened by the management team at WFUSM to provide guidance in the development of the request for proposals, to review proposals received, and to provide technical assistance and continuing education to participating programs.

Each of the 14 programs developed their own unique interventions based on the needs of their community to reach their target populations. Examples of such interventions included: establishing new diabetes education and care programs in existing but underutilized physical facilities; using mobile healthcare units; creating "health depots" (off-site stations where screenings were performed and health information was distributed) in rural communities; staffing satellite sites in community pharmacies, physicians' offices, and other locales; and sending visiting healthcare professionals (e.g., diabetes educators and nurse practitioners) to low-income residential facilities. These interventions are described in more detail elsewhere.[6]

Data Collection

To measure change in quality of care, a baseline and post-intervention chart review was conducted. Since we were unable to conduct an evaluation with separate control and intervention sites, each of the programs served as their own controls, and data are presented in aggregate for the pre- and post-intervention time period. Each participating program identified their patients with diabetes from a list of patients either at their program site or at a collaborating clinic site. Patients were identified on the basis of having at least one diagnosis of diabetes in calendar year 1998 for baseline and calendar year 2001 for follow-up. Eligibility for the follow-up was based on patients who had participated in the interventions at each site. Program-specific and aggregate baseline reports were provided to each of the programs. Aggregate data for the baseline results have been published elsewhere.[7] Cases were eligible for project inclusion if they met the following criteria:

- One face-to-face encounter with a diagnosis of diabetes at baseline or follow-up, and
- Over the age of 18 as of December 31, 1998 for baseline and December 31, 2001 for follow-up.

The lists of eligible patients was provided to Wake Forest University School of Medicine staff. For programs with 60 or fewer patients, all patients were included in the evaluation. For programs with more than 60 patients, a random sample of 60 patients was selected from that site. The random sample was created using a random number generator in SAS Statistical Software Program (Cary, NC). Three of the 14 programs did not participate in the baseline evaluation, and two of the 14 did not participate in the follow-up evaluation. Data for the baseline and post-intervention are presented in aggregate.

Demographic information for project cases was gathered from patient records and imported into an electronic data collection tool developed in collaboration with the Medical Review of North Carolina (MRNC), which is the Centers for Medicare and Medicaid Services (CMS)-designated Quality Improvement Organization (QIO) for North Carolina. The tool was developed to capture information on patient characteristics and care processes from primary care medical records. Specially trained nurses and health information management personnel employed by MRNC entered data into the tool. Reliability was conducted using intra-reader assessment of a 10% sample of charts with excellent results.

Quality Indicators

Project IDEAL quality indicators were based on the national Diabetes Quality Improvement Project (DQIP)[8] and on Health Plan and Employer Data Information Set (HEDIS)[9] diabetes-related measures. The DQIP indicators represented a common set of comprehensive, evidence-based measures supported at the time of program initiation by the American Diabetes Association (ADA), the Foundation for Accountability (FACCT), the National Committee on Quality Assurance (NCQA), and the Health Care Financing Administration (HCFA). For this project, six process measures [testing for hemoglobin A1c, low-density lipoprotein (LDL)-cholesterol, nephropathy, retinopathy, hypertension, and neuropathy] and three outcome

Table 1.
Summary of Quality Indicators for Project IDEAL Evaluation

Indicator	Description	Considerations
Glycemia Assessment	At least one measurement of HbA1c during study period.	
Glycemia Control	HbA1c <9.5% on most recent test or level of control unknown.	Persons with no HbA1c test during study period were considered to not be in good control.
Lipid Assessment	At least one measurement of lipids during study period.	
Lipid Control	LDL-C <130 mg/dL on most recent test or level.	Persons with no lipid assessment in the study period were considered to not be in good control.
Nephropathy Assessment	At least one screening for diabetic nephropathy during study period via urinalysis or microalbuminuria testing (latter only if indicated).	A positive test for macroalbuminuria was considered acceptable, but a negative test for macroalbuminuria required testing for microalbuminuria. Patients with a documented history of nephropathy per medical record review were excluded from the eligible cases for this measure (the denominator).
Diabetic Retinopathy Assessment	Receiving a dilated eye exam performed by an ophthalmologist or optometrist, or having a 30-degree fundus photography read by an optometrist or ophthalmologist during study period.	Cases meeting the criteria for biennial eye exams (having any two of the following: not taking insulin; HbA1c <8.0%; no evidence of retinopathy on previous year's eye exam) were excluded from calculation of the annual eye exam rate.
Blood Pressure Assessment	At least one measurement of blood pressure during study period.	
Blood Pressure Control	Systolic blood pressure less than 140 mmHg and a diastolic blood pressure less than 90 mmHg.	Persons with no measurement of blood pressure during the study period were assumed to not have good control.
Foot Examination	Having a visual foot inspection, a pedal pulse assessment, and a sensory examination during study period.	

measures [control of: hemoglobin A1c (HbA1c), LDL-cholesterol, and blood pressure] were reported. The quality indicators chosen for this project are consistent with DQIP and HEDIS 1999 diabetes related measures with the addition of blood pressure and foot examination measures. These measures, along with the criteria for documenting compliance for each measure, are described in table 1.

Statistical Analyses

All statistical analyses were performed using the SAS Statistical software program (Version 8.0, Cary, NC). Bivariate chi-square tests were performed to determine statistical significance in the proportion of patients meeting each of the quality of care indicators. In addition, the adjusted proportions at each time period were derived by fitting a random effects logistic regression model, which took into account clinic cluster correlation and controlled for age, sex, race/ethnicity, and insurance status. The results were obtained by using the SAS macro GLIMMIX, extracting Wolfinger/O'Conell's pseudo-likelihood estimates, estimating the expected adjusted means at baseline and follow-up, and transforming back to the sample proportions.[10] The 95% confidence intervals of the differences in adjusted proportions were found by bootstrapping using the SAS macro BOOT and selecting the default 200 sub-samples. The normal approximation was used to find the upper and lower bound of the confidence intervals.[11] Additionally, the bootstrapping procedure allowed for the estimated differences in proportions to be corrected for bias. Ordinary adjusted logistic regression was also performed. As the results were similar and the variance estimates from the mixed logistic regression analyses are preferred, only the latter results are presented here.

Results

Table 2 provides demographic and medical history information for baseline and follow-up samples for the aggregate data. The racial/ethnic distribution was significantly different at follow-up compared to baseline (p=0.04), with a larger proportion in the follow-up group of whites and those classified as "other." The follow-up sample was also significantly older (p<0.001) than the baseline sample, which is reflected in the greater proportion of patients at follow-up on Medicare. Patients at follow-up were also less likely to be on insulin therapy (p=0.02).

Quality of care indicators for baseline and follow-up are described in Table 3. All indicators increased from baseline to follow-up. Testing of HbA1c significantly increased from 52.7% at baseline to 72.0% at follow-up (unadjusted difference: +19.3%; adjusted difference: +39.3%, 95% Confidence Interval [CI], 31.7-47.0%). This is a modest estimate of HbA1c testing, since this indicator refers to at least one test per year. HbA1c control increased from 39.6% at baseline to 64.9% at follow-up (unadjusted difference: +25.3%, adjusted difference: +37.5%, 95% CI, 30.6-44.4%). Since persons without an HbA1c measure were considered not in control, we only examined those with at least one HbA1c measurement. If missing values for HbA1c were ignored, control increased from 74.7% at baseline to 89.2% at follow-up. Using more intensive thresholds,[3] control to less than 8% increased from 26.0% to 55.0%, and control to less than 7.0% increased from 13.6% to 36.3%.

Measurement of lipids increased from 44.5% at baseline to 56.7% at follow-up (unadjusted difference: +12.2%, adjusted

Table 2.
Patient Descriptors for Baseline and Follow-up Samples

	Baseline (1998) (n = 429)	Follow-up (2001) (n = 656)	χ^2 P-value
Race/Ethnicity			
African-American	43.8%	35.8%	0.04
White	46.9%	52.4%	
Hispanic	1.6%	1.2%	
Other	7.7%	10.5%	
Gender			
Male	31.9%	34.0%	0.48
Female	68.1%	66.0%	
Age			
< 45	26.3%	13.4%	<0.001
45 – 64	49.4%	50.1%	
65 +	24.2%	36.3%	
Median Age (Years)	53	59	<0.001§
Medical History			
Insulin Use	29.6%	23.1%	0.02
Current Smoker	21.9%	13.1%	<0.001
History of CAD*	19.1%	14.8%	0.06
History of Hypertension	63.6%	62.8%	0.78
History of Nephropathy	6.3%	7.6%	0.40
History of Neuropathy	6.3%	6.9%	0.71
History of Peripheral Vascular Disease	3.7%	4.1%	0.75
History of Non-Traumatic LEA**	0.9%	0.2%	0.12§§
Insurance Status			
Medicaid, Medicare, HMO	25.4	39.6	>.001
Other	66.0	33.8	
Not Indicated	8.6	26.4	

*CAD denotes Coronary Artery Disease
**LEA denotes Lower Extremity Amputation
§ Test of Medians
§§ Fischer Exact Test used due to low frequencies

Table 3.
Percentage of Patients Meeting Quality Indicators at Baseline and Follow-up

Quality Indicator	Baseline	Follow-up	Absolute Difference	Adjusted Difference (95% Confidence Interval)
Hemoglobin (HbA1c) Test	52.7%	72.0%	+19.3%	39.3 (31.7-47.0)
HbA1c Control	39.6%	64.9%	+25.3%	37.5 (30.6-44.4)
Lipid Assessment	44.5%	56.7%	+12.2%	19.7 (13.0-26.3)
LDL Cholesterol (LDL-C) Test	23.6%	41.8%	+18.2%	21.6 (1.5-41.7)
Nephropathy Assessment	8.0%	25.4%	+17.4%	17.0 (10.1-24.0)
Dilated Eye Exam	6.3%	7.3%	+1.0%	4.3 (1.2-7.5)
Blood Pressure Testing	77.9%	82.8%	+4.9%	19.5 (9.7-29.3)
Blood Pressure Control	37.1%	43.6%	+6.5%	7.0 (0-14.1)
Complete Foot Exam	3.3%	21.2%	+17.9%	13.2 (6.7-19.6)

difference: +19.7%, 95% CI, 13.0-26.3%). While 23.6% of the baseline sample had LDL-C within accepted levels at baseline, that indicator increased to 41.8% at follow-up. Control of LDL-C below 100 mg/dL, consistent with Adult Treatment Panel (ATP) III guidelines,[12] increased from 9.1% to 24.4%.

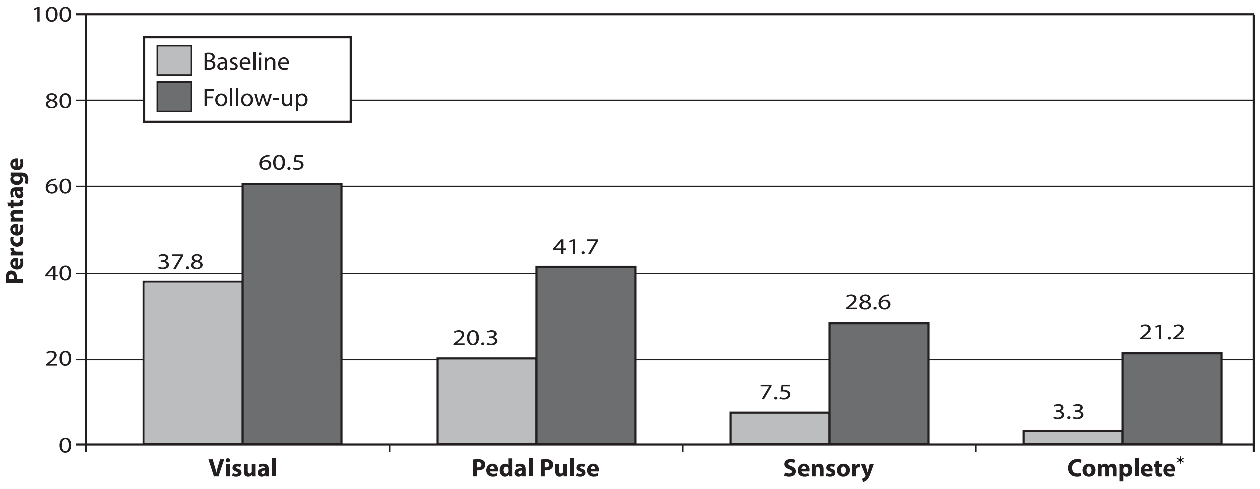
Two of the most problematic indicators identified at baseline were nephropathy and retinopathy assessment. Nephropathy assessment increased dramatically, from only 8.0% of the aggregate baseline sample to 25.4% of the follow-up sample (unadjusted difference: +17.4%; adjusted difference: +17.0%, 95% CI, 10.1-24.1%). The percentage of documented dilated eye exams only increased from 6.3% to 7.3% (unadjusted difference: +1.0%; adjusted difference: 4.3%, 95% CI, 1.2-7.5%); however, the percentage of patients receiving a recommendation for an eye examination nearly quadrupled, from 4.9% at baseline to 19.0% at follow-up (data not shown).

The vast majority of patients received a blood pressure measurement during both study periods. Blood pressure control (defined as systolic blood pressure less than 140 mmHg and diastolic blood pressure less than 90 mmHg) increased from 37.1% at baseline to 43.6% at follow-up, although this difference was not statistically significant. Using the more recent JNC VI high blood pressure recommendations[13] (systolic blood pressure less than 130 mmHg and diastolic blood pressure less than 85 mmHg), the percentage of patients with good control increased from 22.8% to 27.9%.

Foot examinations were another area of concern in the study population. Complete foot exam (having a visual, pedal pulse, and sensory exam) increased from only 3.3% at baseline to 21.2% at follow-up (unadjusted difference: 17.9%; adjusted difference: 13.2%, 95% CI, 6.7-19.6%). All three types of foot exams increased from baseline to follow-up (see figure 1). The most common examination was a visual inspection (37.8% at baseline, 60.5% at follow-up), followed by an assessment of pedal pulses (20.3% at baseline, 41.7% at follow-up).

Further examination of the control measures revealed that

Figure 1.
Distribution of Various Types of Foot Examinations among Project IDEAL Participants, Baseline and Follow-up



* Complete means having all three assessments within the study period.

few patients met all the criteria for adequate control (data not shown). Using the more stringent criteria (HbA1c less than 7%, systolic blood pressure less than 135 mmHg, and LDL-cholesterol less than 100), only 1% of patients met all of those criteria at baseline, and 5% met those criteria at follow-up. Using more conservative criteria (HbA1c less than 8%, systolic blood pressure less than 140 mmHg, and LDL-cholesterol less than 130 mg/dl), 3% met those criteria at baseline and 14% met those criteria at follow-up.

Discussion

This study showed modest to significant increases in the quality of care provided to low-income patients with diabetes among participants in a statewide diabetes initiative. This is important because the dramatic increase in the prevalence of diabetes in recent years translates to tremendous increases in future healthcare costs related to treatment of diabetes and its complications.[14] Reducing the complications of diabetes requires a strong, concerted effort from both the healthcare provider team and the individual with diabetes. While implementation of diabetes clinical guidelines, which are readily available to primary and specialty care providers, has been proven to be effective in reducing the risks associated with diabetes,[3,4] many barriers exist. Racial and ethnic differences in access to and use of healthcare services occur and disproportionately affect the underserved. Low health literacy prevents many patients from making full use of the latest treatments and up-to-date clinical information on their illness. Additionally, provider barriers such as limited clinic time with patients, inability to manage multiple guidelines, and negative perceptions of patients influence healthcare providers' implementation of diabetes care guidelines.[15]

General awareness regarding health-related issues and the benefits of accessing healthcare services could be improved through culturally appropriate community-based outreach and education programs.[16,17] However, each community will face a unique set of barriers, which precludes a one-size-fits-all solution. Healthcare delivery customized by local health leaders, but based on proven guidelines (the method demonstrated in Project IDEAL), may be necessary to achieve maximal benefits for racially diverse and medically underserved populations.

A number of studies have shown that adherence to clinical guidelines is poor for patients with diabetes, and this pattern appears to be consistent across a variety of populations. A sample of these studies is reviewed briefly here. Using the claims from Medicare beneficiaries in 1997-1999, Arday and colleagues[18] observed that only 67.8% of patients with diabetes received an annual HbA1c test, 68.3% received eye exams, and 56.8% received a lipid profile. In an assessment of quality of care among patients at 55 mid-western federally-funded community health centers, Chin and colleagues[19] found that 70% had at least one measurement of HbA1c, 26% had a dilated eye examination, and 51% had received some type of foot care. Using HMO data in California, Peters and colleagues,[20] found that 44% of patients with diabetes had received at least one HbA1c test, 48% had received a test of urinary proteins, and only 6% had received at least one foot examination. Consistent with these data, we also found low levels of adherence to diabetes care guidelines[7] in the baseline sample of low-income, largely ethnic minority patients selected for this project.

Our study has a number of limitations that must be taken into consideration. First, this study did not have a true control group, so the outcomes could have been attributed to factors other than the intervention, such as possible increased awareness of diabetes care in the community and in the healthcare arena, implementation of other local diabetes initiatives, and availability of additional healthcare resources. Also, since all sites participated in the intervention and, thus, were not blinded to treatment group as in a randomized placebo-controlled trial, there is the possibility that outcome measures were more aggressively pursued and recorded to enhance the results of the program initiative. However, this is somewhat unlikely given that systematic improvements were not shown in this study and that these data come from chart review and not from self-report by providers. In most cases, individuals coding data into the medical chart were not directly associated with the study.

The programs participating in Project IDEAL developed and implemented their own unique interventions with financial support from The Kate B. Reynolds Charitable Trust and technical support and evaluation from the Wake Forest University School of Medicine. Many opportunities for improvement were identified in the baseline data from 1998. Follow-up aggregate data revealed significant improvement for most quality indicators that supports the overall program intent: to deliver appropriate diabetes care and services to underserved North Carolinians. However, given the rather conservative assessment of quality care in this report, there is still much room for improvement. Also, the lack of an observed improvement in assessment of diabetic retinopathy indicates that this might be an area for future targeted interventions.

Conclusions

This study has a number of limitations which affect the generalizability of these results. First, there is insufficient data to test the impact of program-specific interventions. Second, the results reflect short-term changes in quality of care measures, which may not be sustained for extended periods of time. Third, these data were limited to medical chart reviews in primary care facilities, which may not adequately reflect the level of care being administered. Nonetheless, these results support the contention that programs that customize the delivery of healthcare to fit the unique needs of the community, such as demonstrated in Project IDEAL, can be successful in improving the quality of care that patients, particularly those of low-income communities, receive in primary care settings. Mechanisms for dissemination and maintenance of these approaches are needed to broaden the impact of diabetes control efforts in the population. **NCMJ**

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Editor's note: These affiliations were current during the committee member's time of service.

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ARTICLE

Accommodating a New Medical Profession:

The History of Physician Assistant Regulatory Legislation in North Carolina

E. Harvey Estes, Jr., MD, and Reginald D. Carter, PhD, PA

In 1967, the first graduates of the Duke University Physician Assistant Program received their certificates and began their practice. The Duke program was the first in the country to train this new professional group.[1] There was no legal framework in place for their practice, other than a ruling from the Attorney General of North Carolina that performance of delegated, physician-supervised activities by a physician assistant did not contravene the licensure laws of the state.[2,3] Other institutions were beginning programs of their own, some using the Duke model, and others a very different structure. National interest in this new manpower innovation was high, as was interest in the new profession by prospective students.[4]

Recognizing their obligation as the innovators and pioneers in physician assistant education, the parent department of the program at Duke University Medical Center, the Department of Community Health Sciences undertook the process of studying the unique problems of regulation of this new professional group and designing model legislation to implement this regulation.[1,2,5]

The process by which this model legislation was designed was unique, as was the regulatory framework which resulted. Following the development of the model, it was framed as a legislative act and considered by the North Carolina General Assembly the following year. It was passed with no major opposition.[6] This framework has served the state, the medical profession, and the physician assistant profession well for over three decades and has been the model for similar legislation in a number of other states.[7]

The purpose of this paper is to describe the process, some of the options that were considered, and some of the factors that led to a new and very unique basis for regulation of physician assistants. At the same time, it will highlight some of the characteristics of the process by which the proposed regulatory system was studied and developed. In retrospect, these appear to have heavily contributed to the favorable reception of the new regulatory process by the medical community within the state. The authors feel that recognizing these characteristics, and duplicating them, can be very useful to those with the responsibility for designing new licensure and regulatory statutes for medical occupations that may evolve in the future.

The Environment and Early Preparation

The Duke Physician Assistant Program arose from the awareness that many areas of the state, especially rural areas, were suffering from a growing shortage of physicians. The first class began in 1965, with a curriculum that resembled a shortened medical school curriculum: 12 months of pre-clinical sciences and 15 months of clinical instruction taught by medical school faculty. Interest in the program was immediate. Other medical institutions began programs of their own, some using the Duke model, and others a very different design, such as the Medex Program at the University of Washington. Entrepreneurial interest was also evident, with for-profit programs offering a certificate after only a few weeks of training. The need for standards for educational and clinical preparation of physician assistants was seen as an urgent priority, as was a framework for licensure and regulation.[5,7]

The Duke Physician Assistant Program was conceived and begun by Dr. Eugene A. Stead, then the Chair of the Department of Medicine.[8] He retired from this position in 1966, just after Duke University formed a new department—the Department of Community Health Sciences (later Community and Family Medicine)—with the first author of this paper as its chairman. The new Physician Assistant Program fit more easily into the mission and interests of this new department, and it was transferred to the new department late in 1966, before the graduation of the first class of students. This department initiated a number of studies of the new profession and also began to explore other required steps for its inclusion as a recognized component of the medical community. In addition to the looming problem of licensure and regulation, there was

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the need for accreditation of educational programs and a process for testing the educational preparation of graduating students. Drs. Estes, Stead, and D. Robert Howard, Director of the Physician Assistant Program, became the planning group for these activities, with the Department of Community Health Sciences as the organizational seat of the activity.[1,9] This paper will only consider those activities related to licensure/regulation.

The federal government recognized the need for uniform standards for the profession, and early in 1969 the Department of Health, Education, and Welfare awarded a contract to the Duke Department of Community Health Sciences to develop model legislation for the regulation of physician assistants. One of the first steps in carrying out the contract was to select a project operating officer, Martha Ballenger, JD, who immediately began to review published information about licensure of medical personnel. Her findings became the basis for a *white paper*, which was used for project planning and as background information for participants in the series of conferences that followed.[2]

This white paper pointed out that the responsibility for physician and other medical occupational licensure is a state prerogative, and there are differences from state to state. Legislation for physician licensure arose in the late 19th and early 20th century to control the rampant quackery and poor medical education characteristic of that time. These licensure acts were framed in very broad and general terms, permitting physicians to carry out any act or task taught in medical school, with no restrictions. As new health professions evolved and gained acceptance, their members were granted more circumscribed licenses, enabling them to perform only those specific functions for which they were qualified by training and experience.

The paper also pointed out that the process of awarding independent licensure for a new professional group was often hotly contested by those professional groups whose professional territory was being invaded. The result was an array of professional groups within healthcare (each with a sharply defined set of authorized functions) with frequent scope-of-practice conflicts as they sought to expand their functions.

Five options were identified for discussion and debate, each with advantages and disadvantages. The "status quo" option was a continuation of the existing policy. Physicians would delegate functions to their assistant, and custom and useage would validate the process over time. This option was seen as leaving both the employing physician and the assistant vulnerable to legal action for improper delegation. Independent licensure of physician assistants was the second option. Difficulty in precisely defining the duties to be permitted was seen as a major problem with this option. The third option was to license the physician or institution that wished to utilize a physician assistant. This was seen as a new function of the Medical Board. The fourth option was create a new statute authorizing general delegation by physicians. Four states were found to have some features of legislation authorizing general delegation within their medical practice acts. Lack of protection for the public was an identified problem with this approach. The fifth and last option was to create a Committee on Health Manpower Innovations, which would report to the medical board. The Committee would evaluate and pass judgment on new types of health workers, based on the need and the ability of the applicant individual or institution to support and supervise the innovation. The need for representation by all health professions on the new Committee was recognized, but at the same time, it was predicted that each of the representatives would tend to be protective of their own turf.

No judgment was offered on the relative merits of each of these options, since this was to be the subject of open discussion and debate in the series of conferences planned for the future. The purpose of presenting options was to encourage consideration of possibilities beyond those in use at the time and to present the unique challenges of the task ahead. Chief among these was the need for flexibility while meeting the responsibility to protect the patient and the public interest.

Drafting the North Carolina Statute for Licensure and Regulation of New Medical Professionals

The next step in the process was to hold a conference on licensure/regulation of new medical professions, with physician assistants as the principal focus.[10] Representation was sought from all groups seen as having a significant interface with the new professional group. The invited participants included:

- Nationally recognized experts on licensure of health personnel, identified from their contribution to the literature on this subject;
- Representatives from medicine, nursing, and hospital administration in North Carolina, including both practicing members of these professions and members of their legal staff;
- Members of the North Carolina legislature, the North Carolina Institute of Government, and the regulatory boards governing medicine and nursing;
- Educational representatives from Duke University School of Medicine and the Physician Assistant Program;
- Members of the newly graduated classes of Physician Assistants and their employing physicians; and
- A representative of the United States Department of Health, Education, and Welfare.

The first conference was held in Durham, North Carolina, on October 26 and 27, 1969. The previously listed options were presented and discussed during the first day. It was the consensus of those present that the best approach would include a combination of several options, most closely resembling option four—a statute authorizing general delegation of functions to an assistant. For the protection of the public, it was felt that this delegatory authority should be restricted to assistants functioning under credentials and constraints reviewed and approved by the North Carolina Board of Medical Examiners. Following the conference, a group of legal consultants met to prepare a first draft of a model statute, which was circulated to all those who attended, with a request for added comments and suggested revisions. Following a rewrite incorporating several of these suggestions, the revised version was again circulated to all who had attended.

A second conference was held in Durham, North Carolina on March 1, 1970, to discuss the product of these revisions, and to discuss in detail a modification proposed by one of the legal consultants. After lengthy discussion, the "October Proposal" was endorsed by the group, and became the proposal forwarded to those responsible for framing new legislation. It was enacted into law, essentially as proposed, in the 1971 session of the North Carolina General Assembly.[6]

At the time of the previously mentioned actions, the North Carolina General Statutes, Section 90, paragraph 18, after prescribing penalties for the unlicensed practice of medicine, read:

> "Any person shall be regarded as practicing medicine or surgery within the meaning of this article who shall diagnose or attempt to diagnose, treat or attempt to treat, operate or attempt to operate on, or prescribe for or administer to, or profess to treat any human ailment, physical or mental, or any physical injury to or deformity of another person: Provided, that the following cases shall not come within the definition above recited."

This was followed by a series of permitted exceptions, including the use of home remedies within the family, the practice of dentistry by a licensed dentist, the practice of pharmacy by a licensed pharmacist, etc. The proposal was exception (14) to this definition of the practice of medicine. It read as follows:

> "(14) Any act, task or function performed at the direction and under the supervision of a physician licensed by the Board of Medical Examiners, by a person approved by the Board as one qualified to function as a physician assistant when the said act, task, or function is performed in accordance with rules and regulations promulgated by the Board."

This proposal established a two-stage method of control. Before the physician assistant could have the benefit of the protection afforded by the statute, he or she must have gained the approval of the Board, through graduation from a recognized educational program. Once approved, the assistant might subsequently demonstrate incompetence or unwillingness to perform within the limits set by the physician, or the physician might be shown to be using his assistant in an inappropriate manner. Thus, there was an implicit power of the Board to deny or revoke approval at a later time. The final clause of the exception requires the Board to promulgate rules as needed.

The model legislation had several attractive features. It avoided specificity in definition of functions allowed by assistants. The functions permitted are, in effect, any functions delegated by the physician. It placed the promulgation of rules in the hands of the Board of Medical Examiners, not the General Assembly, thereby making changes possible without the formal action of an elected body.

Since its adoption in 1971, the afore mentioned approach has had the desired effect of permitting and supporting the function of physician assistants, while safeguarding the safety of the public. It has required very minimal alteration over time, and most changes have been accomplished through changes in the rules and regulations rather than the statute.[12,13] After its enactment, a similar approach was used to permit the medical acts of nurse practitioners. Recognizing that the nurse practitioner is already acting under another licensing authority, the North Carolina Board of Nursing, the legislation added nurse practitioners to the list of exceptions to the unauthorized practice of medicine. Legislation also established a joint committee of both boards to promulgate rules and regulations for nurse practitioners, specifying that both boards must approve these rules.

Still more recently, the same model has been used to permit the function of clinical pharmacist practitioners, who are now permitted to prescribe and manage illness under rules established by a committee with membership from both boards.

The model legislation proposed in 1969-1970 thus proved its merit through its adoption in North Carolina and many other states, and it has proved a very workable and flexible in action. It has also been used as a model for other professional groups that have joined physician assistants in performing medical acts. Physician assistants now work in every medical specialty, and their functions have been accommodated as new tasks have been developed and implemented, in ways that could not have been predicted when the legislation was developed.

The Process of Development of Model Legislation

The development of the model legislation for physician assistants was a very intense process with much debate and exchange of opinion. Yet, at the end, the resulting legislation passed the North Carolina General Assembly with very little dissent. This result has caused the authors to examine the process by which it developed in more detail, and to speculate cause and effect. Several characteristics of the process of development are identified as important in achieving the successful outcome. These are presented and discussed in the following section, with the hope that they will be useful to others who wish to achieve accommodation of a new professional group into the health professions.

The following characteristics are identified as important to the outcome:

- All professional groups identified as being impacted by the new professional group, physician assistant, were represented in the group invited to develop the model legislation;
- Identified national experts, from outside the medical profession, were invited to participate and contribute to the development of ideas;
- The process emphasized, at all stages, that a major objective for the model legislation was protection of the public and the individual patient, not preservation of professional turf;
- The process permitted all participants to review prior work;

submit their own new ideas, and revise old ideas through several iterations of the developing model; and

- The process produced near unanimous agreement on the details of the model before it was sent forward.

It was obvious that the new physician assistant would interact with every other major medical professional group: nurses, hospital administrators, pharmacists, etc. For this reason, an effort was made to include each of these groups in the conference and subsequent discussions. This proved very useful in allaying anxiety and suspicions and in informing all about the provisions of the model legislation.

Physician support was an essential requirement. It was fortuitous that the president of the North Carolina Medical Society was a family practitioner from a rural area, who had seen the need for the new profession firsthand. He was also a very perceptive and innovative individual who had a very warm relationship with many members of the North Carolina General Assembly. This individual, Edgar Beddingfield, MD, had served for many years as the head of the Legislative Committee of the Medical Society of the State of North Carolina (later the North Carolina Medical Society). He was also very active as a delegate and elected officer in the American Medical Association and was very helpful later in establishing a mechanism for accreditation of physician assistant education programs through that organization.

Nursing was represented by Dr. Eloise Lewis, a senior stateswoman in this profession, and the dean of a highly respected School of Nursing. The legal counsel to the North Carolina Nurses Association was also included.

The regulatory boards for both medicine and nursing were also included, with both members and legal counsel from each. This inclusion insured that the point of view of each of these boards was expressed and understood by the other, and the usual suspicions of ill intent, based on fragmentary or distorted information, were avoided.

The inclusion of national experts on licensure of medical personnel had several important effects. Their writings were known from the preliminary research, but their presence as a part of the discussion and deliberation broadened the approach. Their presence also provided an assurance to all participants that all major issues had been considered and that the work of the committee was important. They were also tenacious defenders of the public protection requirements of the model legislation, and their presence lent authority and validity to the product developed.

The emphasis on protection of the public was unifying in many ways. Each professional group could understand that this was not an attempt to restrict or diminish other professional groups, but to serve all interests as, together, we serve our patients.

The last two points can be considered together. Every participant was invited to comment, criticize, revise, object, and contribute to the development of the model. When differences were discovered, these were discussed in detail, and a consensus obtained. When the process was finished, all felt that they had contributed and felt ownership of the product. The group included legislators who were very effective in answering questions from fellow legislators during the debates and at avoiding conflict as the North Carolina General Assembly proceeded toward passage of the measure.

Summary

The first physician assistant program in the United States was at Duke University Medical Center. This program served as a model for other institutions to begin similar educational programs, and the profession has quickly become a major source of medical services throughout the country. Less well-known is the role of Duke University and North Carolina in the development of a unique regulatory system, which also became a national model. This system has been effective in protecting the public and the patient, and has had the flexibility to adapt to changing medical practice and changing standards. The process by which this regulatory system was developed was unique, and its unique characteristics are felt to have been a significant factor in its success. Duplication of these characteristics is recommended for those who wish to incorporate new medical occupations into the larger medical community. **NCMJ**

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The authors would like to gratefully acknowledge the interest and advice of Dr. Eugene A. Stead, the founder of the Physician Assistant Program at Duke University Medical Center, in the preparation of this manuscript. Dr. Stead was a critical participant in the studies and conferences cited, and he has remained an active contributor to the development and evolution of the profession over the intervening years. His friendly but persistent requests for a written record of the development of regulatory legislation led the authors, long his friends and admirers, to honor his wishes.

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POLICY FORUM
The North Carolina Healthcare Safety Net

COMMENTARIES

> *"Lack of health insurance coverage decreases worker productivity; negatively affects the health of children and, thus, their ability to learn; and has unfavorable financial implications for those healthcare providers who provide care to the uninsured."*

INTRODUCTION

Policy Forum:
The North Carolina Healthcare Safety Net

For more than three years, as we have published 20 issues of the *North Carolina Medical Journal*, there have been multiple occasions when we thought the word "crisis" was an appropriate moniker for a situation of urgent importance to the health of North Carolinians or the future of the healthcare services upon which we all depend. Certainly the growing number of North Carolinians without health insurance is an alarming trend. But, when one considers the fragility of the healthcare services available to serve the needs of this rapidly increasing component of our population—now nearly one-fifth of all North Carolinians—here is yet another occasion when the word "crisis" seems appropriate.

The recent analysis of a blue ribbon Task Force on the North Carolina Healthcare Safety Net convened by the North Carolina Institute of Medicine (NC IOM) directs our attention to a set of issues many healthcare providers (individual private practice professionals, hospitals, clinics, and public health departments) have known all too well in recent years. The burden of providing free and uncompensated care to larger and larger numbers of the uninsured (for types of services that range from the everyday concerns of the "worried well" to extensive and expensive specialty care from physicians and intensive hospital services) is putting enormous pressure on providers who are legally responsible for serving all who ask for help or on volunteers who give their time and professional expertise to those unable to pay for the care they receive.

The NC IOM Task Force was ably co-chaired by Carmen Hooker Odom, MPR, Secretary of the North Carolina Department of Health and Human Services, and Sherwood Smith, Jr., JD, Chair Emeritus of Carolina Power & Light (now Progress Energy). Staff leadership was provided by Pam Silberman, JD, DrPH, Vice President of the NC IOM. Dr. Silberman and the two co-chairs, along with other colleagues at the NC IOM, have offered a detailed Issue Brief summarizing the major dimensions of the healthcare safety net problem in our state. Other members of the NC IOM Task Force were invited to discuss particular pieces of this puzzle in a series of commentaries that follow the Issue Brief.

The Task Force acknowledged that one of the most important steps that could be taken to address the problems of the uninsured would be to assure insurance coverage for greater numbers of those without such coverage. There are many strategies by which this could be done, but until healthcare insurance is universal, the uninsured will remain a health policy issue of concern.

The commentaries in this issue of the Journal give a clearer picture of those at risk by not having insurance, the complexities of state and federal regulations that govern the organization and delivery of personal healthcare services to the uninsured, the voluntary outreach of local physicians and other healthcare professionals in service to the uninsured, and the efforts of private pharmaceutical companies to make needed medicines available to those unable to afford them. In addition, the commentaries explain the tremendous burden our hospitals and local public health departments carry, as providers of last resort, through their emergency departments and clinics, respectively. The commentaries also highlight the school-based efforts in providing needed primary and preventive health services to children and adolescents with no other source of care and the way in which North Carolina's Department of

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Health and Human Services has led the nation in the development of rural health centers to serve communities who were without access to needed primary healthcare services.

We also felt like it was important to include a recent (March 9, 2005) letter from Governor Easley to the United States Senators and Representatives of North Carolina. The letter explains how reducing the federal Medicaid match to states would affect North Carolina's healthcare safety net, and, in turn, its medically vulnerable citizens.

Serving the healthcare needs of the uninsured is a demanding job, involving thousands of healthcare professionals, hospitals, health departments, and clinics (many of whom are linked in operative networks to maximize their effectiveness and to lessen the burden on one or a few providers in each community). We hope that this issue of the Journal illustrates the enormity of the problems we face in this area. We also hope it provides some recognition for the citizenship and high-level professionalism of so many individual and institutional providers who have joined together to care for the uninsured. To all of these, we tip our hats and express our heartfelt thanks. It is hoped that in the not to distant future, the numbers of uninsured will be reduced, and some of the problems addressed in this issue of the Journal will be less of a concern than they are at the moment.

Gordon H. DeFriese, PhD
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The North Carolina Healthcare Safety Net, 2005:

Fragments of a Lifeline Serving the Uninsured

Pam Silberman, JD, DrPH, Carmen Hooker Odom, MRP, Sherwood Smith, Jr., JD, Kristen L. Dubay, MPP, and Kristie Weisner Thompson, MA

In 2003, nearly 20% (1.4 million) of North Carolinians under age 65 lacked health insurance coverage.[1] Since the year 2000, more than 300,000 people have lost their health insurance—a 31% increase in the uninsured. With nearly one in five people living without insurance, North Carolina is, without a doubt, in the midst of a major healthcare crisis, and as healthcare costs continue to rise, there is little chance of an immediate respite.

Coping with the large, and still growing, number of uninsured is a national problem, but North Carolina has been harder hit than many states. As a result of recent trade relocation and downsizing, North Carolina lost a large number of manufacturing, textile, and technical jobs, which left thousands of people unemployed and uninsured. The downturn in the economy, together with the rising cost of health insurance, is making it more difficult for people to afford healthcare or healthcare insurance.

Most of the uninsured in North Carolina (62%) have annual incomes less than 200% of the federal poverty guidelines (FPG)—less than $18,620 for an individual and $47,140 for a family of four in 2004.[2] This makes it challenging for the uninsured to pay for needed healthcare. Even people who have insurance sometimes have difficulty paying for needed healthcare, but it is typically harder for the uninsured. The uninsured are less likely to have a regular source of care and are more likely to delay or forgo needed care than people with insurance coverage. The uninsured in North Carolina were far more likely than those with insurance to report that they have no person whom they consider to be their personal doctor or regular healthcare provider in 2003 (50.7% compared to 12.4%, respectively).[3] Approximately 15% of North Carolinians reported that there was a time in the last 12 months when they needed to see a physician, but could not due to cost; however, the uninsured were more likely to report this problem (41.2%) than those with insurance coverage (9.5%). Further, when the uninsured do seek care, they are generally sicker than the insured population and, as a consequence, experience poorer health outcomes.

> *"As a result of recent trade relocation and downsizing, North Carolina lost a large number of manufacturing, textile, and technical jobs, which left thousands of people unemployed and uninsured."*

What Is the Healthcare Safety Net?

The lack of health insurance coverage obviously affects the uninsured person and his or her family, but it also has a broader societal impact. Lack of health insurance coverage decreases

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worker productivity; negatively affects the health of children and, thus, their ability to learn; and has unfavorable financial implications for those healthcare providers who provide care to the uninsured. The state and federal funding sources available to meet the healthcare needs of the uninsured are not keeping pace with the growing needs. The increased numbers of uninsured and inability to raise revenues from third party payers or other sources is creating significant financial strain for many safety net institutions. Without these institutions, the capacity to provide healthcare services for the uninsured and other underserved groups would be seriously undermined.

Safety net providers are those who deliver a significant amount of healthcare to the uninsured, Medicaid, or other vulnerable populations, and offer services to patients regardless of their ability to pay. They typically provide healthcare services at no charge, on a sliding-fee scale, or help make services financially affordable in some other way.

Who Are the North Carolina Safety Net Organizations?

In North Carolina, the safety net consists of federally qualified health centers (e.g., community and migrant health centers), state-funded rural health centers, local health departments, free clinics, Project Access or Healthy Community Access Programs, school-based or school-linked health centers, hospitals, and other organizations that have a central goal of providing care to patients regardless of their ability to pay (see sidebar). Many private providers provide services to the uninsured, albeit not always on a sliding-fee scale.

While some safety net resources exist in most communities, they are not always sufficient to meet the many healthcare needs of the uninsured. Some communities have multiple safety net organizations, but the system of care is fragmented. Others have a basic capacity to provide primary care services, but cannot meet the need for specialty consults or referrals, prescription medications, or more complex care. Still other communities lack even the capacity to meet the basic primary care needs of the uninsured.

The Healthcare Safety Net Task Force

In December 2003, The Kate B. Reynolds Charitable Trust funded the North Carolina Institute of Medicine to establish a Healthcare Safety Net Task Force that would examine the adequacy of the existing safety net structure. The Honorable Carmen Hooker Odom, MA, Secretary for the North Carolina Department of Health and Human Services, and Sherwood Smith Jr., JD, Chair Emeritus of Carolina Power & Light (now Progress Energy), chaired the 48-member Task Force, which included representatives of safety net organizations and provider associations, state and local elected officials and agency staff, non-profits, and advocacy organizations. The Task Force met once a month for nearly one year (March 2004-January 2005).

The goal of the Task Force was to develop a plan to better coordinate and integrate existing safety net institutions, identify

Components of the North Carolina Healthcare Safety Net

Federally Qualified Health Centers (FQHCs)

There are 23 FQHCs in North Carolina with a total of 76 delivery sites, serving more than 272,000 patients in 56 counties. FQHCs, often referred to as community or migrant health centers, provide comprehensive primary healthcare services as well as health education, preventive care, chronic disease management, oral and behavioral health services, all on a sliding-fee schedule. These centers have seen a 32% increase in the number of uninsured patients served in the past five years, serving more than 122,000 uninsured patients in 2003.

State-Funded Rural Health Centers (RHCs)

The North Carolina Office of Research, Demonstrations, and Rural Health Development in the North Carolina Department of Health and Human Services helped to establish 83 rural health centers throughout the state, with 32 of these receiving on-going support from the state. In return for the ongoing operational funds, these centers must agree to provide care to low-income uninsured individuals on a sliding-fee scale. These state-funded centers served 21,252 uninsured low-income patients in 2003.

Local Public Health Departments

There are currently 85 local health departments covering all 100 counties, with 79 of these covering single counties and six serving multi-county districts. These agencies provided clinical and preventive health services to 641,601 patients in 2003, of whom 260,603 were uninsured.

Free Clinics

These are non-profit organizations serving low-income uninsured populations by drawing on local healthcare resources and lay/professional volunteers. There are currently 60 free clinics or pharmacies in North Carolina, serving 48 communities. Most of these clinics are open one or two evenings per week and serve those needing care on a first-come, first-served basis. Free clinics served 69,320 low-income patients in 2003 (with 59,840 offered primary care services and 9,480 served in specialized clinics providing only pharmaceutical or behavioral health services).

Project Access or Healthy Communities Access Programs (HCAPs)

These are local community initiated efforts to fill gaps in the array of healthcare services available to meet the needs of the uninsured. Typically, these initiatives help link the services of traditional safety net providers to healthcare services offered by private practitioners and hospitals in the community. The Project Access model has been implemented in nine North Carolina communities in the following counties: Buncombe, Watauga-Avery, Mecklenburg, Cabarrus, Mitchell-Yancey, Guilford, Pitt, Vance-Warren, and Wake.

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communities with inadequate systems to care for the uninsured and underinsured, ascertain possible funding sources (nationally and locally) that can be used to expand care to the uninsured, and ultimately to expand and strengthen the capacity of healthcare providers and safety net institutions to care for underserved populations. This article provides an overview of the Task Force's findings and principal recommendations.

Are Safety Net Services Available throughout the State?

On the surface, it appears that North Carolina has a wide array of safety net organizations, located throughout the state (see map 1). However, few communities have sufficient safety net resources to meet the healthcare needs of all of the uninsured. The Task Force collected data on the number of uninsured residents receiving care in existing safety net institutions and compared this to the estimated numbers of uninsured in each county. Using these data (the percentage of uninsured with no identified source of primary care), the Task Force determined that only 25% of all the uninsured across the state receive primary care services from safety net organizations. This combined with other studies showing that the uninsured are less likely to have a regular healthcare provider and more likely to report access barriers, suggests that the healthcare safety net is not sufficient to meet the needs of the uninsured.

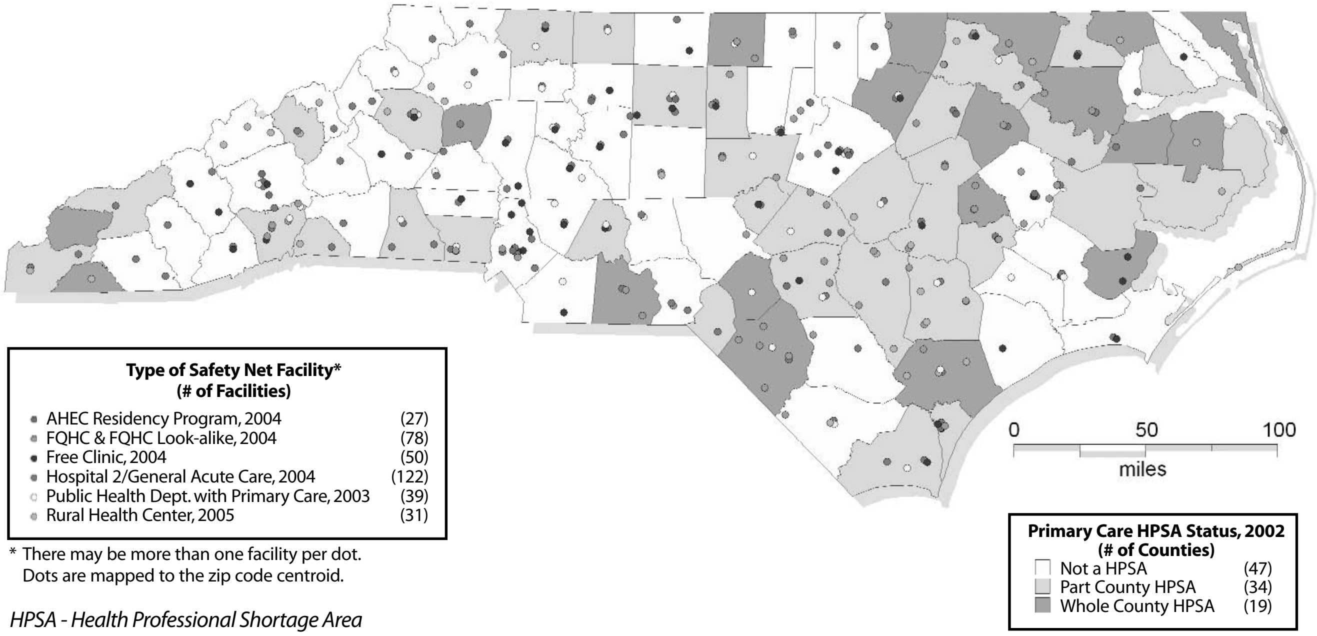
The percentage of uninsured served by the safety net varies widely across the state. Some counties appear to have enough safety net providers to meet the primary care needs all of their uninsured, while others appear to have none. The Task Force identified 28 counties with the least safety net capacity. Thirteen of these counties also had lower than average primary care provider-to-population ratios, suggesting that it would be difficult for the private providers to meet the primary care needs of the uninsured in these counties: Brunswick, Columbus, Davidson, Edgecombe, Franklin, Granville, McDowell, Onslow, Randolph, Rockingham, Stanly, Vance, and Wilkes. Further, access to pharmaceuticals, specialty care, behavioral health, and dental services is still a problem in many communities, including those that have adequate primary care capacity.

A few communities have been able to develop integrated systems of care to address a broader range of healthcare services needed by the uninsured. However, this is the exception rather than the rule. Most communities have fragmented systems of care for the uninsured. This is due, in part, to the difficulties in sharing patient information across providers, turf issues, and/or the need to compete for paying patients to help cover the costs of caring for the uninsured.

The Uninsured and Access to Prescription Medications

Prescription drugs are a critical component of healthcare. More than 40% of all Americans take at least one prescription drug, and 17% take three.[4] There has been a lot of public and

Map 1.
Safety Net Providers—North Carolina 2003-2005



* There may be more than one facility per dot.
Dots are mapped to the zip code centroid.

HPSA - Health Professional Shortage Area

Produced by: NC Rural Health Research Program, Cecil G. Sheps Center for Health Services Research, UNC-CH.

Sources: NC Association of Free Clinics, 2004; NC Division of Facilities Services, 2004; NC Community Health Center Association, 2004; North Carolina AHEC, 2004; Office of Research, Demonstrations and Rural Health Development, 2005; NC Institute of Medicine, 2005; NC Division of Public Health, NC Division of Medical Assistance, 2003; Area Resource File, 2003.

media attention focused on the ability of Medicare recipients to pay for needed medications, but this same problem plagues the uninsured. A 2003 Kaiser health insurance survey found that 37% of the uninsured said that they did not fill a prescription because of costs, compared to 13% of people with insurance coverage.[5]

The pharmaceutical companies have tried to address this problem by offering free or reduced-charge medications through their Patient Assistance Programs (PAPs). Nationwide, 75 pharmaceutical companies offered approximately 1,200 different medications in 2003. More than 270,000 North Carolinians accessed medications through these programs.[6] Yet, it is not always easy to obtain needed medications. Each manufacturer determines which drugs will be offered through their program and sets specific eligibility requirements. The application process can be laborious. It is often difficult for private physicians' offices as well as some smaller safety net programs to take advantage of these free medications, because of the programs' complexity. The North Carolina Foundation for Advanced Health Programs, Inc., with funding from The Duke Endowment, has developed software to assist providers and advocates in accessing appropriate PAP programs. Further, the North Carolina Health and Wellness Trust Fund has provided funding to community groups to help them develop medication assistance programs. These programs help individuals apply for free or reduced-cost medications and provide drug management to patients.

Many safety net providers also help their patients obtain needed medications, either by accessing PAPs or by offering free or reduced charge medications in-house. Despite these resources, ensuring that the uninsured obtain needed medications is still a problem. In many communities, providers are willing to volunteer to treat the uninsured, but are reluctant to do so if there is no assurance that the uninsured will be able to obtain the prescribed medications.

Collaboration and Integration

Few counties have the ability to meet the healthcare needs of all of the uninsured, regardless of how many or how few safety net organizations they have. However, there are some counties that have had more success. These counties have been able to work together to maximize their resources and to identify partners who can help in meeting the unmet healthcare needs of the uninsured.

There are various levels of collaboration and integration that have occurred throughout the state, ranging from periodic meetings of safety net organizations, community planning efforts and joint projects, to more elaborate inter-organizational agreements. In some counties, the hospital has collaborated with non-profit organizations to create primary care clinics for the uninsured. In other counties, local health departments have been successful in working collaboratively with FQHCs to expand care to the uninsured. Other counties have been able to develop more comprehensive systems of care, combining the efforts of traditional safety net providers with private providers

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School-Based or School-Linked Health Centers

Because school-age children, especially adolescents, are not always able to access comprehensive and coordinated systems of healthcare, some schools have established school-based or school-linked health centers to provide comprehensive primary care and mental health services to students. Currently, there are 27 comprehensive centers operating in middle and high schools in the state and another 12 centers that provide primary care services delivered by nurse practitioners or physician assistants. In addition to these health centers, many schools have hired nurses that can provide more limited health services to children.

Private Physicians

Physicians in private practice are a major source of care to the uninsured; many of whom provide services for reduced fees or at no charge. A national survey of households in 2001 revealed that nearly two-thirds of the uninsured reported a private practice physician as their regular source of care, and half of these respondents reported having received services in a physician's office. There has not been a North Carolina study to document the extent to which physicians in this state provide charity care, but most would agree that this is an important component of the healthcare safety net.

Area Health Education Centers (AHECs)

As part of its mission to meet the educational needs of the state's healthcare workforce, the AHECs in North Carolina support five residency programs in family medicine, three in rural family medicine, four in internal medicine, four in obstetrics/gynecology, three in pediatrics, and three in surgery. In 2003-2004, these programs provided services to 35,427 uninsured patients.

Hospitals

Almost all (110 of 113) general acute community hospitals in North Carolina operate emergency departments, which serve as an important safety net provider of last resort, regardless of ability to pay. In 2003, the uninsured represented 10% of outpatient visits, and of those, 22% (672,799 patients) were uninsured patients making emergency room visits.

Prescription Drug Programs

The largest source of free medications for the uninsured is the Patient Assistance Programs (PAPs) offered by private pharmaceutical companies. These programs vary a great deal from one company to another in terms of medications offered, eligibility requirements, and application processes. In addition, a few communities in North Carolina have seen the development of locally-organized pharmacy assistance programs to help low-income uninsured patients obtain needed medications. These programs fill a vital gap in the overall healthcare safety net, but at present levels of funding and availability, they are not able to meet all of the medication needs of the uninsured.

of care. For example, Project Access and Healthy Communities Access Programs (HCAP) help link the services of traditional safety net providers to healthcare services offered by private providers in the community. Generally, communities that have been able to develop integrated delivery systems for the uninsured have been more successful in meeting the healthcare needs of these populations.

Although many counties have been successful in establishing collaborative arrangements across safety net organizations, others have had more difficulty. Because there is little funding available to pay directly for services to the uninsured, safety net organizations often cross-subsidize the care they provide by using revenues from other paying patients. As a result, safety net providers in some counties compete for Medicaid or North Carolina Health Choice patients or other paying patients. Further, funding sources that are limited to certain types of safety net organizations sometimes create ill-will among other organizations that also provide care to the uninsured, but have no source of funding. In addition, there are other barriers—both real and perceived—that make it difficult to collaborate. For example, state medical confidentiality laws are perceived as obstacles to sharing patient information among providers who serve the same patients at different locations.

Financing Options

Many safety net organizations receive some financing from a variety of sources, including Medicaid, Medicare, private third-party insurance, out-of-pocket payments, and charitable donations. The source and proportion of funding from different sources varies across institutions and types of organizations.

By far, Medicaid is the largest funding source for those who would otherwise be uninsured. In North Carolina, the federal, state, and county governments expended approximately $8.5 billion in SFY 2004 to cover 1.5 million low-income individuals during the year; most of these people would have been uninsured but for the Medicaid program.[7] Medicaid is also a major revenue source for many safety net organizations, including hospitals, FQHCs, rural health clinics, health departments, non-profit health clinics, school-based health centers, and other private providers who care for the uninsured. North Carolina Health Choice, the State Children's Health Insurance Program, is another major revenue stream for some safety net providers. The federal and state governments paid approximately $188 million to cover close to 175,000 previously uninsured children through North Carolina Health Choice in SFY 2004.[8]

In addition to funding for Medicaid and North Carolina Health Choice (which pays for services provided to people insured through these programs), there are limited funds available to support care for the uninsured through safety net organizations. For example, the federal government provides some funding to support operational costs for FQHCs, and the state provides limited funds to help pay for care to the uninsured through state-funded rural health centers. In addition, the North Carolina General Assembly appropriated $7 million in non-recurring funds last year (2004) to help support and expand the services available to the uninsured and medically indigent through certain safety net organizations, including FQHCs, FQHC look-alikes, public health clinics, and state-funded rural health centers. At the time this article was being written, it was still uncertain whether these funds would be continued in the 2005 budget. Some new federal funds are available to increase the number of people who can be served by federally qualified health centers through the President's Initiative for Health Center Growth; however, funding under this initiative is competitive, and North Carolina health centers have only been awarded approximately 3% of new funds over the last three years. The federal, state, and/or county governments also provide funds that offset some of the costs of providing specific services to the uninsured (e.g., child and maternal health services or services provided to people with HIV/AIDS).

While limited funding is available to help subsidize care to the uninsured, it is not sufficient to cover all of the costs, and is not well-targeted to those safety net organizations that provide the largest share of care to the uninsured. Certain safety net organizations provide a disproportionate share of care to uninsured patients, and as a result, these organizations collect a smaller share of their revenues from paying patients. This makes it harder for these institutions to pay for the care provided to the uninsured. The proportion of uninsured patients seen by different safety net providers varies across organizations:

- On average, 47.6% of the North Carolina FQHC users in 2003 were uninsured, but this varied from more than 65% in five centers, to less than 30% in seven centers.
- On average, 21% of patients in state-funded rural health centers were uninsured. This varies from more than 30% of patients who were uninsured in four state-funded rural health centers, to less than 10% of patients who were uninsured in two centers.
- The percentage of total hospital discharges attributable to the uninsured varied from a high of more than 10% in nine hospitals to a low of less than 2% in 14 hospitals; and the percentage of hospital discharges attributable to both Medicaid and the uninsured varied from a high of more than 35% in nine hospitals to a low of less than 10% in 10 hospitals.

The increased numbers of uninsured and inability to raise revenues from third party payers or other sources is creating significant financial strains for many of these organizations.

Recommendations

The Task Force formulated a set of 28 recommendations that could help strengthen and expand the capacity of healthcare safety net providers to address the healthcare needs of the growing numbers of uninsured in the state. These recommendations are fully described in the formal report issued by the North Carolina Institute of Medicine,[9] but they are generally described here.

The recommendations offered by the Task Force address four principal sets of issues facing the healthcare safety net organizations in our state. These are: (1) the need to ensure that the uninsured have health insurance coverage; (2) expanding the capacity of the healthcare safety net to meet the needs of the uninsured; (3) developing systems to better integrate existing safety net services in local communities; and (4) increasing funding to support the work of safety net providers. Brief explanations of each of these four sets of issues are offered below.

The need for additional insurance coverage for the uninsured. The primary barrier that the uninsured face in obtaining needed health services is lack of insurance coverage. Not only does lack of coverage affect the ability of individuals to access needed services, but it also affects a person's health status. To address this issue, the Task Force recommended that the North Carolina General Assembly take steps to make health insurance coverage more affordable and to expand health insurance coverage to more individuals and families who are currently uninsured. Until the uninsured have coverage, the Task Force recognized the importance of supporting and expanding existing safety net capacity to be able to meet more of the vital healthcare needs of the uninsured. In a very real sense, the healthcare *safety net* is just that, a stop-gap set of programs and voluntary efforts to minimize the effects of lack of healthcare insurance coverage for a growing segment of our population. The problems caused by lack of adequate health insurance coverage cannot be solved until most or all of those now uninsured, for all or part of a year, are included in some form of insurance to meet their healthcare needs.

The need for increased safety net capacity to address the healthcare needs of the uninsured. Because there is not unlimited funding or resources to support new or expanded safety net services across the state, the Task Force attempted to identify those communities or counties with the greatest unmet needs. The Task Force was able to collect data from some safety net providers about the number of uninsured people who received primary care services in the prior year, but these data were not uniformly available across types of safety net organizations. Data are not currently available from private practitioners, or from hospital emergency departments or outpatient clinics. Further, there are few sources of data to identify the capacity of communities to address the behavioral health, dental health, specialty, and medication needs of the uninsured. The Task Force recognized the importance of collecting these data, in order to target new resources to the communities most in need and to monitor the capacity of the safety net to address the healthcare needs of the uninsured over time. Therefore, the Task Force recommended that the North Carolina Department of Health and Human Services take the lead in monitoring services provided by public and private safety net providers across the state. In addition, the Task Force recommended that the Department, along with other safety net organizations, help develop a planning package and provide technical assistance to communities interested in expanding their safety net capacity.

The Task Force also recognized that there are barriers in existing laws that discourage some private practitioners from volunteering their time to serve the uninsured. Some private providers have expressed concern that they may be subject to a lawsuit for a bad health outcome if they provide services to the uninsured. Although North Carolina already has a Good Samaritan statute that provides protection against monetary liability, it does not currently shelter providers from the cost (either financially or emotionally) of having to defend a lawsuit. The Task Force identified a need to make the act of volunteering to serve the uninsured less of a burden, and recommended that the North Carolina Free Clinic Association work with the North Carolina Medical Society and other safety net providers to explore other ways of reducing the barrier that potential malpractice claims create to encouraging private practitioners from volunteering to serve the uninsured.

The Task Force was also concerned with assuring access to needed medications by those who are served by various safety net providers. A recommended therapeutic regimen is meaningless without the ability to follow through with access to prescribed medications. While there are some resources available to provide needed medications through the pharmaceutical companies' Patient Assistance Programs (PAPs) or through local safety net organizations, the current resources are insufficient to ensure that the uninsured can obtain necessary medications. There is also a federal program that allows certain safety net organizations to negotiate for highly discounted medication prices (called the 340B program). However, federal law restricts the 340B drug discount program to certain safety net organizations, including FQHCs, public health, and some hospitals. The deeply discounted prices are not available to free clinics, state-funded rural health centers, or other non-profit safety net organizations. Thus, the Task Force made a series of recommendations aimed at expanding the availability of low-cost or free medications to the uninsured. First, the Task Force recommended that existing programs to help low-income uninsured individuals access free or reduced-cost medications through the PAPs be expanded and that the pharmaceutical companies streamline and simplify the PAP application process. The Task Force also recommended that Congress expand the 340B drug discount program to include more safety net organizations. In addition, the Task Force recommended that state philanthropic organizations provide funding to help the North Carolina Department of Health and Human Services establish a bulk purchasing program that would help negotiate volume discounts from pharmaceutical companies for safety net organizations around the state.

Strengthening safety net integration and collaboration efforts. The patchwork of services, programs, and organizations serving the uninsured is being stretched in a number of directions as the demand for care among the uninsured has increased. Few communities in our state have been able to meet all the needs of the uninsured, regardless of how many providers of such care there are. The Task Force identified the need for increased levels of collaboration and, in some cases, the potential for the integration of services and organizations, in order to more effectively meet the needs of those served by safety net providers.

In communities with few or no safety net providers, these issues do not arise. But, in communities where multiple organizations are serving, often with overlapping efforts, the same uninsured populations, the need for collaboration is more evident. The Task Force therefore recommended a number of efforts to encourage collaboration among safety net providers and ways to encourage the involvement of professional and business organizations in these community-wide efforts.

The Task Force recognized the need to create an ongoing state-level Safety Net Advisory Council (SNAC) that can continue the work of the Task Force and encourage state-level and local safety net collaborations and integration efforts. The SNAC would be charged with collecting and disseminating "best practices" and models for service organization and delivery. Additionally, the SNAC should work with North Carolina foundations to help convene a best practices summit that would help local communities identify ways to build and strengthen their capacity to meet the healthcare needs of the growing uninsured population and reduce barriers to interagency collaboration and integration.

The Task Force also heard that existing state confidentiality laws have created barriers to sharing patient information across safety net providers—even when providing services to the same patients. The Task Force recommended that the General Assembly enact laws to clarify state confidentiality laws to ensure that safety net providers are allowed to share identifiable health information with each other when providing care to the same patients.

Increased funding to support and expand the existing safety net system. The Task Force identified four strategies that could help provide financial support for care to the uninsured: (1) ensuring that North Carolina receives its fair share of federal funding for safety-net programs, including funding from the President's Initiative for Health Center Growth and Expansion; (2) expanding state funds to support safety net organizations; (3) enhancing Medicaid reimbursement for safety net organizations, to help ensure that Medicaid reimbursement is at least sufficient to cover the costs of treating these patients; and (4) ensuring that individuals who are eligible for Medicaid enroll in the program, in order to make more limited state, local, or federal funds available to serve uninsured individuals who cannot qualify for Medicaid.

Although the Task Force spent considerable time trying to identify new sources of funding, the Task Force's highest recommendation was to maintain the state's major safety net funding source: Medicaid. As noted earlier, North Carolina has 1.4 million people who are uninsured; 62% of them have incomes below 200% of the federal poverty guidelines. The numbers of uninsured would be much larger without the existence of Medicaid and the North Carolina Health Choice programs. There is currently some discussion at the federal level about turning Medicaid into a block-grant program. This could be devastating to the state, safety net providers, and to low-income citizens of the state who rely on Medicaid to cover their healthcare needs. (See the open letter from Governor Easley on page 120-121) In addition, Task Force members felt strongly that the state was not getting its fair share of existing federal funds through the State Children's Health Insurance Program (North Carolina Health Choice), the President's Initiative for Health Center Growth (which funds FQHC health center expansion), Ryan White CARE funds for people with HIV/AIDS, or the Special AIDS Drug Assistance Program. Therefore, the Task Force recommended that the North Carolina Department of Health and Human Services and other safety net organizations work with the North Carolina Congressional delegation to: (1) oppose efforts to limit the availability of federal Medicaid funds and (2) ensure that the state receive its fair share of other funds available to underwrite health services for the uninsured.

Although new federal funds are available to expand the availability of healthcare services through FQHCs, there are barriers that prevent local health departments from applying for these funds. One such barrier is the state-required composition of local health department boards. Federal laws mandate that the governance structures of FQHCs be predominantly composed of the safety net organizations healthcare consumers; however, state law prescribes that local health departments boards be composed primarily of healthcare or other professionals. Thus, even though the populations served by health departments and FQHCs are the same, or very similar, local health departments are ineligible for this federal support. The Task Force recommended that the General Assembly give county commissioners the authority to change the local health department board composition in order to make these agencies eligible for federal funding.

The Task Force also recommended continued and expanded state funding for safety net organizations. Last year, the North Carolina General Assembly appropriated $7 million in one-time funds to expand the availability of healthcare services to the uninsured through new or existing safety net organizations: $5 million to FQHCs and $2 million for state-funded rural health centers and/or local health departments. The Task Force supported the General Assembly's efforts and recommended that this funding be expanded to $11 million on a recurring basis: $6 million for FQHCs and $5 million for state-funded rural health centers, local health departments, or other nonprofit safety net organizations with a mission of serving the uninsured.

Another need that has surfaced in many policy discussions in recent years is the need for additional school health nurses. The Task Force was aware of the important role these nurses play in meeting the primary healthcare needs of children and adolescents in our public schools. For many children, and especially for adolescents, school nurses are the only healthcare professionals they see, yet North Carolina has a shortage of such personnel. The recommended ratio of school nurses to students is 1:750; the statewide ratio in North Carolina is 1:1,918. Last year (2004), the General Assembly appropriated funds to enable the hiring of an additional 145 nurses to work in the public schools (with 65 of these positions time-limited). Even with this additional funding, there is still a need for 973 nurses to meet these recommended ratios. The Task Force recommended an additional appropriation to accomplish this goal.

The Task Force also recommended that the North Carolina Department of Health and Human Services explore options to enhance Medicaid reimbursement to safety net organizations that serve a higher than average proportion of uninsured patients and that the state ensure that local health departments—like other publicly-funded health providers—receive cost-based reimbursement for the clinical services they provide. Any new funding provided to FQHCs, FQHC look-alikes, rural health centers, hospitals, and/or health departments should be targeted toward serving the uninsured.

The Task Force suggested ways to capture savings that the state is currently realizing through implementation of the Community Care of North Carolina program (CCNC), a system that provides case management and disease management services to improve the health of Medicaid recipients with chronic or complex health problems. At the present time, local CCNC networks cannot retain any funds that are saved as a result of improved care management for these Medicaid recipients. In contrast, managed care companies that offer contract services to low-income populations are able to retain realized savings. The Task Force recommended that the Division of Medical Assistance explore the possibility of creating a system of "shared savings" with regional CCNC networks. The shared savings system would enable the networks to use their savings to support the provision of services to the uninsured.

Finally, the Task Force made a series of recommendations to ensure that uninsured individuals who are currently eligible for Medicaid are enrolled in the program. Ensuring Medicaid coverage for those who are eligible would help target the limited state funds for safety net providers toward uninsured individuals who cannot receive coverage elsewhere. National data suggest that only 72% of eligible children and 51% of eligible non-elderly adults enroll in Medicaid.[10] Many eligible individuals do not know they are eligible for coverage or are discouraged because of the stigma attached to applying for public programs. Others are discouraged because the application process is difficult to complete. The state has made significant progress in simplifying the Medicaid and North Carolina Health Choice application process for children, but the state has not yet incorporated these simplifications into the adult Medicaid application process. To address this problem, the Task Force recommended that the state streamline and simplify the Medicaid program for adults, by creating simplified application forms, extending the length of time for recertification, and exploring the possibility of eliminating the resource test for families with children (just as the state has already done for families that apply on behalf of their children only). The Task Force also recommended that the state modify Medicaid policies to make it easier for individuals with high medical expenses to qualify for Medicaid.

Summary

North Carolina is in the midst of a quiet, but growing healthcare crisis. The number of uninsured residents is rising at an alarming rate—and a faster rate than in most other states. Almost one of every five (20%) non-elderly North Carolinians have no health insurance, which means a sizeable portion of our population has unmet healthcare needs. As healthcare costs continue to increase, North Carolina is likely to continue seeing increased numbers of uninsured. Until we can dramatically reduce the volume of the uninsured, there will be a continuing and growing need for governmental, private sector, and voluntary healthcare providers to serve this population.

In this issue of the Journal, we have attempted to draw attention to the volume and variety of services, programs, and organizations involved in meeting this important healthcare need among our state's most vulnerable populations. The organizations involved in rendering these services, and the private physicians and other healthcare professionals who give of their time and talents to meet these needs, are stretched to their limits in most communities. The Task Force has recommended several concrete steps that would shore up safety net organizations' and individual providers' capacity/ability to meet these needs. Some of these steps will require rather straightforward changes in regulations and laws governing the provision of healthcare services. Others will require appropriation of funds to augment the public, private, and voluntary support now given through these safety net provider organizations in support of their efforts to serve the uninsured.

While some effort needs to be made to bring these issues to the attention of the state's Congressional delegation in Washington, DC, many of these problems should not have to wait for federal action. The needs are great, and the demands for service are increasing among those organizations and professionals who have assumed these responsibilities in counties and communities across our state. For those with healthcare insurance, these problems and their administrative complexities may seem of remote interest and concern. But, for the people who depend on the safety net services, these problems can mean the difference between health, work, and opportunity, or between disease, disability, or death. There is a genuine collective benefit to meeting the healthcare needs of the uninsured, for the health and wellbeing of a fifth of our state's population affects the health of all of us. Depending on a stop-gap, safety net to maintain the health of such a large segment of our population is a societal risk we all must confront. Failure of any part of the healthcare safety net could be detrimental to the stability of the larger healthcare system on which we all depend. **NCMJ**

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State of North Carolina
Office of the Governor
20301 Mail Service Center • Raleigh, NC 27699-0301

Michael F. Easley
Governor

Governor Mike Easley sent the following letter to the entire North Carolina Congressional Delegation.

March 9, 2005

Dear United States Senators and Representatives from North Carolina:

Last week, my fellow governors and I met in Washington to discuss issues of importance to all of us, including the proposed Medicaid cuts included in the President's 2005-06 budget. Under the President's plan, $40 billion in costs would be shifted from the federal government to the states. We agreed that these proposals were not sustainable.

Like many states, the rapid growth in North Carolina's Medicaid enrollment – over 200,000 new enrollees in three years – has driven the increase in costs. As we have discussed before, our national trade policy has resulted in the loss of thousands of North Carolina jobs, and some of those families have been forced to seek Medicaid assistance to make ends meet.

Since 2001, North Carolina has taken many steps to control Medicaid costs. We have reduced provider rates and fees, denied some inflationary payments to providers, taken steps such as establishing a maximum allowable cost list and a shift to generic and over-the-counter (OTC) drugs to control costs, increased co-payments to maximum levels allowed by law, implemented technology to reduce fraud and abuse, and reduced the transitional Medicaid period by one year. Quite simply, we have exhausted many traditional cost-saving options.

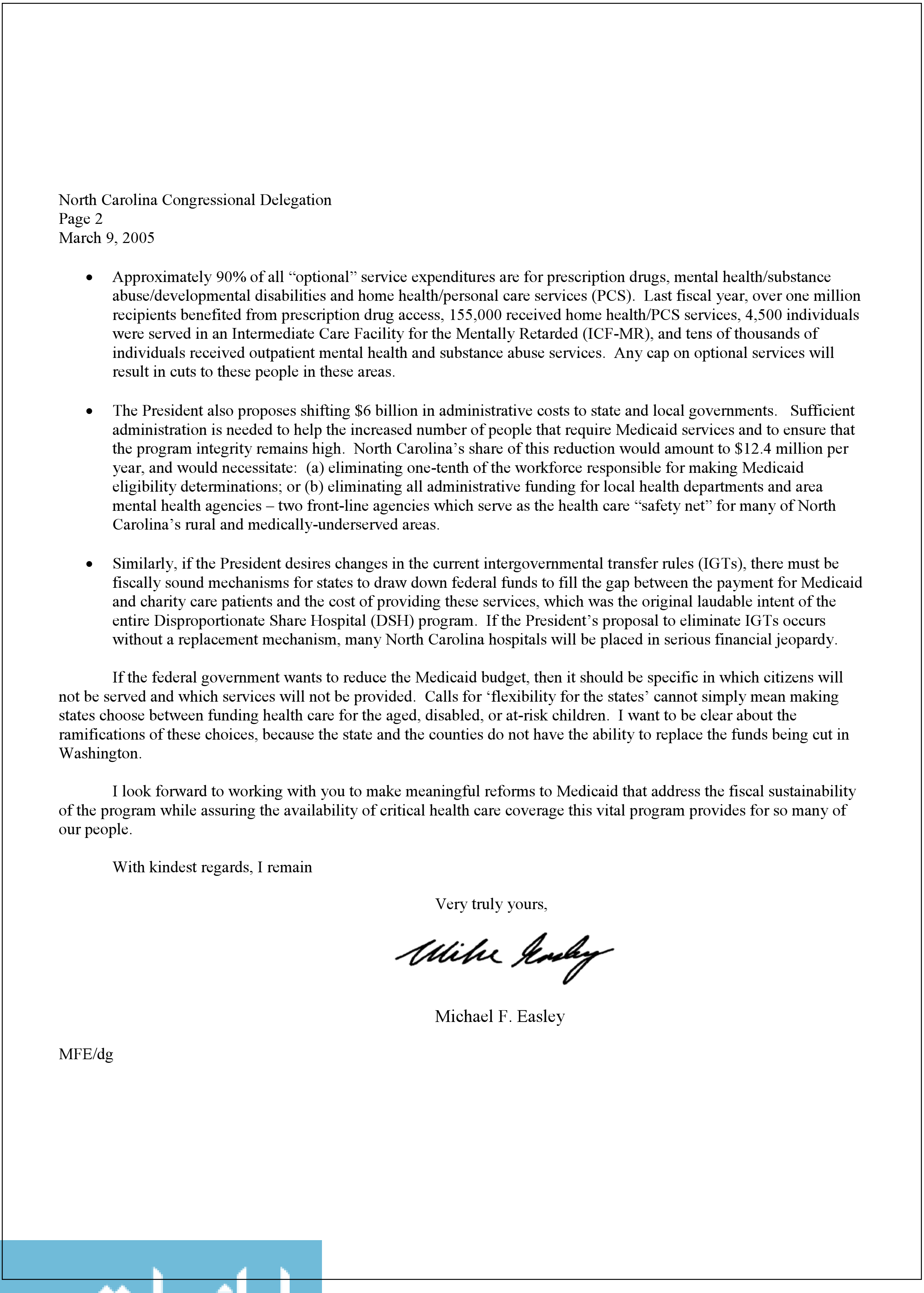
Here are the precise ramifications of some of the President's proposals to North Carolina:

- The President proposes reducing the rate of targeted case management from 62% federal share to 50% federal share. This will eliminate Medicaid case management services to an estimated 3,500 individuals.

- The President recommends a cut in the provider tax rate from a maximum of 6% to 3%. The cut in the allowable provider tax rate would cut payments to nursing facilities by $78 million and result in 600,000 fewer patient days of care provided during the year, the equivalent of 1,644 patients every day of the year.

- There is substantial discussion in Washington of controlling Medicaid costs through capping or cutting optional Medicaid services or populations. A cap or cut in optional services would require the elimination of adult dental care services that benefit 11,000 North Carolinians per month, adult optical services that benefit 3,650 North Carolinians per month, adult podiatry services that benefit 2,300 North Carolinians per month, and adult chiropractic services that benefit 1,600 recipients per month. I decided not to make these reductions in my budget recommendations this year, because these problems left untreated would result in the need for more costly medical care for these people in the future.

Location: 116 West Jones Street •Raleigh, NC • Telephone: (919) 733-5811



- Approximately 90% of all "optional" service expenditures are for prescription drugs, mental health/substance abuse/developmental disabilities and home health/personal care services (PCS). Last fiscal year, over one million recipients benefited from prescription drug access, 155,000 received home health/PCS services, 4,500 individuals were served in an Intermediate Care Facility for the Mentally Retarded (ICF-MR), and tens of thousands of individuals received outpatient mental health and substance abuse services. Any cap on optional services will result in cuts to these people in these areas.

- The President also proposes shifting $6 billion in administrative costs to state and local governments. Sufficient administration is needed to help the increased number of people that require Medicaid services and to ensure that the program integrity remains high. North Carolina's share of this reduction would amount to $12.4 million per year, and would necessitate: (a) eliminating one-tenth of the workforce responsible for making Medicaid eligibility determinations; or (b) eliminating all administrative funding for local health departments and area mental health agencies – two front-line agencies which serve as the health care "safety net" for many of North Carolina's rural and medically-underserved areas.

- Similarly, if the President desires changes in the current intergovernmental transfer rules (IGTs), there must be fiscally sound mechanisms for states to draw down federal funds to fill the gap between the payment for Medicaid and charity care patients and the cost of providing these services, which was the original laudable intent of the entire Disproportionate Share Hospital (DSH) program. If the President's proposal to eliminate IGTs occurs without a replacement mechanism, many North Carolina hospitals will be placed in serious financial jeopardy.

If the federal government wants to reduce the Medicaid budget, then it should be specific in which citizens will not be served and which services will not be provided. Calls for 'flexibility for the states' cannot simply mean making states choose between funding health care for the aged, disabled, or at-risk children. I want to be clear about the ramifications of these choices, because the state and the counties do not have the ability to replace the funds being cut in Washington.

I look forward to working with you to make meaningful reforms to Medicaid that address the fiscal sustainability of the program while assuring the availability of critical health care coverage this vital program provides for so many of our people.

With kindest regards, I remain

Very truly yours,

Mike Easley

Michael F. Easley

MFE/dg

COMMENTARY

Federally Qualified Health Centers:
Providing Healthcare to North Carolina's Communities in Medical Need

Sonya J. Bruton, MPA

"I wouldn't trade Lincoln doctors for nothing. Whatever illnesses I have, they deal with it right away. If I have to see a specialist, they try and send me to one. They don't take chances. They always deal with my heart to make sure that it's in good condition; because, everything starts from the heart."

Sixty-four years ago, Thelma Woods was born at Lincoln Hospital—now Lincoln Community Health Center—in Durham, North Carolina. She grew up receiving care at the Center, and when she returned from New York after 30 years, it once again became her medical home. Ms. Woods discovered during a pre-employment physical that she had a blood pressure reading of 200/200. She sought care at Lincoln the next morning and learned that she had hypertension, high cholesterol, and diabetes. For three years, the medical staff helped Ms. Woods manage those conditions, and on January 18, 1993, they navigated her through a successful open-heart surgery. Today she serves as a member of the Board of Directors, and Lincoln provides medical care to Ms. Woods, her children, and grandchildren. "I think Lincoln has some of the best doctors around," she said. "I know without them caring for my health, I wouldn't be here today."

Lincoln Community Health Center is one of 23 federally qualified health centers operating in North Carolina. Federally qualified health centers (FQHCs) were created 40 years ago to respond to the reality that the poor have fewer options in the healthcare marketplace and are often shut out entirely from private medical practices. The statute authorizing the award of federal grants to health centers can be found under section 330 of the Public Health Service Act and includes a family of broad and specific health options: (1) Community Health Centers (CHCs), (2) Migrant Health Centers, (3) Public Housing Primary Care, and (4) Healthy Schools, Healthy Communities.

FQHC Defined

FQHC-designated community health centers are community-located and -operated clinics that receive federal support to care for residents living in the targeted area surrounding the center. The geographic scope may extend to zip codes or counties in an attempt to provide access to care for those in need. In order to receive federal assistance, the specified community must have a medical need. The need could be for more physicians, for more places willing to accept Medicaid/Medicare, or for a place that will care for community members who have no healthcare coverage. The care offered to these residents must include primary care services, health education, preventive care, chronic disease management, oral health, and behavioral health services. They also have to make sure that language, cultural, or economic factors neither impact a patient's ability to schedule or complete a visit nor stop them from receiving all of the follow-up services that may be needed to recover from an illness. This may mean making sure that medication or specialty services are secured. Federally-funded community health centers offer the following menu of primary care and enabling services to all patients either at the office or through a prearranged referral:

> *"FQHC-designated community health centers are community-located and -operated clinics that receive federal support to care for residents living in the targeted area surrounding the center."*

- Preventive dental services;
- Immunizations;
- Primary medical care;
- Immunizations;

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- Diagnostic laboratory services;
- Preventive services including prenatal, perinatal, and well-child services (such as eye, ear, and dental screenings for children);
- Cancer and other disease screenings;
- Screening for elevated blood lead levels;
- Diagnosis and treatment of communicable diseases;
- Family planning services;
- Preventive dental services;
- Emergency medical and dental service;
- Pharmacy services;
- Substance abuse and mental health services;
- Enabling services including outreach, transportation, interpreters, and case management services; and
- Services to help the health center's patients gain financial support for health and social services.

When referrals are made, health centers must coordinate and oversee the care provided to their patients, and access to care must be available through an after-hours call system or clinic hours that extend beyond the normal 9:00 am-5:00 pm work schedule.

Nationally, the community health center program was created in 1965 as part of President Lyndon Johnson's "Great Society" and "War on Poverty" initiatives. The movement came to North Carolina in March of 1970 with the creation of the Orange-Chatham Comprehensive Health Center in Chapel Hill, North Carolina. This center was followed by Lincoln Community Health Center in June of that same year.

Today there are 23 federal grantees, receiving section 330 funds, operating 76 delivery sites in North Carolina. These primary care facilities serve 56 counties and nearly 300,000 patients. In addition, there are three community-based primary care providers that are in compliance with Section 330 program requirements, but do not receive federal grant support. Instead, these centers, known as federally qualified health center look-alikes, receive:

- Drug pricing discounts;
- Special Medicaid reimbursement rates;
- Onsite Medicaid eligibility workers;
- Waived Medicare deductibles;
- Ability to waive co-payments of patients <200% of FPG;
- Medical providers through the National Health Service Corps; and
- No-cost vaccines for children.

Nevertheless, the proportion of residents without a usual source of care is much higher than the national average in North Carolina. At least one-in-five residents has no regular provider of care.[1] As a result, the push to develop more FQHCs throughout North Carolina continues. Research indicates that more health centers would significantly diminish the Hispanic/white and black/white primary care visit disparity.[2] One study recently found that a 10% increase in the number of health centers per 10,000 population would lead to a 6% increase in the probability of visiting a physician.[3] In general, expanding health center capacity reduces unmet need and increases the percent of the uninsured with a regular source of care.

Governance Structure

One of the foundations of the FQHC program is the mandate that governance of the health center organization involve a Board of Directors made up predominately of the people who use the health center's services (consumers/users). A consumer member should have used the health center services within the last two years and consider the health center his or her medical home. Health center expectations indicate that a user should be an individual who considers the health center his or her medical home for the purposes of receiving primary and preventive care.[4] For example, if upon becoming ill with the flu, an individual makes an appointment at the health center for diagnosis and treatment, the person would be considered a user of the health center's services. Conversely, if an individual uses the health center annually for a blood pressure check, but uses the services of a private physician in the community when he or she becomes sick, the individual would not be considered a health center user for the purposes of satisfying the requirement, because he or she is not using the health center as the principal source of primary healthcare. The section 330 implementing regulations state, "a majority of board members shall be individuals who are or will be served by the center and who, as a group, represent the individuals who are or will be served by the center and who, as a group, represent the individuals being or to be served in terms of demographic factors, such as race, ethnicity, sex."

From the inception of the health center program, Congress indicated that health centers should be governed predominately by the people who would care most about, and have the greatest interest in and commitment to, the scope of services offered by the health center, the health center's location and accessibility, the hours that services would be available, the programmatic priorities that the health center would pursue, etc.—the patients themselves.

Financial Stability

This year, the federal Community Health Center program celebrates its 40th anniversary. Also celebrating 40 years of service is the Medicaid program. In 1977, Dr. Karen Davis, President of the Commonwealth Fund, said, "the two programs were specifically designed to work in tandem with one another to make access to quality healthcare available to millions of Americans who previously had, at best, extremely limited access to needed care and who, as a result, experienced the worst health status among all Americans."

At 40, the FQHC program is thriving and growing under President George W. Bush's campaign to double the number of communities and people served by the end of 2006; while the Medicaid program is facing escalating costs that threaten its ability to offer coverage through the existing formula.

The weakened position of Medicaid, combined with an increasing number of uninsured, increasing healthcare costs, and downsizing of worker health benefits threaten the financial position of Community Health Centers. Approximately 25% of North Carolina health center patients are Medicaid beneficiaries, resulting in nearly 43% of North Carolina FQHC total revenues. FQHCs are left to wonder how they will continue to deliver high quality primary care to their vulnerable patients in the face of a disproportionate funding-to-need ratio environment. During this fiscal year (2005), federal grant dollars to North Carolina health centers decreased by nearly 1% across the board. Reductions to North Carolina Medicaid funding could result in increased cost sharing, forcing health centers to subsidize Medicaid using the already dwindling federal grant dollars intended for the uninsured. **NCMJ**

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COMMENTARY

North Carolina State Government and the Healthcare Safety Net:

Building the Nation's Most Extensive Network of Rural Health Centers

Torlen L. Wade, MSPH, and Andrea D. Radford, MHA

Since its inception in 1973, the North Carolina Office of Research, Demonstrations, and Rural Health Development has worked to transform government into a catalyst for improving access to quality and cost-effective healthcare services for underserved residents of North Carolina. Under the leadership of its founding director, James D. Bernstein, the Office adopted a state/local partnership approach and made community investment the cornerstone of its improvement strategy. Bernstein focused on five key philosophies that have remained the guiding principles of the Office's partnership initiatives over the last 30 plus years:

- Ownership is vested with community participants;
- Roles and responsibilities of all participants, both community and governmental, are clearly defined;
- In-depth technical assistance is provided on a continuous basis;
- Accountability is clear and measured; and
- Meeting patient and community needs remains the focus of all activities.

Jim Bernstein believed strongly that if improvement in care or service was the goal, then those who were responsible for making it happen must have ownership of the improvement process. State government could not merely issue edicts or dangle money; it had to engage in meaningful partnerships, be prepared to make long-term investments in communities and nurture the leadership needed to deliver the desired improvements.

Community Involvement

The Office began to apply these principles in its initial rural health development work. When the Office was founded in 1973 as the Office of Rural Health Services, it was charged by the North Carolina General Assembly with assisting North Carolina's rural areas in tackling a critical shortage of primary healthcare services in their communities. As large numbers of aging general practitioners retired in the early 1970s, they were not being replaced by younger physicians. The prospects for North Carolina's isolated rural communities to attract replacements were dim. The programs to train the new specialty of family practice physicians were just getting underway, and the competition for the few physicians available was intense. Meeting the growing rural healthcare crisis required new strategies and new infrastructure.

To help rural communities address these challenges, the Office promoted two important structural changes to North Carolina's healthcare delivery system. The first structural change was the development and use of community nonprofit boards, comprised of local residents, as the owners and operators of their community's healthcare program. To support this level of

"State government could not merely issue edicts or dangle money; it had to engage in meaningful partnerships, be prepared to make long-term investments in communities and nurture the leadership needed to deliver the desired improvements."

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community involvement, the Office designed and developed a comprehensive set of support services that helped make community ownership and direction a reality. By building a cadre of specialized technical expertise, the Office was able to assist interested communities in establishing nonprofit corporations, organizing fund raising campaigns, designing and building facilities, recruiting and hiring staffs, and overseeing medical operations. The combination of community leadership and the comprehensive technical assistance delivered by the Office was a highly effective approach in making medical care available to their residents for many rural communities. What was viewed as a radical development in the early 1970s is an integral component of North Carolina's medical landscape today. More than 80 community-owned rural health centers developed with Office of Rural Health assistance now serve approximately 350,000 North Carolinians across the state.

Using Physician Extenders

The second structural change that was a centerpiece of the Office's initial efforts to increase access to healthcare in rural communities was the reliance on non-physician primary care providers—family nurse practitioners and physician assistants—to provide needed medical services. Major changes in medical practice and reimbursement rules and regulations were initiated to enable these non-physician primary care providers to practice in medical offices geographically removed from a supervising physician. Family nurse practitioners and physician assistants became, and still are, important providers at many rural health centers.

Key Programs Serving the Medically Vulnerable

The principles from which the Office of Rural Health developed over 30 years ago in addressing access to care in rural communities across the state are now used to guide the Office and its partners in bringing about improvement in other healthcare areas that target the underserved and medically vulnerable, including:

- *Community Care of North Carolina*. Managing the care of Medicaid recipients through community health networks that are organized and operated by local physicians, hospitals, health departments, and departments of social services. The 15 Community Care networks, serving more than 600,000 Medicaid recipients, are putting in place the management systems needed to achieve long-term improvement in the quality, cost, and health outcomes of recipient care;
- *Medical Assistance Plan (MAP)*. Providing direct funding for primary care services to indigent patients served by nonprofit providers in high-need counties;
- *Prescription assistance*. Improving providers' ability to access free and low-cost medications for their low-income patients; and
- *Farmworker healthcare*. Targeting the unique healthcare needs of seasonal and migrant farmworkers across the state by building up local delivery systems in high-impact areas.

Future Planning

As the Office of Research, Demonstrations, and Rural Health Development moves into the 21st century, it looks to build on the legacy of community ownership and collaboration established as guiding principles in the early days of the Office. Establishing and sustaining successful safety net providers still requires the active participation of the community to be served and coordination with existing healthcare providers. Challenges seen in the early days of the Office, key physicians retiring with no one to replace them, and medical students choosing specialty practice over primary care, are re-emerging and call for creative solutions that require communities, providers, and government agencies to work together. The needs of North Carolina's uninsured and medically vulnerable citizens are greater than current resources. Collaboration among both communities and healthcare providers is critical to avoid duplication of effort, to develop programs that are sustainable over time, and to use limited resources wisely. While common problems plague the safety net as a whole, each community has its own unique set of circumstances and offers its own unique set of resources to tap into. The time-tested philosophy of community-driven healthcare avoids a one-size fits all solution and seeks to work with a community to maximize the impact and effectiveness of existing resources and to assist them in designing workable approaches to healthcare needs. This philosophy of community-driven healthcare is one of the key factors that allowed North Carolina to build and sustain the nation's most extensive network of rural health clinics. **NCMJ**

Free Clinics in North Carolina:
A Network of Compassion, Volunteerism, and Quality Care for Those without Healthcare Options

Olivia Fleming, MA, and John Mills, CAE

Ida and her husband Jim both worked full-time. Ida's job did not provide health insurance, but Jim paid extra so his insurance policy would cover both of them. Jim developed multiple sclerosis, which progressed rapidly causing Jim to lose his job. Despite their limited financial resources, they were able to continue his insurance through COBRA. Unfortunately, they did not have the resources to continue hers. Ida was faced with managing her hypertension without insurance. She turned to Urban Ministries Open Door Clinic (ODC) in Raleigh for treatment and medication. A routine screening mammogram revealed a lump in Ida's breast. Uninsured and frightened, she turned again to the ODC. ODC coordinated care and, within a month, Ida had a mastectomy and had begun a chemotherapy regimen. One year later, Ida is cancer-free and has found a new job with healthcare benefits, leaving the ODC with an opening for another person in need without other healthcare options.

Nancy, a young woman in her late 20's, came to ODC because she didn't feel well. Diagnosis: diabetes mellitus. Her hemoglobin A1c was 15, and other clinical measures were similarly high. Nancy entered ODC's specialized diabetes management program, the Diabetes Care and Risk Reduction Program. By meeting regularly with a certified diabetes educator; making significant changes in her eating and exercise habits; and receiving medications, a glucometer, and test strips at no charge, Nancy has brought her hemoglobin A1c to 5.2 and other clinical measures are in line. She is able to move toward her goal of getting pregnant, something that six months ago was not advisable due to her health status.

Approximately 1.4 million North Carolinians are uninsured, and that number is larger when statistics include individuals who lack health insurance at a given point during the year. It is a common misconception that low-income individuals are eligible for Medicaid coverage. To be eligible, one must fit into a few limited categories, such as being pregnant, being under 18 years of age or younger, age 65 and older, or before being disabled. There are also maximum resource and income levels allowable for each category. Simply being poor does not qualify one for governmental healthcare. Free clinics are a community response to the crisis facing these uncovered individuals. The clinics are by no means a comprehensive solution, but they represent a compassionate, economical, and proven source of healthcare. More than 50% of free clinic patients are employed, many working more than one job to make ends meet. However, they work for low wages and for employers who do not offer affordable healthcare insurance. It is in this environment that concerned individuals began to seek ways to improve access to healthcare in their communities.

> *"More than 50% of free clinic patients are employed, many working more than one job to make ends meet."*

What is a Free Clinic?

Free clinics rely on community collaboration and the spirit of compassion that leads persons to volunteer their services to assist their less fortunate neighbors. Free clinics in North Carolina reflect the needs and resources of their individual communities. There is no template, yet there are similarities. They are non-profit organizations, directed by concerned community leaders. Typically, the clinics provide services through a

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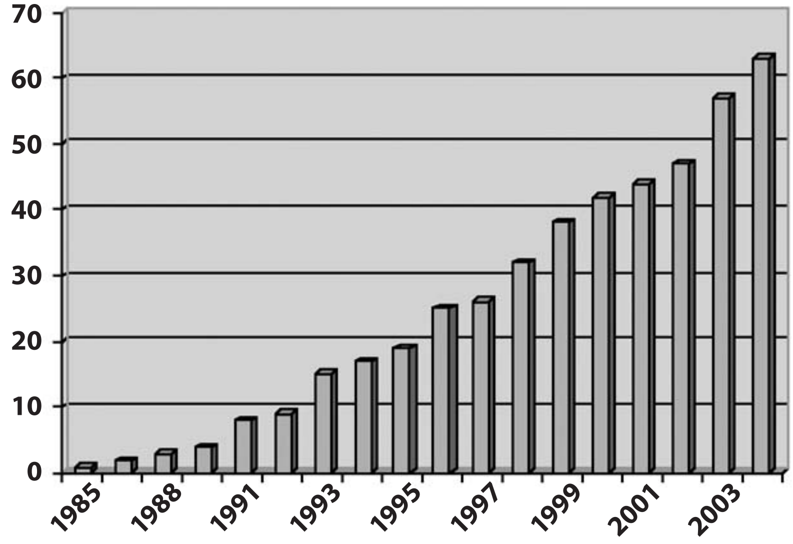
combination of paid staff and volunteers—physicians, nurses, pharmacists, laboratory personnel, and support personnel. They share other common characteristics:

- *Free care.* There is little to no charge for services or prescriptions.
- *Target population.* The target population includes people who have low-incomes and are uninsured (i.e., have no health insurance, no Medicare, no Medicaid, no Veterans Benefits). Low-income determinations are made by the individual clinic and range from 100-200% of federal poverty guidelines.
- *Core values.* Delivery of high-quality, compassionate care based on a belief that lack of income should not prevent access to healthcare. Free clinics place strong emphasis on providing non-judgmental, compassionate care while respecting the dignity and self-worth of every patient.
- *Volunteer driven.* The majority of services are provided by volunteers, who receive no compensation for their services.

Figure 1.
Growth of Free Clinics in North Carolina



Volunteerism is the major difference between free clinics and other safety net providers. Services are provided by individuals who are at the free clinic because they want to be. Volunteers consistently say that they receive more than they give in their encounters with patients. Physicians, with no managed care constraints or productivity requirements are able to practice medicine as they see fit. It reminds many of them of the practice setting that lured them into medicine in the first place. A collegial atmosphere exists in free clinics, with frequent communication and interchange about patients among nurses, physicians, and pharmacists. This atmosphere, with leading professional provider volunteers, results in the delivery of high-quality medicine to free clinic patients.

Development of Free Clinics in North Carolina

In the 1970s, concerned physicians began free clinics in the Winston-Salem area. Those clinics operated from area churches, but were not able to sustain operations and closed in the late 1970s.

In 1985, Dr. Don Lucey and other community physicians developed a free clinic, the Open Door Clinic, at the Urban Ministries in Raleigh after recognizing that lack of health and resulting poor health status were causes of unemployment and increased the potential of homelessness. Urban Ministries Open Door Clinic is one of over 60 free clinics serving uninsured North Carolinians at the present time (see figure 1).

"It's places like this that renew your faith in humanity."

North Carolina leads the nation in the number of free clinics with 53 medical clinics, approximately 25 with state-licensed pharmacies (10 with stand-alone pharmacies or pharmacy programs). In 2003, North Carolina's free clinics served more than 69,000 patients, dispensed 450,000 prescriptions, and provided $50 million in healthcare services.

Free Clinic Services

North Carolina's free clinic services vary by community, depending on needs and resources of the individual communities. Services may include the following:

- Medical—acute episodic medical treatment; management of chronic diseases,
- Dental,
- Pharmacy,
- Laboratory and other diagnostic tests,
- Physical therapy,
- Podiatry,
- Behavioral health,
- Medical specialty services—including ophthalmology, orthopedics, cardiology, and dermatology among others, and
- Social work.

Even though services are provided at no charge, most free clinic patients receive the full-range of services needed for their medical condition. Patients receive medical care, laboratory services, referrals for other diagnostic or therapeutic services, health education, prescription medications, and specialty care. If a needed specialist is not available on-site, most free clinics have arrangements for community physician specialists to see patients in their offices.

Patients are emotionally invested and touched by the concerned and high-quality care they receive in these free clinics. As one Urban Ministries Open Door Clinic patient recently stated, “It’s places like this that renew your faith in humanity.”

Financials and Free Clinics

Free Clinics receive no federal or state funding. Because they receive no revenue from their patients, free clinics must turn to their communities for support. They are funded with cash and in-kind donations from a variety of sources including:

- Individual contributors,
- Churches,
- Businesses,
- Hospitals,
- United Way, and
- Foundations.

In 2004, free clinics raised over $13 million from private funding sources. Because they use volunteer providers and secure donated supplies, medication, and ancillary services, free clinics were able to leverage these gifts into over $50 million in healthcare services to their patients.

In 2004, the Blue Cross and Blue Shield of North Carolina Foundation announced a five-year, $10 million grant to the North Carolina Association of Free Clinics for the support of existing free clinics and the creation of new clinics in underserved areas.

Challenges Facing Free Clinics

North Carolina’s free clinics face multiple challenges as they continue to offer compassionate healthcare services to those without other options, including:

- *Meeting changing demographics*. Providing culturally appropriate services to diverse racial/ethnic populations is challenging. Access to interpreters in rural areas of the state is increasingly difficult.
- *Volunteer recruitment and retention*. Free clinics’ dependence on volunteers for service delivery requires them to continually recruit and retain licensed volunteer providers.
- *Finances*. Sustaining funding to operate the clinics once they have been operating for several years is challenging. Start-up grants are generally available, but they are short-term funding solutions.
- *Infrastructure issues*. Lack of funding to support staff is an issue. Most clinics operate with small staffs who must recruit, retain and support volunteers, and develop and maintain systems to ensure high-quality care delivery.
- *Liability concerns of volunteers*. While there is no history of a malpractice suit brought against a North Carolina free clinic, the specter of liability is prominent in the minds of most volunteer providers. Clinics must find an affordable solution for offering liability protection for providers.

Free clinics do not profess to be the answer to the crisis of access to healthcare for North Carolina’s uninsured, but they are a continuing stop-gap measure until there is a more comprehensive funding stream for indigent medical care. As Don Lucey, MD, states, “In 1985, when we started Open Door Clinic, we thought we’d be around for only a couple of years, until the country dealt with this problem of access to healthcare. Twenty years later, we’re still waiting.” **NCMJ**

COMMENTARY

Local Physicians Caring for Their Communities:

An Innovative Model to Meeting the Needs of the Uninsured

Gillian K. Baker, MHA, Alan T. McKenzie, and Paul B. Harrison, MPH

"Thank you for saving my feet, and my life." Those words warm the heart of the physicians who care for Joe.

About a year ago, Joe was not feeling well. He felt something was wrong, but he knew he did not have the money to go to the doctor, so he tried not to worry about it. However, as his health began to deteriorate, a friend told him about how physicians in his county will take care of him, even if he cannot pay. A local project coordinates healthcare for folks like Joe, who do not have insurance and cannot afford to go to the doctor.

Joe was very excited about the possibility of being able to get the much-needed healthcare and applied for the project. Joe met the criteria and was accepted into the project and assigned to a primary care provider. On Joe's initial visit to the doctor it was discovered that he has diabetes. Through the project, Joe is able to get the medical care, tests, medications, and supplies he needs to get and keep his diabetes under control. In addition, it was discovered that the disease has caused sores on Joe's feet that, which without the care of a specialist, could result in Joe's feet needing to be amputated. Through Joe's visit to a specialist, his feet have gotten better, and he has been able to avoid an amputation.

In your county a project like this might be called Project Access, or Appalachian Healthcare Project, or maybe Community Care Plan, but it is all the same—physicians donating their time and talents to do what they do best—helping those who are sick.

There are now many counties throughout North Carolina that have volunteer physician care projects, and the number of them continues to grow in North Carolina and throughout the country. For example, Charlotte/Mecklenburg County began officially serving patients through its Physicians Reach Out initiative in late 2004. But, it all began in Asheville, in 1994, when a grant from the Robert Wood Johnson Foundation started Project Access. The premise of these projects is that local physicians participate in a volunteer medical service program designed to meet the medical needs of residents who have no health insurance and have incomes typically below 150% to 200% of the poverty guidelines. Hospitals also donate care to patients enrolled in such projects. The projects coordinate donated inpatient and outpatient services and pay for limited outpatient medication requirements.

In Buncombe County, the Buncombe County Medical Society administers the first Project Access program, which serves as a model for replications throughout the state. Private physicians can participate in one of two ways in Buncombe County: (1) They can commit to serve patients at one of the safety net clinics, and/or (2) They can agree to see a certain number of patients in their office per year. Eighty percent of the physicians in private practice have agreed to participate in the program. Primary care providers agree to see 10 uninsured

> *"The premise of these projects is that local physicians participate in a volunteer medical service program designed to meet the medical needs of residents who have no health insurance, and incomes typically below 150% to 200% of the poverty guidelines."*

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low-income patients, and specialists agree to see 20 patients per year. Local hospitals donate all lab tests and inpatient and outpatient services. Patients who visit a specialist (or a primary care doctor) in their private office can obtain their medications through a county-funded medication assistance program.

In an effort to document the care being delivered by the project, the County Medical Society processes standard insurance claims forms voluntarily submitted by physicians, hospitals, and pharmacies to document which services were provided and the value (i.e., the usual cost) of the services. Patients referred by private physicians have their eligibility determined through the Medical Society. The average program enrollment period is approximately six months, but this varies based on the patient's needs and length of time that he or she is uninsured.

These projects help address problems associated with donated care including: physicians concern that they would be inundated with requests; patient eligibility, differentiating which patients could afford to pay; and concern that uninsured patients would be able to obtain needed medications or diagnostic services. In addition, the project office eases some of these concerns by verifying patient need and distributing patient referrals equitably among many different providers. This helps spread the burden/risk of caring for the uninsured. In addition, reminder phone calls are made to reduce no-shows and help ensure that patients can obtain specialty and ancillary services and needed medications.

Today people with incomes below the allowed Federal Poverty Level have access to comprehensive care through a network of primary care clinics and private physicians seeing patients in their practices and in the hospital. There is a system of specialty care referral, free pharmacy, and other services. Doctors are routinely donating their time and talent to provide treatment for diabetes and hypertension and perform procedures like heart surgery, knee surgery, and even brain surgery. All of this is done in their private practices and at local hospitals without regard to a patient's ability to pay.

Physician Leadership Role

Project Access initiatives are dependent on physician leadership and the identification of local physician champions. Physician leadership develops and executes all aspects of physician recruitment in an organized volunteer care program. The message of the physician champion is straightforward: the indigent population needs to have better care, and the only way it will be delivered is if the medical community contributes to this care in a way that does not unfairly tax any individual provider. All segments of the healthcare delivery system need to participate, and there needs to be organization, documentation, and controls to ensure the system is treating those in need (both economically and medically) as efficiently and effectively as possible. With a commitment from a significant portion of the medical community, the process can move forward.

Physicians are recruited to participate in the project. By the point of project implementation, 35% to 100% of the physicians in each of the counties where the project is active have joined the effort. Primary care physicians agree to accept 10-12 patients as their responsibility. Specialty physicians agree to accept 20-24 patients per year from the program. Local medical societies, hospitals, health departments, county governments, departments of social services, and area pharmacies have participated in these initiatives to varying degrees based on program location.

Why Physicians Participate

Physicians report great satisfaction from the personal rewards they receive as a result of the service they are providing to the community. They note that the image of their medical community has been enhanced through the positive publicity that the program brings to the profession as a whole, as well as individual participants. This increased awareness of the significant contributions physicians make to the safety net has, in turn, led to increased credibility and political and social influence in their community and at the state and national levels.

There is renewed camaraderie and pride in the medical profession and commitment to the general welfare of their communities. These physicians have discovered that by working together in their communities they can make a difference. They have improved the health of their communities and their profession.

Clearly, physician leadership at the local level produces dramatic results: enhanced healthcare delivery, improved health of communities, and a renewal of the only inexhaustible resource of the healthcare delivery system—the compassion of its caregivers.

Measuring Outcomes

Access to Continuum of Care Increases

In Buncombe County during 2004, of the 210,000 total population, there were approximately 38,000 uninsured. Of the uninsured, approximately 65% (or 25,000 residents) had incomes below 200% of the federal poverty guidelines. Amazingly, over 24,000 of these estimated 25,000 low-income uninsured patients were seen at least once in a safety net clinic or in a private primary care physician's office during that calendar year. Of these, 2,800 were referred for specialty care, hospital services, and/or medications beyond the scope of services available in these free clinics and community clinics. Ninety-three percent of all county residents now report having a medical care home.

Health Status of Uninsured Improves and Charity Costs Decrease

Community-wide health assessments conducted in Buncombe County found that the uninsured were more likely to report being in good or excellent health than the insured. The uninsured were also less likely to report using the emergency room than the insured. Of the patients served through Project Access, 25% reported improved productivity on the job, and 17% reported reduced absenteeism. Per patient charity care costs decreased, perhaps related to improved health status and increased access to primary and preventive care services fostered through the collaboration of private doctors, hospitals, safety net clinics, and area pharmacies. Area hospitals have documented an average of $3 million annually in avoided charity care costs.

History of Replication

In late 1998 Buncombe County Medical Society was selected from nearly 1,700 applicants to receive the prestigious Ford Foundation Innovations in American Government Award. With that award came a commitment by the Medical Society to help others replicate its system of care. As a result of the experience gained by the Buncombe County Medical Society, it has now developed a sophisticated approach to helping communities adopt and adapt the Project Access model to their unique circumstances; and thereby, dramatically expand access to care in their communities by better organizing existing resources. Using Project Access as a model, many North Carolina counties have operational systems, including Avery, Watauga, Mitchell, Yancey, Wake, Mecklenburg, Pitt, Cabarrus, Guilford, Forsyth, Caldwell, Vance and Warren Counties, while others have secured necessary funding and are in the process of organizing their systems. Nationally, there are project access systems operating in dozens of communities, such as Wichita, Kansas; Spokane, Washington; Austin, Texas; and Marquette, Michigan. A more comprehensive listing with links to program web sites may be accessed at www.apanonline.org.

Project Access can be replicated in both rural and urban settings such as these projects in Wake and Watauga-Avery Counties.

Appalachian Healthcare Project: A Rural Model

While the Project Access model is easier to establish in communities with large provider bases and existing safety net providers, Project Access models have been established in less resource-rich environments as well. The first rural Project Access program, the Appalachian Healthcare Project, serves Watauga and Avery Counties. Watauga County has a population of 42,857 people with 25 primary care providers and 60 specialists. Avery County has a population of 17,610 with 17 primary care providers and two specialists.

In the spring of 2000, the only place for low-income uninsured patients to receive care was the hospital emergency department. There were no safety net organizations or free clinics providing comprehensive primary care. The Appalachian Healthcare Project was made possible by the commitment of the medical communities in these two counties. Each provider pledged to see anywhere from 12 to 24 patients per year. In addition, the local hospitals offered inpatient, outpatient, and diagnostic services to Appalachian Healthcare Project patients. The commitment of the medical community allows the patient load to be distributed equitably among the physicians. Since the project was implemented in April 2001, approximately 600 people have been served. On average, there are about 200 active patients at any time. In 2004, the medical community provided nearly $2 million in medical care and medications to Appalachian Healthcare Project patients.

Wake County Project Access: An Urban Model

Urban volunteer service programs, like Project Access, are dependent on community stakeholders working collaboratively for the "common good." In this instance, the presence of six physician champions during the 12-month planning period persuaded leaders of the three hospital corporations and 450 physicians to sign on as participating providers.

The program has allowed the medical community to document the volume of donated care for patients who would not likely be able to pay for services. For this reason, hospital-based physicians and hospital corporations could only gain by their participation in Project Access, which has been strongly supported by local private practice physicians.

The project works collaboratively with an array of primary care safety net clinics, the health department clinics, hospital emergency departments, and private practice physicians. Since its inception in late 2000, Project Access of Wake County has enrolled 5,030 patients and has generated $20 million in donated care provided by physicians and hospitals. Operating expenses, including the cost of outpatient medications, account for $1 million, which yields a ratio of cost-to-donated care equal to $1:$20.

Current Needs for State Policy Development and Funding

Nationally, over 70% of physicians report providing charity care to the uninsured, yet this remains an often-overlooked component of our state's safety net services to the uninsured. In the absence of more thoughtful policies at the state level, the "specialty care" gap between primary care safety net services and hospital-based services will continue to widen, and many more patients will "fall through the cracks."

While scant state or federal policy has been developed to support continued private physician practice-based charity care, communities are stepping forward and producing dramatic gains in access, improved health, and reduced costs in serving the uninsured. These communities are investing in:

- Creating accountable safety net systems that improve the health of the uninsured and demonstrate significant returns on investment through reduced community costs and improved business productivity from healthier workforces.
- Building and sustaining physician-led administrative support that better organizes and celebrates physician charity care.
- Strategic planning that creates a healthcare safety net providing the full continuum of needed services.
- Systems that assure that uninsured patients receive the medications prescribed by physicians.
- Outcomes measurement systems that document the return on community investment.

State and federal policies are needed to help communities with these needed investments. In addition, the North Carolina Institute of Medicine North Carolina Healthcare Safety Net Task Force Report[1] calls for careful analysis of the

North Carolina's Good Samaritan legislation to assure that it provides appropriate liability protection for doctors donating their care to the uninsured, in particular to assure that this protection extends to cover doctors who are seeing patients for free in their private practices. Current legislation provides protection for patients who are referred by community clinics, but the protective legislation does not clearly extend its coverage to doctors who are participating in organized systems of charity care and seeing patients (for free) in their practices who may not have been referred by a clinic.

Conclusion

While our healthcare finance system cannot be based on charity, care donated by private physicians is a vitally important, yet vastly undervalued, component of our state's healthcare delivery system. Clearly charity care exists and will exist for the foreseeable future. Strategic investment in better organizing and integrating this care has been demonstrated to produce significant return on investment and public policy should be pursued to deliver this care effectively. **NCMJ**

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The Hospital Emergency Department:
An Anchor for the Community's Healthcare Safety Net

Jeffrey S. Spade, CHE

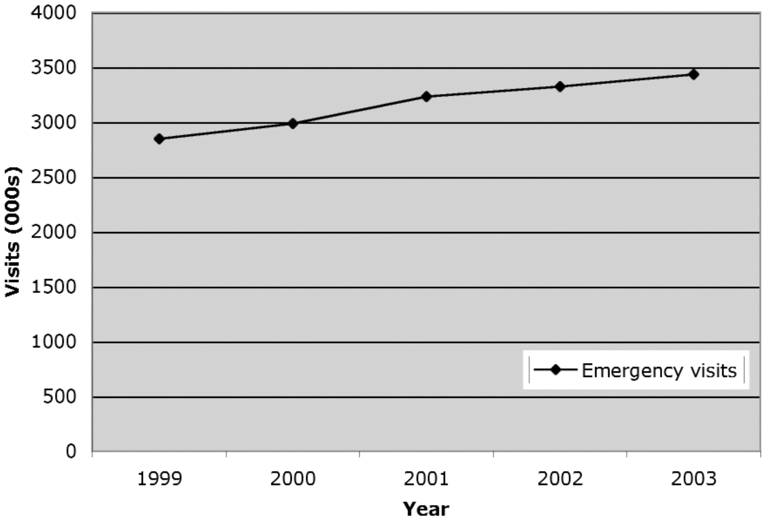
North Carolina's community hospitals have a long respected tradition of undergirding the health and welfare of citizens and communities across the state, wealthy or poor, urban or rural, healthy or frail. One hundred thirteen (113) community hospitals provide needed healthcare services for North Carolina's 100 counties, ensuring local community access for both basic healthcare requirements and more complex interventions and therapies. North Carolina's community hospitals are also a prime anchor of the safety net that protects the state's most vulnerable citizens: the elderly, those with chronic disease, the poor, the disadvantaged, and the uninsured. Without a local hospital, many North Carolina communities would struggle to maintain even the most basic health services.

The North Carolina Healthcare Safety Net Task Force Report[1] by the North Carolina Institute of Medicine effectively describes the increasing burden of the uninsured and the poor, while documenting the "frayed edges" and the "worn patches" that shore up the state's healthcare safety net. While hospitals represent the virtual anchors of the safety net, hospital emergency departments are the ever-present backbone of the safety net's architecture. Emergency departments are often the first line of defense against community epidemics, like influenza and respiratory diseases, a provider of hope and life for citizens faced with debilitating disease or life-threatening injury, and a provider of last resort when no other avenues for healthcare seem available.

North Carolina Emergency Departments Carry a Huge Burden

In 2003, North Carolina hospitals provided emergency services to 3,433,432 patients, an increase of 21% percent over five years (see figure 1). North Carolina's rate of increase exceeds the national growth in emergency visits, which increased 11.6% over the same five-year period.[2] In a national survey completed in 2002 by the Centers for Disease Control, abdominal pain, chest pain, and fever were the most commonly recorded principal reasons for an emergency visit, accounting for one-fifth of all emergency visits. The most frequently reported diagnoses were contusions, acute upper respiratory infections, open wounds, and abdominal pain. Diagnostic/screening services, procedures, and medications were provided at 86.8%, 43.2%, and 75.8% of emergency visits, respectively. Additionally, 12% of emergency visits result in hospital admission; and more than one-third of patients admitted to the hospital are first treated in the emergency department.[3]

Figure 1.
North Carolina Hospital Emergency Visits, 21% Increase in Visits Since 1999



In North Carolina in 2004, 21% of the emergency visits were attributed to patients without health insurance; 22% of

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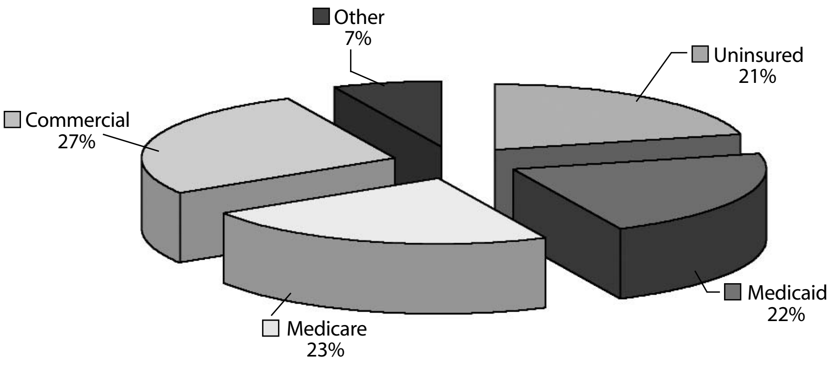
Figure 2.
North Carolina Hospital Emergency Visits by Payment Type in 2004



Total Emergency Visits for North Carolina Hospitals in 2003 = 3,433,432

emergency visits were by those with Medicaid; and 27% of the emergency visits in 2004 were covered by commercial insurance (see figure 2). The rate of uninsurance (21%) in North Carolina's emergency departments is greater than the national rate (16%). Furthermore, North Carolina's hospitals experience higher use of emergency services by the poor and elderly (Medicare and Medicaid) and lower rates of commercial coverage than the average emergency department nationally. Fifty-six percent (56%) of North Carolina's emergency visits occur in urban hospitals and 44% in rural hospitals. North Carolina's large hospitals, those with 200 licensed beds or more, accounted for 64% of emergency department admissions in 2004. North Carolina's largest hospitals, those hospitals with 400 or more licensed beds, serve the greatest proportions of uninsured and poor emergency care patients (23% uninsured and 26% Medicaid, respectively, 49% combined). For the average North Carolina hospital, the uninsured and poor account for 43% of the emergency admissions.[4]

The Multiple Roles of Hospital Emergency Departments

In the National Hospital Ambulatory Medical Care Survey by the Centers for Disease Control (CDC), the authors state, "the primary role of the hospital emergency department is the treatment of seriously ill and injured patients. However, the emergency department provides a significant amount of unscheduled urgent care, often because there is inadequate capacity for this care in other parts of the healthcare system. The emergency department also serves as referral site for other providers to evaluate and stabilize patients."[5]

A May 2004 study published by the CDC examined the characteristics of emergency departments serving high proportions of safety net patients. Interestingly, the study defined a "high-burden safety net emergency department" as having greater than 40% combined services to Medicaid and uninsured emergency patients. Given that the average North Carolina hospital emergency department treats 43% uninsured and Medicaid patients combined, many North Carolina emergency departments would readily meet the CDC definition as serving a high burden of safety net patients.

Furthermore, the CDC study found that emergency departments serving high proportions of poor and uninsured patients have a greater proportion of visits made by children and minority residents; have higher percentages of non-urgent and 'urgent, but primary care-treatable' cases; and higher percentages of cases that left the emergency department without being treated. Of note, the CDC study found that the percentages of 'emergent conditions that were avoidable with preventive care' were not significantly different between hospital emergency departments with varying (high versus low) proportions of the uninsured and poor. In addition, hospital emergency departments with higher proportions of uninsured patients had lower percentages of emergency cases that were 'avoidable with primary care' in comparison to hospitals with high proportions of Medicaid visits to the emergency department.[6]

Comparable data describing the use, characteristics, and demographics of emergency departments and patients in North Carolina are lacking. Therefore the appropriateness of emergency department admissions and the reasons for seeking emergency care by vulnerable populations, such as the poor and the chronically ill, are not well documented.

However, recent developments will improve the understanding of emergency care in North Carolina. A new partnership between the North Carolina Division of Public Health (NCDPH) and the North Carolina Hospital Association (NCHA), with support from two nationally prominent information technology companies, Solucient and MercuryMD, organized and developed the North Carolina Hospital Emergency Surveillance System (NCHESS). The main purpose of the NCHESS partnership is to capture near real-time emergency care data to quickly assess and manage public health or population health emergencies.

Biodisaster preparedness is the reason NCHESS was developed. Because of this unique and successful partnership, North Carolina is the first state in the country to develop and implement this advanced biopreparedness warning system. An important and valuable by-product of the NCHESS development will be the collection and analysis of emergency department diagnoses, trends, demographics, and outcomes. In the near future, NCHESS will help the state's healthcare systems and providers understand the usage trends in emergency services and, in turn, be able to design interventions and healthcare access models to improve community health. NCHESS will greatly contribute to the understanding of the adequacy of the healthcare safety net in North Carolina.

Emergency Department Care: Often Inappropriate and Expensive When No Alternatives Exist

While specific North Carolina data are unavailable, national studies routinely conclude that providing care for non-emergent or primary care-treatable conditions in emergency settings is expensive, sometimes inappropriate, and often inefficient. The federal Agency for Healthcare Research and Quality (AHRQ) recently published a study examining the health and economic costs of the lack of preventable primary care for diabetes patients. The study estimates nearly $2.5 billion in savings annually if patients received more appropriate primary care for diabetes complications.[7] Community Care of North Carolina networks across the state have documented reductions in emergency department usage by patients with chronic diseases, namely asthma and diabetes, when the local and regional primary care systems collaborate to improve and support chronic disease management in the community setting.

A national study by the Center for Health System Change concludes that uninsured citizens rely on emergency departments for one-fourth (25%) of their ambulatory care visits, compared to 8% for the privately insured population.[8] The authors posit that the greater reliance by the uninsured on emergency departments for primary care is likely due to a decline in access to office-based providers. The same study indicates, however, that contrary to popular wisdom, uninsured patients are not driving the increased use of hospital emergency departments. Instead, privately insured patients and Medicare beneficiaries accounted for two-thirds of the overall increase in emergency department visits, nationally, between 1996 and 2001.[8]

The Center for Health System Change suggests that capacity constraints experienced by office-based providers, combined with a loosening of managed care restrictions, may contribute to the increase in non-urgent emergency visits, a trend apparent in all payer segments. The Center's 2003 Issue Brief states, "other research shows that more patients are having difficulty making appointments with their doctors, and more people have long waits for appointments. For their part, more physicians report having inadequate time to spend with their patients and are increasingly closing their practices to some new patients, despite spending more time in direct patient care activities. With extended hours and no appointment necessary, emergency departments increasingly may be viewed by many patients as more convenient sources of primary care than their regular physicians. For uninsured patients, emergency departments are one of the few remaining primary care options."[8]

A 2005 report by the National Association of Community Health Centers tracks the federal government's plan to place federally-funded community health centers serving the poor and uninsured into every poor county in the United States. The report identifies 47 poor counties in North Carolina, divided into 20 counties with a community health center (CHC) and 27 North Carolina counties without a CHC.[9] With the rising numbers of uninsured and poor in North Carolina, the ability of the public system of care (health departments, CHCs, indigent care clinics, rural health clinics and centers, free clinics, etc.) to accommodate the increasing indigent care burden is certainly being stretched.

Hospital emergency departments are increasingly the last remaining reliable and routinely available source of primary healthcare in many North Carolina communities. If the uninsured visit rate of 21% is applied to the emergency visits tabulated for North Carolina in 2003 (3.43 million emergency visits), then North Carolina hospitals experienced more than 721,000 uninsured emergency visits in 2003. Adding in Medicaid, hospital emergency departments provided care for nearly 1.5 million uninsured or poor North Carolina residents in 2003.

> *"Emergency departments are often the first line of defense against community epidemics..., a provider of hope and life for citizens faced with debilitating disease or life-threatening injury, and a provider of last resort when no other avenues for healthcare seem available."*

The Emergency Medical Treatment and Active Labor Act (EMTALA) of 1986 has had a profound effect on hospital emergency departments. EMTALA requires emergency departments to screen and stabilize all patients that present to the emergency department regardless of ability to pay. The federal government does not guarantee such expansive access to any other segment of the healthcare system. Thus, emergency departments are often viewed as the ultimate safety net providers, ensuring a minimum level of care and services regardless of the patient's disease category, background, ethnicity, immigration status, or insurance class. While EMTALA is viewed as an unfunded federal mandate and presents enormous compliance issues for the hospitals, the concept of the hospital emergency department as a guaranteed source of immediate healthcare is important and vital to sustaining and improving community health.

Challenges Faced by North Carolina Hospitals' Emergency Departments

It is comforting to know that North Carolina's hospitals and emergency departments are a solid anchor and backbone for the state's healthcare safety net. However, regardless of the strength and commitment of community hospitals to emergency care, hospitals face many difficulties in maintaining this important aspect of the safety net anchor. Among the issues that impact hospital emergency departments are reasonable and adequate financing, increasing volumes of uninsured patients, access to capital for expansion and technology enhancements, adequate physician coverage for unassigned and uninsured patients, the unstable nature of mental health reform in the state, the rapid influx of immigrants and foreign-born citizens requiring care, and the rising cost of malpractice insurance premiums. Several of these issues are worthy of further examination.

> *"...the concept of the hospital emergency department as a guaranteed source of immediate healthcare is important and vital to sustaining and improving community health."*

Financing the Care of the Uninsured. Operating and maintaining a modern, fully equipped, adequately staffed and appropriately sized emergency department is an expensive proposition. Yet, emergency care is such a basic and essential aspect of community health networks that almost every community hospital in North Carolina offers emergency care. The primary financing mechanism for emergency departments is insurance coverage for health services. For the average North Carolina hospital, one in five patients (21%) is uninsured, with very little or no resources to pay for their care. Another 45% of emergency care is provided to Medicare and Medicaid patients. Obviously, maintaining adequate levels of reimbursement, especially from the government payers, Medicare and Medicaid, is essential if hospital emergency departments are to remain viable and accessible. Cutting hospital payments in Medicare and Medicaid, especially at a time when the numbers of uninsured residents are rising, will definitely impact the quality and availability of essential, yet expensive hospital services such as emergency departments. In the federal 2006 fiscal budget, Medicaid expenditures are under attack, threatening the ability of the state of North Carolina to adequately fund its Medicaid program. The retraction or reduction of Medicaid funding by the federal government cannot be allowed. This one factor alone, inadequate Medicaid funding, is a major threat to North Carolina's healthcare safety net.

Malpractice Insurance Costs. The rapid rise of malpractice insurance premiums also hampers the emergency department safety net. Some North Carolina hospitals and physicians have experienced malpractice premiums increases of 300% or more over the past few years. The malpractice cost increases are so dramatic and expensive that some physicians can no longer afford to cover certain services, such as labor and delivery, or even general surgery. Also emergency department back-up coverage is often considered a high-risk, high-liability service, which can influence the cost and/or availability of malpractice insurance, driving physicians to curtail or drop emergency department coverage from their privileges. Losing community physicians from the coverage panel for the hospital emergency department is a serious problem. Having fewer physicians available for emergency patients, especially those patients who present at the hospital without a regular physician, means that hospital emergency departments may be unable to provide care for some very basic, yet essential, healthcare services. Solving or at least abating the malpractice crisis in North Carolina will give some respite to hospitals and health providers that struggle daily to maintain adequate emergency care coverage.

Growth of the Numbers of Uninsured. The expanding ranks of the uninsured in North Carolina cannot be ignored either. The loss of manufacturing, tobacco, and textile jobs in North Carolina will continue to push the number of uninsured residents into record territory (almost 20% of residents under age 65 in 2004). Uninsured residents frequently do not have a regular source of primary healthcare. Thus, uninsured residents may seek primary care in hospital emergency departments, often too late, after a treatable condition has progressed into a true emergency. If the rate of increase of the uninsured continues at the current pace, then hospital emergency departments may be one of the few remaining care settings available for uninsured patients. A hospital emergency department with 30% or more of its care provided to uninsured patients and 20% or more emergency care being provided to Medicaid patients is at serious risk for financial failure.

Mental Health Reform. Mental health reform is a vastly important issue for hospital emergency departments. The state of North Carolina is currently undergoing major reforms to the mental health system. As a result, the mental health system in North Carolina is very fragile; not enough providers, too few community-based services, inadequate reimbursement, uneven insurance coverage, and an increasing demand for service. The rate of uninsurance is 70% higher for mental health visits to the emergency department than the average emergency visit. If mental health reforms, such as the development of community service alternatives and mental health reimbursements, are not adequate or incomplete, then hospital emergency departments will be overwhelmed with patients requiring care for mental health conditions. In fact, many hospital emergency departments across the state already report significant increases in patients requiring mental health service with few options for community referral.

The Need for Expanded Primary Care Options. Besides preserving and protecting Medicaid funding, one major solution is recommended to help maintain the hospital emergency department's strength and viability as a safety net anchor: the commitment to create and maintain multiple and additional community access points for primary care service for the uninsured, the poor, and the vulnerable. Community health centers, rural health clinics and centers, public health departments, free clinics, mental health centers, and community physician practices must be developed and supported in close collaboration with the local care networks, especially in the neediest communities and counties. If additional primary care access points for the uninsured are not developed and funded, then hospital emergency departments will become increasingly crowded, suffer from inadequate staffing and less advanced equipment and technology, and require more financial subsidies. **NCMJ**

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COMMENTARY

Our Healthcare System Is Failing

J. Douglas Yarbrough, MBA

What do we think when we hear about someone who has no health insurance coverage? Our first thought is that they may not get the care they need. Then we wonder if they could lose their savings and/or incur massive debts if they or someone in their family has a catastrophic illness. This should concern us, but this is not the whole picture. In reality, providing medical care for the uninsured is an even greater problem for our healthcare delivery system. In fact, it is crippling our system; and if left unresolved, it will destroy our system. Nationally, there are approximately 44 million people without medical coverage. Another 38 million have inadequate coverage. That means approximately 28% of the United States population is without adequate healthcare coverage.[1]

With some exception, uninsured people pay very little of the cost of providing their healthcare at the hospital level. For years, we in the hospital industry have referred to the uninsured as "self-pay." For financial purposes, we classify our patient receivables as Medicare, Medicaid, other government, commercial, or self-pay. We informally refer to self-pay as "no-pay." That is because we collect a very small percentage of what we charge the uninsured. Many of them are classified as charity care, and a large portion of their care is written off. Some uninsured patients have the ability to pay, but decide not to, and their balances become bad debts. Some fall into a monthly payment category where they make very small monthly payments (without interest). How do hospitals deal with the cost of the uninsured? Like any business, we pass it on to the paying customers. It becomes a piece of overhead. Call it what you want, but it is a part of the total cost, and somebody has to pay for it.

> *"How do hospitals deal with the cost of the uninsured? Like any business, we pass it on to the paying customers."*

From a financial perspective, accounting for healthcare is much like accounting for any other type of service. We must have enough revenue to cover our costs. If we cannot make a profit, we cannot replace worn out plant and equipment or invest in the latest technologies. However, there is one difference unique to the healthcare field. That is the enormous amount of free care and under-paid care we deliver. We must charge each patient more to recover the unreimbursed cost of care provided to the uninsured and "government payers." As a result, hospitals write off 40-50% of what they charge.

Hospitals Are Underpaid by Medicaid and Medicare

Let me explain why government payers present another unique problem for healthcare providers. Earlier I referred to the classification of patients as Medicare, Medicaid, other government, commercial, or self-pay. In North Carolina, hospitals are not receiving enough payments from government payers to cover the cost of treating government-pay patients. Medicare payments to hospitals are not based on what hospitals charge, and, in most cases, do not cover the true cost of providing the care. Imagine owning a business where your customers walk in, take your product or service, and then tell you what they are willing to pay. Why can Medicare do this? Medicare covers half of the patients that come to our hospitals. Medicare is the number one payer by far; they can virtually enforce any payment system they choose, and hospitals have no choice but to accept. Historically, the Medicare program has grown much more than government estimates, and they had to come up with payment systems that allow them to meet their budget. For the first 18 years of Medicare's existence, the program paid hospitals for the "cost" of the care provided. However, since 1983, the payments have been slowly declining in relationship to the actual cost of providing care, and now hospitals are receiving less in payments than the actual cost of the care. How do hospitals recover this shortfall? Simple: they pass it on to other payers.

Unfortunately, Medicaid, the second largest payer for many

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hospitals, has been doing the same thing as Medicare. They are paying less to hospitals than the cost of providing care to Medicaid patients. Hospitals are burdened with yet another class of payer that does not cover the cost of care provided. What do hospitals do to cover that short fall? Obviously, the same remedy is to pass that on to other payers. Unfortunately, the only payers remaining are commercial insurance carriers. Insurance companies have historically paid hospital bills based on billed charges rather than a government imposed payment scheme.

Insurance Companies Demand Deep Discounts

In recent years the number of commercially insured patients has dwindled. With factories closing and workers attracted to jobs with little or no insurance coverage, the problem is exacerbated. Employers have reached the boiling point with health insurance costs, and they are beginning to increase employee deductibles and coinsurance, passing the cost on to their employees. The insurance companies are tired of paying the shortfall for all the other payer classes. Consequently, insurance companies are beginning to negotiate deep discounts and alternative payment systems. This creates a great dilemma for hospitals. There is no one left to absorb the cost of the uninsured.

Hospitals Are Left with Few Acceptable Business Options

Many hospitals in North Carolina have run out of ways to recoup the cost of providing free care, and they are now losing money on their bottom lines. Where does the money come from to fund those losses? Like any business, losses come out of surplus—surplus that should be used to replace worn out plant and equipment and purchase new technologies. Hospitals operate in a high-tech, labor-intensive environment, and they cannot survive without the latest technologies. When a hospital uses its surplus to fund loses from operations, sooner or later, they have either to cut services drastically or close. Unfortunately, we have some hospitals in North Carolina that are now in that situation. We also have many hospitals that are currently losing money and will be in that situation if nothing is done to break the cycle.

How do we break the cycle? If hospitals were like other businesses, they would simply discontinue unprofitable services, add profitable lines, lay off employees, and certainly stop giving away their services. As we all know, none of these solutions will work for hospitals, particularly the not-for-profit community hospitals. We are not here simply to make a profit. The services we provide are essential to the community. Our mission is to improve the health of our community, regardless of patients' ability to pay, regardless of how profitable or unprofitable the service is. We are the last place for many patients to go. We are their "safety net." Our emergency rooms are full, and we will continue to take care of them as long as we can. Unfortunately, under the current system, our days are numbered.

Suggestions for Change

So, what are we going to do? I will share a few of my suggestions. First, we, meaning all of us, providers of care, insurance companies, Medicare, Medicaid, etc., must quit playing the blame game. We are in this fix because we have spent the last four decades blaming each other for these problems. Our problems will continue until we all come together and take equal responsibility for fixing them. Hospitals and healthcare providers should not be the fall guys in the system. The enormous burden of the uninsured must be borne by all of us.

Second, we need meaningful reform on the legal side of healthcare. Regardless of who is right or wrong about tort reform, the legal climate is terrible. At one time in this country, many of our physicians came from physician families. Now, physicians are encouraging their kids to go into other fields. The fear of malpractice suits, complicated billing and payment systems, and government regulation is discouraging new physicians from going into private practice. In order to have enough physicians in rural areas, hospitals are forced to contract with physicians as employees or guarantee them a fixed income. This further depletes hospital resources and puts them at financial risk.

A very large hidden cost in our system is the increasing volume of unnecessary diagnostic testing. Fear of being sued is the number one reason why physicians order so many tests. The number of MRIs, CT scans, x-rays, etc. are growing each year, simply because physicians are afraid not to order them. One lawsuit can destroy a physician's livelihood. Most physicians feel trapped in a system where sensible, conservative medicine can no longer be practiced. Defensive medicine is costing us a fortune.

Last, we must educate our communities. Not only do we all need education on healthier lifestyles and preventive medicine, but also we must learn to make wise choices about our care. We must also learn to form reasonable expectations about our healthcare system. Everyday, I am amazed at the level of dedication exhibited by our healthcare workers. They are compassionate and caring. They work around the clock to be here whenever we need them. But, medicine is not an exact science, and people are not perfect. We need to take the profiteering out of our legal system. **NCMJ**

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Public Health Departments:
The Under-funded Provider of Last Resort

George F. Bond, Jr., MPH, and Wanda L. Sandelé, MPH

To understand a healthcare safety net, perhaps we should begin by reflecting back on our days as children at the circus watching that daring young girl on the flying trapeze and her strong "catcher," both poised 50 feet above the floor. The only thing standing between them and certain death is that thin rope safety net just above the floor. With that image in mind, three basic characteristics of a safety net stand out. First, it is *effective* in avoiding certain death, it must work! Second, it should offer *complete* coverage. A net, covering 90% of the arena is useless to those who fall on the 10% not covered. Third, the *net must always be there*. Do you recall when the ringmaster called for the removal of the net for the last five minutes of the act just to heighten tension and excitement in the audience? When the poles holding up the net were removed, it fell to the ground and *there effectively was no safety net!*

> *"Public health is known as the 'silent miracle' because the process of preventing epidemics, assuring food safety, and providing clean water is invisible and, all too often, taken for granted."*

Let us now turn our thoughts from the circus to an examination of the healthcare safety net in North Carolina. When most healthcare professionals define the healthcare safety net, they include payment sources such as Medicaid and Health Choice; they include rural health centers and free clinics; and they almost certainly will include federally qualified health centers (FQHCs) and FQHC look-alikes. Rarely is the local health department mentioned in these definitions, even though the evidence clearly shows them to be an integral part of the net and indeed the "provider of last resort" in many North Carolina counties.

Effective?

Traditional safety net providers would like to be 100% effective in providing care for the uninsured and underinsured. Sadly, however, they are seriously under-funded by state and federal sources to respond to that need. Their funders, and indeed their own balance sheets, tell them that they need to be self-sufficient. Thus, when times get tough, co-pays, deductibles, and lab fees go up by necessity, and sometimes patients without a payment source are turned away. Last year, local health departments provided more than $11 million in un-reimbursed prenatal care alone to low-income clients who could not pay for their healthcare. When community health centers have to turn away patients because of mounting operational deficits, those patients go to the *local health department*.

Complete Coverage?

Community health centers are located all over North Carolina, but coverage is still incomplete. In western North Carolina, for example, there are community health centers in Hot Springs, Asheville, and Hendersonville; but beyond that line, there is not a single community health center in any of our eight western-most counties. Those eight counties tend to be poor, they have high unemployment rates, and they meet virtually any definition of medical need. Probably because of

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their sparsely populated nature these counties have not been attractive sites for new community health centers. However, every single one of those eight counties has a *local health department*! Local health departments last year provided an estimated *$40 million of uncompensated care*!

The Net Is Always There?

Across North Carolina, community health centers have grown up as independent, freestanding organizations with consumer boards. While independence has advantages, it leaves community health centers financially vulnerable because they are not connected to a "deep pocket" such as a county government, a hospital, or a university. Thus, when the local economy stumbles, cash flow constricts, and there are only limited reserves from which to draw. Either fees have to go up, or costs have to come down. Either way, access for the low-income patients is threatened. Our rapidly increasing Hispanic population faces financial challenges as well as language barriers to health access. Health departments are required by the Civil Rights Act to serve this challenged population. There is a local health department within a 30-minute drive of every resident in every county in North Carolina.

We should all be proud of our fine system of community health centers working tirelessly in our state delivering quality healthcare. However, we cannot say in good faith that those traditional safety net providers alone form an impervious healthcare safety net. In fact, there are large holes in that net, both in terms of eligibility and geography. There is, however, a system already in place with buildings that deliver healthcare in every single county in North Carolina. There is at least a minimal level of healthcare staffing on the payroll of a "deep pocket" that either already provides, or has the potential to provide, primary care to the uninsured and underinsured in every county. There is already access to at least some basic level of clinical service in all 100 counties from Hanging Dog in the west to Hatteras on the coast. That system is our 85 *local health departments*. We believe that the current value and future potential of health departments as safety net providers have largely been overlooked.

Public health is known as the "silent miracle" because the process of preventing epidemics, assuring food safety, and providing clean water is invisible and, all too often, taken for granted. Public health is the "provider of last resort." The term suggests that the local health department somehow miraculously picks up the loose ends when the private sector either finds certain services or segments of the population unprofitable or inconvenient. "Provider of last resort" also suggests that the care is of lesser quality and only a temporary, desperate measure that must suffice until something better comes along. The truth is that thousands of citizens receive high-quality clinical service from their local health departments, perhaps because they have an overdue balance at their private provider, or since no other provider accepts Medicaid, or maybe because of their transportation and language challenges. We in public health are honored to be able to fill some of today's gaping holes in the safety net.

Because we are required to complete a Community Health Assessment every four years, health departments learn about access problems through our data gathering and analysis. A health department that chooses to embrace the function of "provider of last resort" unfortunately positions itself to operate continuously in a crisis mode, especially when the economic climate or the personality of the healthcare community changes. Most health departments do not have large primary care programs, but maintaining even a small clinical program assures capacity and allows for rapid expansion to greater volume when circumstances dictate. Such was the case in one eastern North Carolina county where the only two obstetrical practices merged and decided that they could not see pregnant women covered by Medicaid. Overnight, the prenatal workload at the health department more than tripled. This could not have been accomplished on such short notice if the program did not already exist. Since expansion is always easier than absolute creation, local health departments struggling to serve the low-income population have more than once questioned why a brand new community health center gets approved, funded, and built right down the street when the dollars could better be spent shoring up their existing program.

The explanation for this apparent lack of collaboration lies both in federal regulations and in state law. The system of FQHCs, begun in the 1960's to extend primary care access, did not allow North Carolina health departments to fulfill that vital community role, even though a number were already major providers of such services in their communities. By federal regulation, an FQHC must have a board with a majority of consumers. Standing in direct opposition, North Carolina statutes do not currently permit a board of health, which governs the health department, to exist in that form. That artificial barrier to FQHC status needs to be removed. We are pleased that the North Carolina Healthcare Safety Net Task Force Report[1] contains a recommendation for the removal of the legal barrier that prevents health departments from becoming FQHCs.

Adequate Funding

The real problem with the safety net lies not at the feet of the providers. The problem is that *no one has adequately funded care* for the uninsured at the federal, state, or local levels. It matters not whether the organizational structure is run by a consumer-dominated board, a hospital board of trustees, or a board of health—somebody has to be willing to "foot the bill" for those who cannot pay. Even though the public health department directors are prone to complain about other members of the safety net who are not seeing their "fair share" of the indigent, in reality, the only way any of us are able to see the uninsured is through a combination of donations or local appropriations and the very skillfully orchestrated practice of cost-shifting. Even though health department staff are government employees, they still must be paid, they still have to buy medical supplies, and there must be phones and heat in the building. County Commissioners in some counties have chosen to support their local health departments in the provision of medical service to the uninsured. That does not render medical care at the health department free; it just means that someone has accepted a responsibility to pay for care not covered by insurance. All we really need in this state to complete our safety net and make it impervious—stretching from the mountains to the shore—is funding for the uninsured. We already have a voucher system available to some providers to pay for the uninsured. If that program could be expanded significantly, if federal dollars can be attracted to support new FQHCs, and if statutory barriers to FQHC status for local health departments could be removed, then North Carolina, as a state, with all the safety net providers working together as a system, can and will address the needs of those who currently are denied routine access to our healthcare system.

In a nation that long ago walked on the moon and currently supports over 125 heart transplant centers, surely we can muster the political will to solve the problems with our safety net. Health departments can play a significant role in the implementation of that solution. President Bush has proposed a dramatic increase in the numbers of community health centers across the nation. Federal dollars of this magnitude have not been available for many, many years. We must aggressively act on this historic funding opportunity. We must also pledge to work together to develop a reliable funding stream to cover uninsured patients.

Forty years ago, President John F. Kennedy challenged the nation to put men on the moon by the end of the decade. We need that same kind of bold political leadership in North Carolina to answer the problems of the uninsured. The uninsured cannot solve the dilemma of access to care for all North Carolinians. They do not speak for themselves with a loud political voice. In fact, they may not speak at all, or they could speak in a foreign tongue. However, we can and we must speak for them! **NCMJ**

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COMMENTARY

Pharmaceutical Companies Meet the Needs of the Poor and Uninsured:

An Important Element in the Healthcare Safety Net

J. Andrew Hartsfield IV, JD

> *"I am writing to say that I really appreciate the help you gave me in getting my medications. . . You may not realize how life-saving you are. . . I can never thank you all enough for helping me when I so desperately needed it."*
>
> — Excerpt from patient letter to GlaxoSmithKline

Our government spends hundreds of billions of dollars on healthcare entitlement programs every year, the largest programs being the federal Medicare program for senior citizens and the disabled; the federal/state Medicaid program for low-income patients; and the State Children's Health Insurance Program for children, up to age 19, who are not already insured. Despite the scope of these programs, there are many low-income people who do not qualify for any of them. These people depend on the complex and vast array of sometimes confusing public and private programs that make up the healthcare safety net.

As part of their commitment to improving access to medicines, pharmaceutical companies play an important and essential role in helping low-income, uninsured, and other vulnerable populations get the medicines they need as part of this safety net.

At GlaxoSmithKline, we do not want a lack of insurance coverage or financial means to put a patient at risk by causing them to either not fill a prescription or to fill it through unsafe channels. Thus we—like most other major pharmaceutical companies—offer programs designed to ensure that vulnerable populations get the prescription drugs they need.

Pharmaceutical Industry Patient Assistant Programs

More than six million patients across America received more than 22 million free or discounted medications with a wholesale value topping $4.17 billion from pharmaceutical companies last year.[1] Expanded outreach efforts continue to increase use of these programs.

The industry also launched an innovative program that serves as a clearinghouse for the more than 275 public and private prescription assistance programs available. Augmenting these efforts, the industry's trade association, PhRMA, launched a new web site, www.pparx.org, making it much easier to learn about the many different public and private programs available and to identify ones that can help patients on an individual basis. These efforts are designed to increase awareness of and enrollment in existing programs.

As part of these efforts, GlaxoSmithKline's patient assistance programs, Bridges to Access and Commitment to Access™, provided over $372 million worth of prescription medicines to eligible low-income, uninsured patients in the United States

> *"As part of their commitment to improving access to medicines, pharmaceutical companies play an important and essential role in helping low-income, uninsured, and other vulnerable populations get the medicines they need as part of this safety net."*

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during 2004. In North Carolina alone, more than 25,900 patients received medicines worth nearly $20 million from GlaxoSmithKline.[2] Importantly, GlaxoSmithKline's programs also provide a bridge for patients, offering coverage under the program during the time a patient applies to other programs, such as the AIDS Drug Assistance Program, where waiting lists and delays can often mean a long wait for the patient.

The success of GlaxoSmithKline's and the industry's programs are rooted in the local support of community health groups, physicians, and many others. Working together, these partnerships reach out to vulnerable individuals, conduct training sessions on enrollment, and spread the word that help exists for people who need it.

Discount Card Programs

Pharmaceutical company patient assistance programs are one important part of the safety net, but there is also help for patients who don't qualify for these programs due to income. Many pharmaceutical companies also offer free discount card programs through which qualified individuals can receive significant discounts on their medicines. A few programs are highlighted below.

Orange Card℠

GlaxoSmithKline introduced the Orange Card℠ in 2001. It was the first such manufacturer discount card offering significant savings for low-income senior citizens. More than 175,000 seniors, including 13,000 North Carolina seniors, have an Orange Card℠. Through the Orange Card℠, qualifying seniors can get their GlaxoSmithKline medicines at a savings of about 20-40% off the usual price paid. To qualify, Medicare beneficiaries must have no public or private prescription drug insurance and have an income under $30,000 for a single person or under $40,000 for a couple.[*]

Together Rx Card™

Soon after the launch of the Orange Card℠, seven pharmaceutical companies created the Together Rx™ free prescription drug savings program. Together Rx™ is a discount card through which the participating manufacturers offer savings of approximately 20-40% off their brand-name medicines. Patients can save on more than 155 FDA-approved medicines, and some pharmacies offer savings on generics as well. Medicare enrollees who have no other prescription drug coverage and earn less than $28,000 ($38,000 for couples) are eligible.[†]

Resources for Drug Assistance

America's pharmaceutical companies want patients to be able to get the best and safest medicines available. For low-income patients there are a number of resources and programs available to help. Here are some web sites that provide information on programs and eligibility requirements:

HelpingPatients.org
www.helpingpatients.org

GSK Orange Card℠
www.OrangeCard.com

Together Rx Card™
www.Together Rx.com

Together Rx Access Card™
www.TogetherRxAccess.com

Bridges to Access™
Bridgestoaccess.gsk.com

Commitment to Access™
commitmenttoaccess.gsk.com

Medicare
www.medicare.gov

Nearly 1.5 million seniors, including more than 75,000 North Carolina seniors, have a Together Rx™ card, and to-date seniors have saved over $700 million on their medicines.

Both the GlaxoSmithKline Orange Card℠ and the Together Rx™ card will be available until the Medicare prescription benefit takes effect in 2006.

Together Rx Access Card™

The Orange Card℠ and the Together Rx™ card programs provide savings for low-income Medicare beneficiaries. Yet, there are millions of Americans who lack health insurance that don't qualify for Medicare. In January, GlaxoSmithKline and nine other major pharmaceutical companies introduced an innovative program to fill that gap and help many of those uninsured. The Together Rx Access Card™ helps Americans without prescription drug coverage better afford their medications by providing them with meaningful savings on many brand-name and generic products—at local pharmacies.

To be eligible, individuals must not be eligible for Medicare, have no prescription drug coverage (public or private), and

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[*] Income limits may be different in Alaska and Hawaii; GlaxoSmithKline (GSK) expects Orange Card℠ participants to realize out-of-pocket savings ranging from 20-40% of the price individuals without drug coverage would usually pay their pharmacies for GSK medicines. Actual savings will vary depending on a pharmacy's customary pricing for a specific GSK medicine. GSK offers Orange Card℠ participants direct savings on their outpatient GSK prescription medicines equal to 25% of our wholesale list price. See application for important details and limitations.

[†] This program is for Medicare enrollees who have an annual income that is less than $28,000/singles ($38,000/couples) and do not have prescription drug coverage (public or private); this range of savings reflects the savings presently offered. Savings may vary depending on a pharmacy's customary pricing for a specific medicine and the savings offered by the participating company that makes it. (Participating companies independently set the level of savings offered and drugs included in the program. Those decisions are subject to change.) Income limits may be different in Alaska and Hawaii.

have a household income equal to or less than $30,000 for a single person, $40,000 for a family of two, or $50,000 for a family of three.[‡] Participants can expect to save about 25-40%—and sometimes more—off the usual pharmacy price paid on these prescription products. More than 275 FDA-approved prescription products, as well as a wide range of generics, from 10 major pharmaceutical companies are included in the program, including dozens of medicines used to treat diabetes, hypertension, high cholesterol, cancer, allergies, asthma, arthritis, and depression, which are among the most common conditions affecting Americans. Together Rx Access™ could benefit approximately 80% of the 45 million Americans—including more than eight million children—who are uninsured and don't have prescription drug coverage.

Ninety-eight percent of pharmacies nationwide will accept the Together Rx Access™ Card. The goal of the Together Rx Access Card™ is to help the millions of Americans without prescription drug coverage gain access to the prescription products they need and to help them take care of what's most important—their health. Since January, Together Rx Access™ has enrolled more than 300 uninsured North Carolinians.

Medicare Prescription Drug Benefit

One of the most important recent efforts to increase access to healthcare was the enactment by Congress of a Medicare prescription drug benefit. Enrollment for the Medicare prescription drug benefit begins in November 2005, and it is an important change in the nation's healthcare safety net. Beginning in 2006, Medicare beneficiaries will have access to a benefit that will cover outpatient prescription drugs. The benefit will be administered by private prescription drug plans, and seniors will have a choice of which plans to join. The new program is especially beneficial to low-income patients. They will get full coverage with minimal copays and will not have to pay premiums or deductibles. Every low-income senior citizen should take advantage of the new Medicare prescription drug benefit. Also, seniors with high prescription drug costs can benefit from the catastrophic coverage offered under the new benefit.

Until the prescription drug benefit goes into effect, there are Medicare prescription drug discount cards available. These cards offer discounts on prescription drugs and can charge a premium. But again, for low-income seniors, these cards are a great deal. Qualifying low-income seniors can get a card with up to $600 already available for them to use toward the purchase of prescription drugs.

Conclusion

Lack of access to even basic medication and healthcare facilities is a situation nobody should experience. GlaxoSmithKline recognizes the importance of our nation's healthcare safety net and is committed to playing a role in helping people avoid this crisis. No single organization can produce a solution; we will continue to work with other stakeholders to improve the health of our nation and improve our healthcare system. **NCMJ**

[‡] Savings may vary depending on the pharmacy's customary pricing for each product and savings offered by the participating company that makes it. Participating companies independently set the level of savings offered and the products included in the program. Those decisions are subject to change. Income limits may be different in Alaska and Hawaii.

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2 WAC (wholesale acquisition costs) is GlaxoSmithKline's listed price to wholesalers and warehousing chains, not including prompt pay, stocking or distribution allowance, or other discounts, rebates, or chargebacks. The listed price may not represent prices charged to other customers, including specialty distributors.

COMMENTARY

Free Prescriptions? Yes, There Is a Way!

Margaret P. Elliott, MPA

There may not be such a thing as a free lunch, but you can get your prescription medication free if you qualify. Just ask the Martin family. I'll never forget their story. This couple's niece called from Ohio to our free pharmacy to see if anyone could help her aunt and uncle whom she discovered were paying $700 per month for their prescription medications. To make matters worse, she learned that they were paying for them by charging the cost of their medications on a credit card. In debt, reaching beyond their ability to ever pay it back, the Martins turned to Crisis Control Ministry in Winston-Salem, which houses North Carolina's first state-licensed free pharmacy.

In one hour's time, after an interview to determine the couple's financial situation, the Martins were enrolled as certified clients of our pharmacy, and able to have their $700 worth of prescriptions filled for free! In addition, our pharmacy was spared the cost of their medications, thanks to the drug assistance programs offered by the pharmaceutical companies who manufactured the couple's medications. By completing applications that verified their inability to pay, our staff helped steer this couple through the guidelines of programs that vary depending on the company. Their medications were mailed to a local physician and dispensed to the couple at our free pharmacy.

Just six years ago this scenario was very different. Every day the free pharmacy staff faced very real challenges to meeting the needs of the individuals who visited us and could not afford their life-sustaining prescription medications. Even though we purchased medications, some were just too expensive to buy. If we happened to have received some sample donations from local physicians, we called it providential and were grateful to have the donation to dispense. Unfortunately, that didn't happen every day. We had to ask some patients to call back later to see if we received the medications. We had to tell others that we just didn't have their medication, and we couldn't afford to buy them, even at a discount wholesale price.

In 2000, the annual budget for Crisis Control Ministry's free pharmacy in Winston-Salem was $400,000. Four years later, we operated on less than half that budget, with costs offset by donated drugs. In 2003-2004, we dispensed nearly 34,000 prescriptions, 21% more prescriptions than in 2000—medications valued at over $2.1 million on a $197,000 budget thanks to pharmaceutical donations from local nursing homes and our participation in helping patients enroll in pharmaceutical companys' Patient Assistance Programs (PAPs). In 2004, our free pharmacy received $423,000 worth of drugs from drug manufacturers—drugs that we earlier had purchased or simply could not afford to provide.

Many people are no longer able to afford their medications due to the rising cost of prescription drugs. These individuals may be eligible for the patient assistance programs and discounts offered by pharmaceutical companies, but these programs are complicated. They are all different, and it is not always easy to get the information you need to use them.

> *"One of the most important roles we play as advocates and human service providers is educating and helping our neighbors in need to access the services that are available to them."*

Pharmaceutical manufacturers have designed programs to serve the most financially needy patients, those who lack health insurance or financial resources, and those who have exhausted all other options to cover needed medications. Though these programs are very beneficial, locating information and navigating through the complex application process is sometimes an overwhelming task.

The majority of brand name as well as generic medications are available through PAPs. Although eligibility requirements vary according to manufacturer, there are requirements that typically must be met:[1]

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- *United States Residency.* Depending on the program, some companies simply require that patients be permanent residents of the United States. Others require that they reside in the United States legally and others require United States citizenship.
- *No prescription coverage.* The patient must not be covered or eligible for coverage under any public or private insurance that covers prescriptions.
- *Low income.* Each company has its own eligibility standards regarding income. Most will not provide assistance to patients with monthly incomes that exceed 200% of the federal poverty guidelines.
- *Chronic medical conditions.* Patients who require on-going medication to treat chronic medical conditions are typically the only patients who will qualify for assistance. Since the application process may take several weeks, these programs are usually not appropriate for acute medication needs.

Benefits of Patient Assistance Programs

There are many benefits of PAPs to patients, healthcare providers, communities, and drug manufacturers. Patients are provided access to much needed, sometimes life-sustaining, prescription medications for free or at a reduced cost. This enables the patient to use his or her remaining financial resources to provide for other basic life needs, such as food and shelter. The patient experiences less emotional stress and, with the provided medication, has improved health.

Healthcare providers benefit because the patient stays compliant with a recommended course of treatment. There are fewer trips to the emergency room and fewer admissions into nursing homes. Sample medications can be used for other purposes.

The community benefits by supporting safety net providers who help provide access to the PAPs. Resources saved can be directed toward other needs in the community.

Drug manufacturers, who are not required to offer these programs, benefit with PAPs by providing an opportunity to contribute to improved patient outcomes. PAPs also allow companies a marketing opportunity, help with public relations efforts, and offer potential tax deduction.

Details of Patient Assistance Programs[1]

Individual Programs. The complexity of accessing free medications through PAPs is revealed in the challenges one faces while completing the applications. The eligibility criteria, system of medication delivery (either to the patient, the physician, or accessed through a voucher to use at a retail pharmacy), and application forms are different for each program. Safety net providers, such as free clinics or social workers, assisting patients with the process must learn the criteria of each company's program.

Access to forms. Most forms are available on the pharmaceutical company's website or through specialized software that accesses the forms. Some forms must be requested each time a patient is identified. Waiting to receive a form in the mail only delays the application process.

Citizenship/Residency requirements. Many programs require patients to be legal residents or United States citizens to be eligible for PAPs. This serves as a barrier in communities that seek to serve undocumented residents or those who are not yet citizens.

Frequent changes. The application process, the medications covered, and the eligibility criteria can change quite often; therefore, it is imperative that healthcare providers keep up with them in order to complete the patient enrollment forms correctly.

Long waiting times. It is not unusual for a patient to wait four to six weeks to receive medication ordered through a PAP. During these waiting periods, healthcare providers and safety net providers must seek other ways to access medications to provide for the immediate needs of the patient.

Reapplication required. Many programs provide only a 90-day supply of medication and require the patient to reapply for the next supply. This requires a tremendous amount of organization and reminder cues to ensure continuity of care for enrolled patients.

Detailed documentation. Supporting documentation necessary to qualify for patient assistance programs sometimes includes pay stubs, tax returns, or a letter from the Medicaid office verifying that the patient was denied enrollment in that program.

Conclusion

Though the process of acquiring free medications from pharmaceutical providers is tedious and time consuming, the cost savings to safety net providers is worth the effort. One of the most important roles we play as advocates and human service providers is educating and helping our neighbors in need to access the services that are available to them. The safety net providers in our state are aptly described as being part of a patchwork system of responders who attempt to meet the needs of individuals and families who lack financial resources and are part of the growing number of uninsured. I recently was invited to meet with the presidents of two local hospitals. One of them had never even heard of patient assistance programs offered by pharmaceutical manufacturers. I was not so surprised. I am the first to say that the patchwork of services such as those provided at free clinics and free pharmacies across the state are not the long-term solution for the uninsured population. In the meantime, until the political process allows for affordable health insurance for all of our residents, we safety net providers become experts at pooling our resources and at figuring out ways to serve the economically poor families whose healthcare needs would otherwise be unmet. **NCMJ**

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Integrating Multiple Service Providers in Service to the Poor and Uninsured:

The Critical Conditions for Effective Collaboration

Thomas G. Irons, MD

Roberta Burgess, a HealthAssist Nurse Case Manager, was made aware through community contacts that Mary M. was in trouble. An employed but uninsured 49-year old woman who lived alone in a mobile home, she had become morbidly obese and was about to lose her job. She was woefully under-medicated and rapidly progressing toward disability and irreversible cardiovascular disease. Roberta made a home visit, finding Mary barely able to rise from of her chair or walk without assistance. With the help of Lynn Howard, a project social worker, she found Mary a walker and, with her, embarked on a journey of recovery. First it was necessary to control her diabetes, hypertension, and hyperlipidemia. Regina Coyle, a nurse practitioner, saw her in a series of clinic visits, prescribed appropriate medications, and placed Mary on a carefully limited exercise and weight-loss program. Meanwhile, HealthAssist team members were making contacts with several community and state agencies. The progress toward recovery was slow but continuous, and in 2004 Mary had successful gastric bypass surgery, funded by the North Carolina Division of Vocational Rehabilitation Services. As of this writing, she is employed full-time and soon will require no HealthAssist services. Roberta said recently, "She came by to see me and I hardly recognized her. She looked wonderful!"*

*HealthAssist is the original program component of the Eastern Carolina Community Health Consortium (ECCHC).

> *"In no case has complete integration been approached, but many have achieved broad-based, genuine collaboration among diverse entities."*

For a long time now, I have, on a few moonless nights every year, fished a flounder net in the lower Pamlico River. Because of its large and flexible 5 1/4 inch mesh, it spares most other fish, and the flounder's physiology allows him to rest on the bottom until I remove him. Around mid-July and extending into mid-September, blue crabs become a serious problem. The ones I usually catch are free-swimming as "doublers," meaning they are occupied with the business of reproduction. They get themselves all wrapped up, and I often must break a strand to get them out. One broken monofilament strand doubles the size of the hole formed by the mesh, and pretty soon, as we say Down East, I've got "holes you could walk through." One might say, stretching the metaphor a bit, that the fisherman's success depends on the "connectedness" of his net. Once it gets really "holey," he'll still catch a few flounders, but most will escape. The healthcare safety net is disturbingly similar. At best it is a fragile, "patchwork array," with certain relatively consistent components, the compromise of any one of which can create a major service gap. A brief look at those components might be helpful.

The Components of the Healthcare Safety Net

Most communities of medium-to-large size have at least one free clinic and even some small rural areas have found ways to provide limited, part-time free health services. In addition to primary care services, these entities often provide medication support, ranging from sample distribution to helping clients access drug company programs and/or purchasing and distributing limited

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medications. In some cases, pharmaceutical assistance is provided, but there is no direct healthcare. Public health departments, in addition to their traditional prevention-focused programs, provide a range of primary care services ranging from minimal to comprehensive, the outstanding example of the latter being in Buncombe County. These exceptional programs notwithstanding, few public health departments can provide medication support outside that required for management of sexually transmitted diseases, pregnancy prevention, and tuberculosis. The community health centers often referred to in this report as federally qualified health centers (FQHCs) are the most economically viable model for comprehensive indigent health services, and some across the state have done so with remarkable effectiveness. Greene County Health Care, headquartered in the tiny rural community of Snow Hill, recorded encounters with over 18,000 people last year. They offer comprehensive primary care including prenatal services, dental care, and an award-winning Latino outreach program. Still, despite the so-called "President's Initiative," new center applications are highly competitive, and regulations prohibit establishing centers in many areas. Private physicians carry a share of this burden as well, depending upon variables such as workload of insured patients, the availability of volunteer "off time," and the availability of Project Access-like programs that allow them to provide donated services within an organized structure. Public hospitals, of course, bear a huge "charity care" burden. There are many other community organizations and agencies, both public and volunteer, providing human services that are essential to improving the health of low-income people.

> *"Early on, we agreed on a simple sentence that captures the essence of this element: 'We will do what is right, we will do it well, and we will do it together.'"*

How Likely Is Collaboration or Integration to Occur?

Across the board, these services are rarely integrated, though notable exceptions exist. Among them, Community Care of North Carolina (CCNC) has had the greatest impact. Thanks in large part to the visionary leadership of Allen Dobson, MD, President of Community Care of Cabarrus County, and James D. Bernstein, founding Director of the state's rural health program, CCNC has managed to contain Medicaid cost increases, while significantly improving health outcomes and provider and patient satisfaction. Using a nurse case management strategy and depending upon volunteer physician leadership, it has helped communities across the state coordinate services to Medicaid recipients. There are a number of local examples, often operating in coordination with CCNC. Many have been temporarily funded under the United States Health Resources and Services Administration Healthy Communities Access Program (HCAP). These include, but certainly are not limited to, the Eastern Carolina Community Health Consortium (ECCHC), headquartered in Greenville, the above-mentioned Buncombe County coalition, and a similar one operating in Cabarrus County. In no case has complete integration been approached, but many have achieved broad-based, genuine collaboration among diverse entities.

The Essential Elements of Community-Level Collaboration

As I have traveled around the state to advise others engaged in this work, I have spent many hours reflecting on the elements of successful programs. The following five components are, I believe, the essential ones:

- *The Right Kind of Leadership.* Organizational self-interest ("turf") and mutual mistrust are the absolute enemies of collaboration. Public service and charitable entities are far from immune to these and cannot easily set them aside. One who leads these coalitions must be generally well-known, absolutely trustworthy, and have the maturity to put aside personal biases and respond in a non-reactionary way to negative or confrontational situations. Often these are physician leaders, like Allen Dobson in Cabarrus, Lindsey De Guehery in Wilson, and many others.

- *A Clear, Simple, and Continually Reinforced Value.* Collaborators must agree upon a common value that can be easily articulated. In the eastern North Carolina group, we agreed that all are committed to improving the health status of poor and low-income people, *period*. When conflict has arisen or our spirits have lagged, we have stopped and asked, "What are we here for?" reinforcing this core value. Early on, we agreed on a simple sentence that captures the essence of this element: "We will do what is right, we will do it well, and we will do it together."

- *A Source of Funding.* Many would list this component first. I do not for two reasons. First, acquiring funding before genuine collaboration has been achieved is a sure prescription for failure. All of us who are engaged in this work can cite numerous examples. Secondly, it is not only possible to build a coalition of committed partners with little or no outside funding, it is essential. If the entities involved are not committed to each other and the coalition's core value, the program will fail whatever its financial condition. On the other hand, programs that can demonstrate in a grant application or site visit that genuine collaboration is present are far more likely to be funded.

- *Inclusiveness.* No community is likely to be successful in bringing all stakeholders to the collaborative table. Still, coalitions should make it their goal to do so. In building the ECCHC, we faced numerous threats. Perhaps the most serious one was the historically strained relationship between the components of the University Medical Center and Greene County Health Care (GCHC). Program leaders recognized early on that GCHC could bring extraordinary strength to the coalition, and GCHC leaders, likewise, saw the need for healthy partnership. Solving this problem required clear communication about issues of disagreement and demonstrated commitment from both parties to rebuilding trust. This was slow and difficult work, but its success was assured from the beginning by the mutual commitment of leaders from both entities to effective collaboration. Much of this work was done in a highly productive series of private meetings between the GCHC Executive Director, Doug Smith, MBA, and this author. In another example, these same entities are cooperating in the construction of a 15,000 square foot community health center in northern Pitt County, with GCHC agreeing to operate the center as an expansion site. This expansion could compromise an important program operated by the Pitt County Health Department, its prenatal care clinic. Because the Pitt County Health Director, Dr. John Morrow, is an active coalition leader, discussions among the appropriate parties were held early on and the potential conflict averted.

- *Flexibility.* Finally, successful coalitions, like my flounder net, must have sufficient flexibility to stretch as much as possible without tearing. Sudden changes in political priorities, funding streams, population need, etc., are inevitable. Such flexibility requires a constant reinforcement of the mission and an underlying spirit of optimism, a belief that doing what is right will ultimately be both successful and rewarding.

My own observation, as one coalition leader, is that I am responsible for upholding this spirit among our partners, and to work continually to praise and thank those who do the day-to-day work. When I find myself discouraged, I remember our vision, and say to myself, often aloud, "We will do what is right, we will do it well, and we will do it together." **NCMJ**

COMMENTARY

Rising Student Health Needs Require a School Safety Net

Leah M. Devlin, DDS, MPH, and Marilyn K. Asay, RN, MS

The fourth grader was lethargic and gray. Thin to begin with, he had lost six pounds in the past four to six weeks. After two days of very reduced alertness in class, the school guidance counselor and the boy's teacher contacted the school nurse. The nurse, newly hired by the school district as its first-ever nurse, reviewed the boy's symptoms and called his mother for permission to check his blood sugar. The nurse then contacted a local pharmacist who donated blood sugar testing supplies that same day. With a blood sugar of 578 mg/dl, the nurse urged the mother to seek immediate medical attention for her son. The boy was hospitalized and diagnosed with Type I Diabetes. In collaboration with the boy's physician, mother, and teacher, the nurse subsequently began preparing for the boy's return to school by developing a care plan and training the teacher, principal, and counselor in monitoring the student's self-care. The teacher reports that thanks to the school nurse, who identified this child's diabetes and managed his successful reentry into school, this student is "back to his normal self, has more energy, and is learning better."

> "...each of North Carolina's school nurses [are] responsible on average for approximately 1,900 students, ...rather than the nationally recommended 1:750..."

A freshman came into his high school's health center for a sick visit. While there, the staff asked him to complete a health risk questionnaire in order to get more information about his risk-taking behaviors and conditions. The multi-disciplinary team at the center (which includes a nurse practitioner, nurse, mental health professional, nutritionist, and health educator) treated the young man for high blood pressure, rosacea, and acne and provided mental health and weight management counseling. He was enrolled in the North Carolina Health Choice Program (North Carolina's State Children's Health Insurance Program) and received glasses from the Lens Crafters Gift of Sight Program. By integrating and delivering his medical and mental health services at the school-based health center, this student was able to miss very little school while receiving multiple services, and his mother missed very little work. He is now a senior with a brighter future ahead of him.

At a metropolitan high school, the school nurse splits her attention between two boys. A 16-year-old football player has fallen and may have re-injured a broken ankle. A 15-year-old freshman, taking medication for both bipolar disorder and attention deficit hyperactivity disorder, is feeling light-headed. The nurse examines the students, calls the parents, and assists in coordinating primary care and specialty providers. Across town in another school, with no school-based nurse, the health needs of students are addressed as best as possible by teachers, secretaries, and administrators.

These true stories are but three examples of the variety of health concerns that students bring with them to school each day. These health problems impact their ability to be successful in school and require that the school healthcare safety net be strengthened. The needs of students have also changed dramatically in the past ten years, creating increased demands for appropriate care while at school. For example, the North Carolina Annual School Health Services Report for Public Schools for 2003-2004 reported that:

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- Over 161,000 (12%) students suffer from chronic illnesses or special healthcare needs (diabetes, asthma, seizure disorders, etc.).
- More than 14,000 students needed one or more invasive procedures performed during the school day (nebulizer treatments, tube feedings, urinary catheterizations, tracheostomy care, blood glucose monitoring, and the management of insulin pumps, etc.).
- At least 7% of students received medications at school, including controlled substances.

In addition to the growing numbers of children with complex health problems that often require intensive management at school, the prevalence of risk-taking behaviors continues to be elevated. These include substance abuse, homicide, suicide, child abuse and neglect, and developmental problems such as Attention Deficit Hyperactivity Disorder (ADHD). Mental health issues such as anxiety, depression, school refusal, anger, and eating disorders are increasing and are affecting attendance, school performance, and student well being. Prevention programs have become a greater focus in schools, as the obesity epidemic is affecting children and adolescents at earlier ages. One in four North Carolina teens and one in five children ages five to 11 years of age are now overweight. The ability to learn at school is directly related to the status of a student's health. "Students who are hungry, sick, troubled, or depressed cannot function in the classroom, no matter how good the school,"[1] according to the Carnegie Council on Adolescent Development. Students who drop out of school experience more health problems, delayed employment, and poverty. Data from the United States Bureau of the Census underscore that high school dropouts have the lowest expected lifetime earnings compared with workers at all other levels of educational attainment. It is well documented that people in poverty are less likely to have access to healthcare and less likely to engage in healthy lifestyles. The Council of Chief State School Officers and the Association of State and Territorial Health Officials have jointly noted this interdependency between health and education by suggesting that "healthy kids make better students and better students make healthy communities."[2]

> *"The absence of a strong safety net of nurses in North Carolina's schools represents one of our most critical missed opportunities to help children be successful."*

The School Nurse as a Safety Net "First Responder"

When nurses are present in the school, parents often rely on them as first responders for early identification, referral, and follow-up for their children's primary care needs. Often the school nurse is the first person a parent seeks out in order to make a decision about the need for health services. "Go see the school nurse, and if she thinks you are sick enough to go to the doctor, tell her to call me." With each of North Carolina's school nurses responsible on average for approximately 1,900 students (often scattered over a minimum of three to four schools), rather than the nationally recommended 1:750, it is very difficult to provide the level of safe care needed and to assist families in locating and using local healthcare resources. Teachers and other school staff are asked to assume more and more health related responsibilities, and school nurses are expected to provide training and on-going supervision for these individuals.

The North Carolina General Assembly, understanding the school nurse's role in the development of healthy students who are more likely to achieve academic success, appropriated money for the School Nurse Funding Initiative (SNFI) to the Division of Public Health in 2004. The Initiative included an annual state appropriation of $4 million to fund 80 permanent positions and approval of Maternal and Child Health Bureau funds of $3,250,000 annually for 65 time-limited (two-year) positions. Governor Easley has called for 165 additional nurses in the budget over the next two years. Many of these nurses will work in Child and Family Support Teams to further link children at-risk to community services

School Health Centers: A Second Safety Net for Some Schools

With regard to comprehensive services for adolescents, the safety net in most communities is thin. While access to comprehensive services has improved for some adolescents in the state, most service delivery remains fragmented and categorical, with treatment for illness, sports physicals, mental health services, or counseling for nutrition concerns all being provided at different locations. School-based and school-linked health centers located on or easily accessible to school campuses have brought comprehensive, "one-stop-shopping" opportunities to adolescents and a focus on emerging health problems. The obesity epidemic, for example, is receiving increased attention in these centers as evidenced by the requirement for state-funded health centers to include a body mass index (BMI) performance measure.

With parental permission, students can receive help in these health centers for a variety of medical and psychosocial needs. Currently, there are 27 comprehensive centers operating in middle and high schools in the state and another 12 centers that provide primary care services delivered by nurse practitioners or physician assistants.

Health Is Academic

With high school graduation rates falling in North Carolina from 64% in 1990 to 60% today, it is essential that every student has access to healthcare and the opportunity to develop healthy behaviors so they can learn and graduate. The absence of a strong safety net of nurses in North Carolina's schools represents one of our most critical missed opportunities to help children be successful. Closing the health disparity for children is a critical strategy to close the achievement gap. We must ask ourselves, "Have we done all that we can to make certain that children and teens are ready and able to learn supported by healthy families?" North Carolina is now answering this question under the leadership of the Governor, the General Assembly, the State Board of Education, local schools, and health departments with their respective boards. The State Board of Education is also requiring all districts to create School Health Advisory Councils bringing parents, healthcare providers, and community organizations to the school health table as well. This momentum is critical, for it will take all of us working together to strengthen the school health safety net and thereby our children's chances for success in school. **NCMJ**

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COMMENTARY

AHEC Teaching Clinics in Service to the Uninsured

Thomas J. Bacon, DrPH

One of the primary reasons for establishing the North Carolina Area Health Education Centers (AHEC) Program in the early 1970s was to create a statewide infrastructure to expand the training of primary care physicians in the state. With support from the North Carolina General Assembly, AHEC today supports eight residency programs in family medicine, four in internal medicine, four in obstetrics and gynecology, three in pediatrics, and three in surgery. These programs employ 260 full-time faculty and 285 residents, which is nearly 15% of the total number of residents in training in the state.

These AHEC residency programs, in close partnership with their community teaching hospitals, provide a significant amount of safety net care throughout North Carolina. As with teaching programs across the country, the clinics operated by these residencies and teaching hospitals take all patients, regardless of ability to pay. In addition, the teaching services serve as the means to admit patients to hospitals that come through the emergency room and have no regular physician. Frequently, these patients do not have insurance coverage.

> *"...AHEC residencies work closely with other safety net providers to create better systems of care."*

During 2003-2004, AHEC teaching services provided more than 450,000 outpatient visits and more than 184,000 inpatient visits of care. Nearly 100,000 of these outpatient visits were for uninsured patients, and more than 36,000 of the inpatient visits were for uninsured patients. AHEC clinics also have high numbers of Medicaid and Medicare patients, and the reimbursement rates of both public programs have not kept up with the rising costs of care.

Beyond their own clinics, AHEC residencies work closely with other safety net providers to create better systems of care. Most work closely with health departments to improve the safety net, including rotating residents to health department clinics, coordinating and in some cases integrating health department and AHEC clinic services, and seeking grants to establish new models of care. In some AHECs, such as Wilmington, faculty lead outreach clinics in surrounding rural counties to expand access for the uninsured. In Fayetteville, the AHEC hosts the regional child abuse clinic, and supports HIV/AIDs and other outreach clinics in nearby rural counties. AHEC faculty have taken the lead in developing new community-wide safety net programs, such as the role Mountain AHEC faculty played in establishing Project Access in Asheville.

The workforce development role of AHEC residencies is also critical to maintaining and strengthening the safety net services in the state. AHEC residencies were initially established to expand statewide capacity to train physicians to meet the physician workforce needs of underserved communities. Data from the past 25 years indicate that the AHEC residencies are effectively fulfilling that mission. Over 1,500 residents have graduated from AHEC primary care residencies, and two-thirds of them have remained in North Carolina to practice. In addition, graduates of AHEC residencies are more likely to settle in rural and other underserved communities than graduates of residencies at a university medical center.

As with other safety net providers, AHEC and hospital-based clinics face a number of financial challenges. The number of uninsured patients seeking care continues to grow as employer-based health insurance becomes more expensive and less available. State appropriations for AHEC and other related programs have declined over the last four years, and federal grant support via the Bureau of Health Professions has also declined. At the same time, costs for malpractice premiums, new technology, and recruiting and retaining faculty have all increased.

In spite of the challenges, the AHEC Program remains committed to maintaining and strengthening its statewide network of primary care residencies. As the population of North Carolina continues to grow at a rate faster than the national average, it may be necessary to further expand the number of residency positions to assure that the physician supply for the state remains adequate to meet the growing needs of our population. **NCMJ**

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COMMENTARY

Who is at Risk of Losing Safety Net Healthcare?

Adam G. Searing, JD, MPH

Ms. McDaugherty, a 30-year-old widow with two children, works as a waitress. Her job pays enough to put her income slightly above eligibility for the North Carolina Medicaid program ($11,425 annually), but offers no health insurance coverage. Her earnings of roughly $1,000 a month are quickly used to pay for rent and utilities for an efficiency apartment ($700), food ($150), and public transportation ($100).

Just as she was starting to get on her feet economically, less than a year after she lost her husband, Ms. McDaugherty found a lump in her breast. Tests performed at a community clinic found that she had a malignant tumor that had already spread to her lymph nodes.

Since her income is slightly above the federal poverty level, she can only qualify for Medicaid as an "optional benefitiary" because she has been diagnosed with breast cancer. Because of Medicaid, Ms. McDaugherty was able to see a specialist who advised her that she needed a lumpectomy, followed by chemotherapy and radiation treatment. The Medicaid program currently covers all of Ms. McDaugherty's cancer treatments, including medications for the side effects of chemotherapy, which help her continue working part-time.

As an "optional beneficiary," she would be one of the first to completely lose health coverage as a result of federal or state budget cuts to Medicaid, since her income is slightly above poverty level. Even if coverage is continued, North Carolina could select a narrow list of services that would be covered for people like her. For example, the state might limit the drugs that help control the side effects of her cancer drugs and allow her to work.[i]

Strengthening the Safety Net, Covering the Uninsured, Controlling Health Costs

Three years ago I wrote an article for the *North Carolina Medical Journal* entitled "The Uninsured and Medicaid."[1] I surveyed the Medicaid program and the situation of the uninsured, noted the drivers of rising costs, the necessity of denying healthcare to people currently covered by Medicaid to achieve truly substantial cost savings called for by proposed state budget cuts, and the need for new revenue to sustain the program in a time of economic downturn so that even more people would not join the ranks of the uninsured.

To borrow an apt example from a noted health policy researcher,[2] Bill Murray in the movie "Groundhog Day" and I have much in common as I address this issue again for the Journal. Medicaid costs continue to increase along with general healthcare costs and as we ask the program to absorb more people who have lost insurance. Substantial budget cuts are proposed by the federal government that could only be covered by denying Medicaid coverage to tens of thousands of North Carolinians.[3] Once again, we need to find new revenue in order to address growing health costs and the growing numbers of the uninsured. Finally, there are no detailed plans for reform under consideration by political leaders in North Carolina.

Although the problems are the same today as they were in 2002, they could be much worse. Unlike many states, North Carolina chose to enact incremental tax increases over the last three years so we could maintain state health, education, and other vital services for our residents. While there have been some cuts, we have avoided the examples of states as diverse as Oregon, Texas, and Mississippi, where hundreds of thousands of vulnerable seniors and children have joined the ranks of the uninsured after being cut from Medicaid coverage.

Still, the picture in North Carolina is grim. New reports show that from 2000 to 2003, over 457,000 North Carolinians

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[i] This example is based on a real person and was developed by FamiliesUSA and the North Carolina Health Access Coalition. See "The Bush Administration's Proposed Structural Changes to Medicaid: Hurting Real North Carolinians," www.familiesusa.org.

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have lost health insurance due to rising health costs and the economic downturn—one of the highest rates in the country.[4,5] Over 300,000 people have joined the ranks of the uninsured since 2000, and we have added over 230,000 people to Medicaid. Premiums for employer-based plans in North Carolina have risen by 43.4% between 2000 and 2003.[4] A family health insurance plan in North Carolina now costs about $9,000 per year.[5] There are now 1.5 million people on Medicaid in North Carolina and 1.4 million people without health insurance.

When people talk about health reform, they often imagine a magic bullet that will decrease health costs, extend coverage, and not cost any more than we spend right now. Over the last 70 years, no magic bullet has appeared, although many have been proposed. The current crop includes medical malpractice changes, health savings accounts, a single payer health system, and electronic medical records. While each of these ideas probably has some positive aspects, none of them is either politically feasible or will really have any appreciable effect on the underlying problems our health system faces.[7,8,9,10] To really address the growing numbers of the uninsured, our overstrained safety net, and rising health costs, reform in North Carolina must take a different path.

Successfully strengthening the safety net in North Carolina means three mountains must be climbed. First, our tax system must be reformed so it collects (consistently from year-to-year) the revenue necessary to fund the public health safety net services we already have. Second, we must collect more revenue through the tax system to cover people now currently uninsured and make health insurance more affordable for those who are already insured—both reforms the public says it wants. Third, we need to develop a plan for reform that businesses, advocates for the uninsured, policymakers, and other stakeholders can support.

Reforming the Tax System to Fairly Meet the Health Needs of North Carolinians

Health and related human service programs account for approximately 25% of North Carolina's state budget spending. The majority of this spending is on safety net programs like Medicaid, Health Choice, and other health and child development programs.[11] All but about 5% of other state government spending goes for education, justice, and public safety programs. That nearly 95% of state spending is for these public services should not be surprising. Education, healthcare, and justice services all enjoy broad popular support among North Carolinians. For example, a recent survey of North Carolina voters shows that 87% support Medicaid to fund healthcare for low-income people in the state.[12]

North Carolina's tax system has not kept pace with the public's interest in funding these key state services. This is not an argument that more revenue needs to be generated from taxes, just that the current laws on the books mean that the tax burden is distributed unfairly and cannot respond to our growing state population. Our tax system is antiquated and so full of loopholes that it does not fund state needs over time and is easily affected by economic downturns. An example of this is the sales tax that extends to most products while not covering services people increasingly buy instead of products. The person who used to pay sales tax on the purchase of a lawn mower now pays no sales tax on the purchase of a lawn mowing service. Because of problems like this, “families earning less than $15,000 in North Carolina pay the greatest share of their income [10.9%] in state and local taxes while the top 1% of income-earners pay the lowest share of their income [6.3%] in taxes.”[13]

> *“...our tax system must be reformed so it collects (consistently from year-to-year) the revenue necessary to fund the public health safety net services we already have.”*

Another example of why we need tax reform is the shift of the tax burden away from corporations to individuals.[14] As revenues from corporate taxes decline, the state must look to individuals to make up the difference, often with inequitable results. A major Fortune 500 company in North Carolina, BB&T, had basically no state income tax liability (0.1%) from 2001-2003 despite making $4.6 billion in profits.[15] Without reform of our tax system, we will not have the money to fund current state safety net programs that have broad public support, like Medicaid and Health Choice, much less enough money to make improvements in the future.

Generating Revenue to Strengthen and Expand the Safety Net

A reformed tax system would better keep up with the growth of state safety net programs and services now available. However, any expansion to address the problems facing the safety net or to extend coverage to the growing uninsured population will need new revenue.

Recently a group of farmers came to demonstrate at the General Assembly in Raleigh with two demands: (1) keep and increase tax breaks for farmers, and (2) make health insurance more affordable.[16] This call highlighted one of the main obstacles to strengthening the safety net and addressing the problem of the uninsured—people want the government to do something to make healthcare more affordable and accessible, but they believe they pay too much for government services already and want lower taxes. These two goals are simply not compatible.

Strengthening North Carolina's Medicaid and other safety net programs to insure parents of already covered children would begin to reduce North Carolina's uninsured rate. This costs money. Ideas like establishing a statewide reinsurance pool for employees in small businesses with extremely high health bills could reduce small business health premiums significantly. This costs money. Allowing medically uninsurable North Carolinians to buy into state health plans would reduce the numbers of uninsured. This costs money.

Any one of these reforms is achievable within the context of North Carolina's $15 billion budget, but at least some new revenue will have to be generated to meet these needs and the public's other priorities in education and public safety. The bottom line is that for significant health reforms to have a chance, people who want health reforms must also advocate for a tax system that will generate enough revenue to fund reforms.

Steps to Strengthen the Safety Net and Expand Health Insurance Coverage

Developing a plan to strengthen the safety net and extend affordable health coverage is the easy part, once enough revenue has been raised to achieve real reforms. Proposals abound, but funding them is always the critical component. The following proposals would each individually slash the number of people without health insurance. Enacting all of them would elevate North Carolina to the status of a national leader in reducing the costs of health insurance for business and individuals, while extending coverage to the uninsured.

- Expand Medicaid and North Carolina Health Choice (children's health insurance) to offer affordable coverage to low-income parents of children currently covered if a family's income is under 200% of federal poverty guidelines ($31,340 annual income for a family of three).
- Direct more funding to safety net health centers like community health centers, rural health centers, and public health clinics to enable them to expand and provide services to the growing number of people either uninsured or covered by Medicaid.
- Allow childless adults, children, and parents to buy into the state employees' health insurance plan if their income is below 300% of federal poverty guidelines ($47,010 annual income for a family of three). Charge premiums on a sliding-fee scale with families and individuals who have higher incomes paying the full cost of coverage.
- Establish a state high-risk insurance pool that would subsidize coverage for people who, because of a health condition, cannot find affordable coverage anywhere else.
- Start a state reinsurance pool for small and mid-size businesses that would take over paying for the health costs of any employee whose medical bills exceeded $50,000. By removing the risk of paying for catastrophic care, employer health premiums would drop, and coverage would become more affordable.

Treading water is simply not acceptable. As costs mount in tandem with calls to cut Medicaid, North Carolina's major health safety net program; as employers find they can no longer afford coverage for employees; and as the numbers of uninsured grow, we cannot simply stand by. Federal action is unlikely, and North Carolina must begin to address the problem of affordable health coverage and the uninsured on its own. Without action by the federal government, it is unlikely that North Carolina will be able to completely strengthen the healthcare safety net and extend health coverage to 100% of people without health insurance. However, indifference in Washington is no excuse for North Carolina not beginning to address these serious problems with its own innovative solutions. **NCMJ**

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Take Note

Book Review:

Scientific Publications by Walter Kempner, MD: Volume II. Radical Dietary Treatment of Vascular and Metabolic Disorders. Edited by Barbara Newborg, MD. Gravity Press, Durham, NC, 2004. 557 pages.

For this reviewer, this volume is a trip back to 50 years ago, when Dr. Kempner was the most renowned clinician at Duke University Medical Center. He is best known as the originator of the rice diet, and the first to demonstrate that severe hypertension and glomerulonephritis could be successfully treated by its application and that malignant hypertension, a common, largely fatal diagnosis of that time, could be treated and reversed.

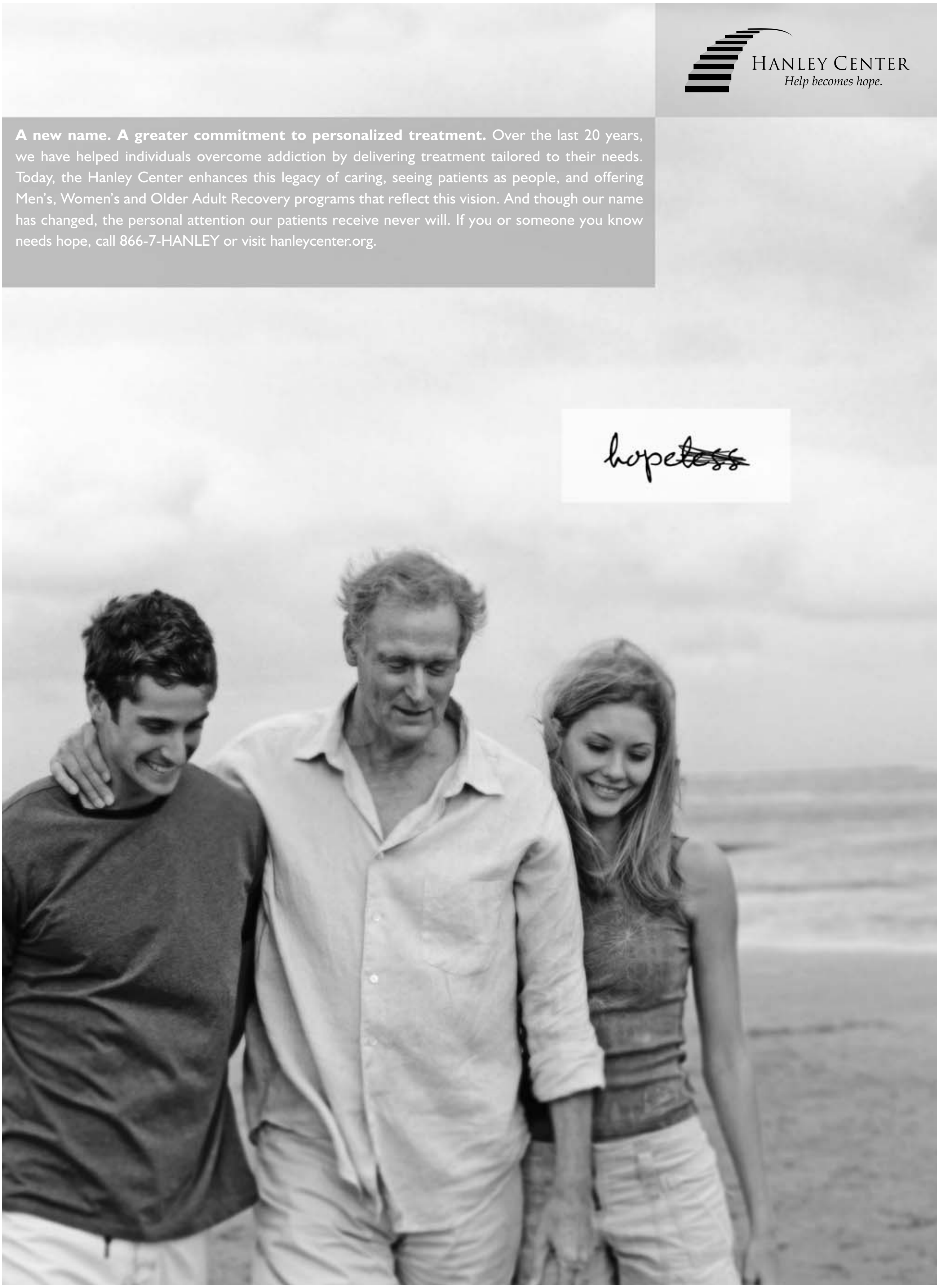
The book is not a biography, nor is it a discussion of his radical dietary therapy. It is a collection of his scientific papers, plus those of other closely associated team members at Duke. It is of special interest to readers of this Journal and North Carolina physicians, because most of the earlier Kempner papers were published in the *North Carolina Medical Journal* in the early 1940's. The volume also includes papers about Kempner by physicians who knew and worked alongside him, such as Morton Bogdonoff, Jay Skyler, and Eugene Stead, all of whom contributed to a symposium in Kempner's honor in the *Archives of Internal Medicine* in 1974 on the occasion of his retirement from the Duke faculty.

These papers are remarkable in many ways and worth reading. They reflect the limited knowledge base of that time relating to hypertension and kidney disease, and they also reflect the meticulous and detailed data collection and recording that are a part of Kempner's legacy. There are extraordinary before and after pictures of ocular fundi showing the resolution of papilledema and chest films showing reversal of cardiomegaly. These are so dramatic that they caused some well-known physicians of the time to doubt their validity. They also demonstrate the effective use of flow sheets in patient care, long before these became popularized as part of the problem-oriented record.

It is regrettable that these papers cannot portray the personality and power of this remarkable man. He began his career as a bench scientist, working in the laboratory of the famous Otto Warburg in Germany, and continued his studies of cellular physiology in his early years at Duke. He became a clinician again during World War II, when many of the Duke faculty departed to join the Duke hospital unit in England. His early successes with the rice diet were published and noted, but his earliest presentations were not well received. Such success in the treatment of diseases previously considered incurable was too good to be believed! His patients—most of whom came to him after receiving a death sentence from their physicians at home, and most of whom returned home much improved, and even "cured"—were his staunch supporters and returned to his care over and over again, bringing their friends and making him a wealthy man. Many at Duke were jealous of his success, and it is said that the recruitment of Eugene A. Stead, Jr., MD, to Duke in 1946 was favored by those who thought that Stead would force him out. Instead, Stead recognized the importance of his work and adopted his techniques for his own patients, which is documented in Stead's comments in this volume. Stead defended and supported Kempner, and he, in turn, provided Stead, in his earliest years at Duke, with the financial means to develop his department into a world leader.

Kempner's diet was a combination of severe sodium, fat, and protein restriction, which was found to benefit a number of significant morbid conditions: hypertension, kidney disease, vascular disease, diabetes, obesity, etc. The development of diuretics, potent antihypertensive drugs, and cholesterol reducing agents, plus the difficulty of remaining on this difficult and different diet, made the rice diet less important and even outmoded in the opinion of some, but he was never convinced that any of these "advances" were more beneficial to the patient than his diet. Clearly, much of his success reflects the strength of conviction and a personality that helped motivate his patients to remain on the diet. This complex and remarkable man deserves full credit as the first physician to offer a ray of hope to those with several previously irreversible illnesses, to which the papers in this compilation give convincing documentary evidence.

— E. Harvey Estes, Jr., MD
Professor Emeritus
Department of Community and Family Medicine
Duke University Medical Center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North Carolina Voluntary State Registry of Advance Healthcare Directives

In 2001, the North Carolina General Assembly passed legislation authorizing the NC Secretary of State to create a voluntary on-line registry of advance healthcare directives for the benefit of the citizens of the state and their healthcare providers under circumstances where immediate access to such directives would be needed. Citizens wishing to register their notarized directives may place three types of healthcare directives and an organ donor card on the Internet web site maintained by the Office of the Secretary of State at the following Internet location:

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Government Services

Running the Numbers

A Periodic Feature to Inform North Carolina Healthcare Professionals
About Current Topics in Health Statistics

From the State Center for Health Statistics, North Carolina Department of Health and Human Services
www.schs.state.nc.us/SCHS

Uninsured and Underinsured Adults in North Carolina

The United States spends more per capita on healthcare than any other industrialized nation. It is also the only industrialized nation that provides no universal healthcare for its citizens. Therefore, there must be a "safety net" of healthcare providers who cover the uninsured and underinsured. The United States spends billions of dollars treating the uninsured once their health problems become too severe to be ignored. The uninsured receive less preventive care, are diagnosed with more advanced disease, and receive less therapeutic care once diagnosed than the insured. In North Carolina, preventive services for the uninsured are most often provided by local public health departments and community and migrant health centers.

The North Carolina Behavioral Risk Factor Surveillance System (BRFSS) is a random telephone survey of persons ages 18 and older. Each year, a question is asked about whether the respondent has health insurance. In 2004, several questions were included to address the issue of underinsurance. Following are selected BRFSS data on the uninsured and underinsured, weighted to reflect the entire adult population of the state.

- 17% of North Carolina adults had no health insurance.
- Among persons ages 18-24, those with less than a high school education, and those with household income less than $25,000, approximately 30% had no health insurance.
- 65% of Hispanic adults had no health insurance—35% of English-speaking Hispanics and 75% of Spanish-speaking Hispanics.
- 41% of uninsured adults reported that there was a time in the last 12 months when they needed to see a doctor, but could not due to the cost, compared to 10% of adults with health insurance.
- 35% of uninsured diabetics reported that there were times in the past 12 months when they were unable to obtain testing supplies and diabetes medicines due to the cost, compared to 9% of diabetics with health insurance.
- 51% of uninsured adults reported that they have no personal doctor or healthcare provider, compared to 12% of adults with health insurance.
- Among the BRFSS respondents who did have health insurance, 17% reported that they had to give up some living expenses in the last year to pay healthcare costs.
- Among those with health insurance, 18% reported that they took a tax deduction for healthcare expenses on their federal tax return, 16% said that someone in their household had problems paying medical bills, and 13% said that their household had been contacted by a collection agency about owing money for medical bills.
- Among those with health insurance, 20% said that their total out-of-pocket healthcare expenses (including health insurance premiums) were more than $5,000 during the past year, including 5% who said they spent more than $10,000.

Contributed by Paul A. Buescher, PhD
State Center for Health Statistics, North Carolina Division of Public Health

Readers' Forum

New Directions in End-of-Life and Palliative Care

The following was previously published in the Raleigh News & Observer, March 27, 2005 and is reprinted here with permission.

Reaching for reassurance at the end of life

CHAPEL HILL—"What would you do?" I've been asked this question hundreds of times since I started medical school in 1983. I was asked it as a medical student, as a surgical resident, as a trauma surgeon, a critical care specialist, and as the director of an ICU in a rural North Carolina hospital. I've been asked it about a variety of issues, but most commonly I've been asked it by families who were making end-of-life decisions about their loved ones.

Should they put a feeding tube in their grandmother, now too demented to eat? Should they donate the organs of their brain-dead son? And what about their father and his massive stroke—should they disconnect him from the ventilator?

"What would you do?"

For years, this question made me nervous. It was a relic of the old days, before I came along, when doctors had all the answers, when we simply went ahead and did what we thought was right without much input from patients and their families. I didn't train in the era of paternalism. I trained in the era of patient autonomy, so when families asked, "What would you do," I thought that they were asking me what they should do, as if there were some kind of objectively right answer, separate from the wishes of the people for whom they were speaking.

For years, I sidestepped this question. I told families that I didn't know what I would do in their situation. I said you never knew what you would do until you were the one that was having to do it. In fact, however, this was often a lie. Generally, I knew what I would have done: I wouldn't have put in the feeding tube, I would have donated the organs, I would have turned off the ventilator.

But for years I didn't tell people that. I didn't want them to do what I wanted them to do. I wanted them to do what the patient would have wanted. I thought that injecting my own opinion would make them think more about me and less about the patient, that the possibility of doing something their doctor disagreed with would only make their decision more difficult.

Over time, though, I began to notice something. I wasn't the only person hearing "What would you do?" Families asked nurses too, and they asked the nursing assistants whose job it was to bathe the patients, change their sheets, empty their catheters, turn them side to side to prevent them from developing pressure sores. When I moved to rural North Carolina, the family meetings at which we discussed all this expanded to include "church family" and the patients' ministers. They faced the question too: "What would you do, Reverend?"

After a while, I began to realize that the families weren't actually asking what they should do. In fact, most of them already had an idea about what they should do. Most of them felt they should withdraw life support, because the majority of my families knew that somewhere along the line, the patient had told his brother or his wife or his daughter or his mother something about not wanting to be kept alive by tubes and machines.

And so I came to understand that the families weren't asking what they should do. Instead they were asking us all for permission to actually do it—permission to withdraw life support and allow the patient to die. They weren't asking for legal permission—they knew it was legal. But they were asking for true social sanction. They wanted to know that other families did this, that people from the church wouldn't think of them as murderers, that their neighbors wouldn't fault them when the word got out.

Families were also asking for reassurance that the patient wouldn't suffer. They needed to believe that if they elected to withdraw support, we could continue to comfort patients and alleviate their suffering as they moved toward death.

Families asked nurses and nursing assistants as often as they asked me, because they knew the nursing staff well. They had seen the nurses rub lotion on the patient's dry feet. They had seen the aide comb out the patient's matted hair. They had watched techs readjust tape and bandages and tubes and IV lines so they didn't tug and tear at the patient's fragile skin. Family members, watching this, were touched by the staff who cared the most for their family member. When they asked staff members what they would do, they chose the ones that they trusted most. They chose ones that they knew would never have done anything that would have increased the suffering of the patient.

I am dismayed that the president and Congress, particularly the physician members of Congress, have elected to intervene in the Terri Schiavo case. The physicians above all should understand the delicate, carefully wrought relations of trust that are an essential part of patient care and decision-making, especially at the end of life. The name-calling and grandstanding that have accompanied this case will only make it more difficult for families in the future to make end-of-life decisions.

Just as sadly, I think, they will cause families who have already had to make these painful decisions to question themselves and the decisions for which they so plaintively begged reassurance.

Elizabeth Dreesen, MD, is a fellow of the American College of Surgeons and a specialist in surgical care. Formerly the Medical Director of the Critical Care Unit of the Lincolnton Medical Center and in private practice, she is now on sabbatical in Chapel Hill. She can be reached at 919-967-3529.

Alzheimer's Disease and Family Caregivers

To the Editor

Your January/February 2005 issue (66:1) of the *North Carolina Medical Journal* is truly overwhelming because of: the staggering numbers of us who will have one day, by current projections, Alzheimer's Disease; the depiction of the incredible amount of sad work involved in care giving; the financial burdens families must bear; the description of the pathos/grieving associated with being around these patients; and because of the paucity of policy options available to North Carolina or the United States.

Sixteen million people afflicted with dementia by 2050 will clearly require a carefully planned/well-funded system of organized, standardized care. Such a system can only be achieved by the design/construction of a very large number of Alzheimer domiciliaries patterned after the concept of tuberculosis in sanitaria as built in the late 1800s-early 1900s. Patchwork of respite options, as in the table from Karisa Derence's commentary will not suffice and almost certainly would not prevent bankruptcies within families, churches, or governmental agencies. Of course building a multitude of structures for patient's with TB had the notions of "healthy" food/air contributing positively to the treatment of and the need for isolation to prevent contagion as a powerful force to get the policymakers to act.

For Alzheimer's dementia, the impeti are the logistics of financing such care, defining the care to be provided, and the recruitment of an adequate sized army of caregivers. Remember, some of the requirements of these 16 to 50 million folk will be: housing; feeding; protection from cold/heat; prevention of injury to self/others while permitting maximum freedom to pace, wander, or babble early on in the disease; preserving some activities of daily living for as long as possible; cleanliness; and dignity; however society chooses to define it by then. Such requirements extrapolate into the need for unique interiors/furnishings for this kind of housing. Then, there are the matters of: choking/feeding for many who can't chew or swallow or have lost the ability to use knife/fork/spoon; air handling of odors, washability of repeatedly soiled every day items (beds, bedding, chairs, walls, floors, etc.), and an endless supply of diapers, diaper changers/diaper disposals to mention just a few. Finally, in the last trimester of the illness our hosts and their staff will have to make hard decisions about how/whether to treat malnutrition, dehydration, skin breakdown, urinary tract infections with resistant organisms, pneumonia, sepsis; exacerbations of the other chronic medical conditions that were on the problem list before the onset of dementia or developed during the dementia; and the occasional intercurrent acute surgical event.

No matter how such "hotels" are financed, whether at the state or federal level, there will still be a need for volunteerism beyond any exhibited in this country to-date. As an aside, we must not limit such volunteerism by requiring bureaucratic certification in feeding, bathing, dressing, or walking with these cognitive invalids. Indeed, perhaps we will need a form of universal subscription (say between the junior and senior years of high school) to swell the ranks of caregivers.

There are, of course, many objections to this proposal, such as: how much dare we spend on a structured solution lest we siphon funds away from the promise of a cure by research or from the cost of a truly effective chronic treatment; the unfair requirement in some less populated states that visitors might have to travel for a day to visit a relative or loved one; and the logistical problem of who will and how to decide about eligibility for admission. Perhaps a happy long-term concern will be what to do with all that new construction once the disease joins the list of easily preventable or successfully treatable disorders. If we're optimistic, then we should plan on multipurpose structures and consider geography accordingly.

Be assured that despite the anticipated letters and outcry by social scientists, politicians, clergy, and ethicists to what appears to be a calloused practical solution to a challenge of staggering proportions, there will be millions of relatives clamoring to get a loved one admitted when the institution is as conceptualized in my mind and as it could/should be.

"If we build them, they shall come!"

Harold R. Silberman, MD, FACP
Professor Emeritus
Duke University Medical Center
Durham, NC

The North Carolina Institute of Medicine
Since January 2002,
Publisher of The *North Carolina Medical Journal*

In 1983 the North Carolina General Assembly chartered the North Carolina Institute of Medicine as an independent, nonprofit organization to serve as a non-political source of analysis and advice on issues of relevance to the health of North Carolina's population. The Institute is a convenor of persons and organizations with health-relevant expertise, a provider of carefully conducted studies of complex and often controversial health and healthcare issues, and a source of advice regarding available options for problem solution. The principal mode of addressing such issues is through the convening of task forces consisting of some of the state's leading professionals, policy makers and interest group representatives to undertake detailed analyses of the various dimensions of such issues and to identify a range of possible options for addressing them.

Members of the North Carolina Institute of Medicine are appointed for five-year terms by the Governor, and each task force convened by the Institute typically includes at least one-third of its membership from among the appointed members. Topics to be addressed through task force efforts are chosen following requests from the Governor, the General Assembly or agencies of state government. In some cases, topics are selected on the basis of requests from a number of stakeholder organizations across the state where this type of analytical process is considered to have potential value.

The North Carolina Institute of Medicine assumed the role of publisher of the *North Carolina Medical Journal* in January 2002 through an agreement with the North Carolina Medical Society, which founded the Journal in 1845. The Institute views the *North Carolina Medical Journal* as an extension of its mission. The Journal provides a forum for stakeholders, healthcare professionals, and policy makers and shapers to study and discuss the most salient health policy issues facing our state. Like many states, North Carolina is grappling with issues such as an increasing number of uninsured, the unmet health needs of the growing Latino population, a critical shortage of nursing personnel, the health risks of tobacco and obesity, rising prescription drugs costs, mental health system reform, the increasing societal burden of chronic illness care, the threat of bioterrorism and the necessity of assuring adequate public health preparedness—all in the midst of an economic downturn. Each of these issues presents unique challenges to healthcare providers and state policy makers. Yet, a fully implemented task force to consider each of these sets of issues is not feasible. The Journal makes it possible to present an organized and balanced overview of some of these issues, six times per year, and allows interested persons the opportunity to engage in the ongoing discussion of these issues throughout the year. The Institute hopes that our readers of the *Journal* will, in this way, become involved in the continuing debate about the most promising avenues for assuring the highest standards of health and healthcare for all North Carolinians.

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North Carolina
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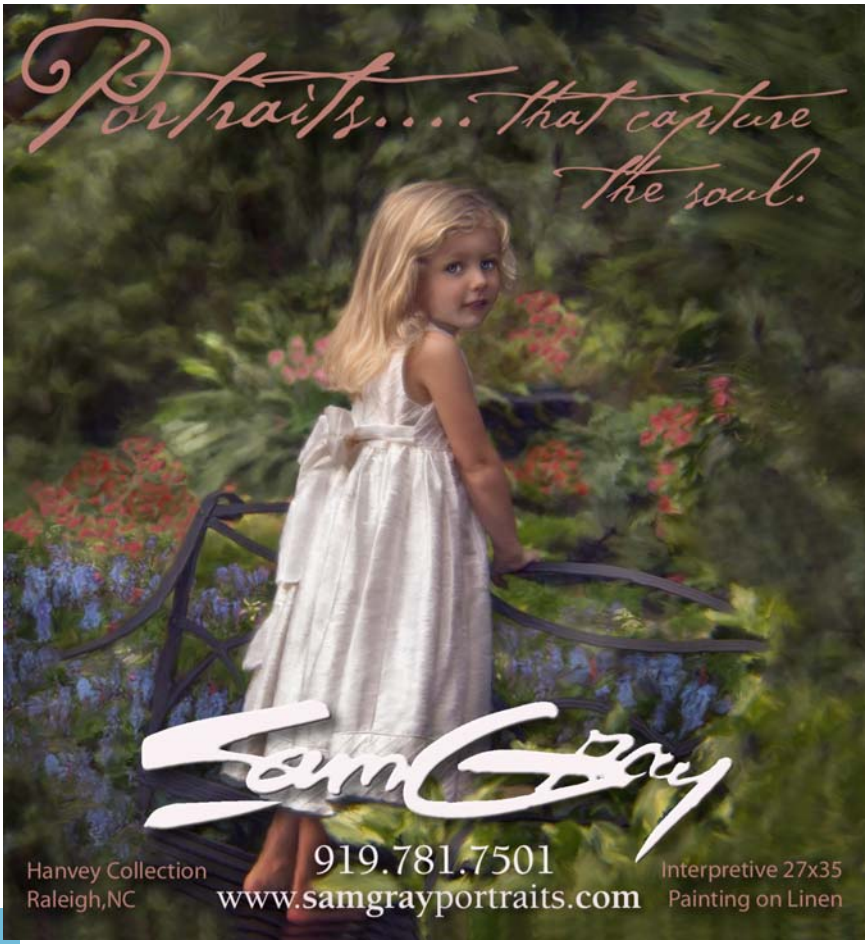
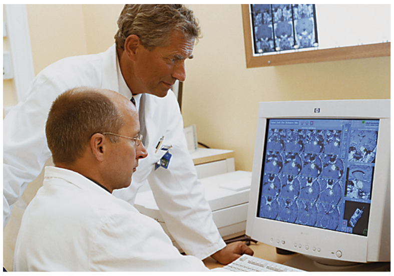


A partnership that's working for eastern North Carolina



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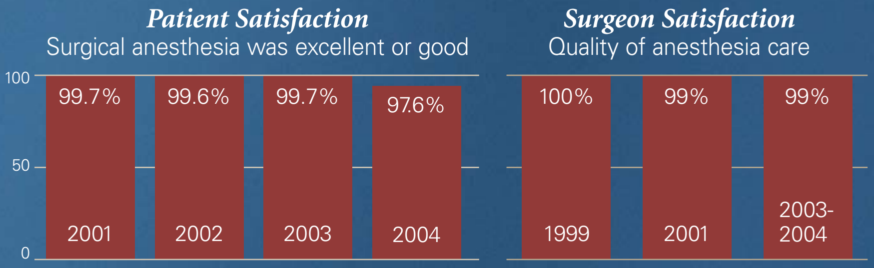

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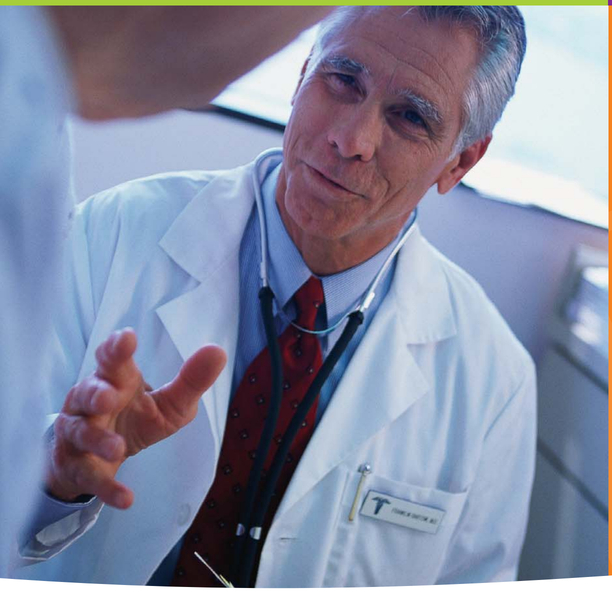

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ARTICLE

Health-related Quality of Life among North Carolina Adults with Diabetes Mellitus

Deborah Patrick Wubben, MD, MPH, and Deborah Porterfield, MD, MPH

Abstract

Background: *Previous research on health-related quality of life among people with diabetes used subgroups of diabetics who were not representative of a larger population and long questionnaires that are not practical for surveillance.*

Objective: *To identify people with diabetes in North Carolina who are at risk for a poor quality of life based on demographic and medical characteristics using surveillance data.*

Methods: *Analysis of Behavior Risk Factor Surveillance System data from North Carolina, years 1998 through 2001, to examine associations between demographic and medical characteristics among people with diabetes and four different health-related quality-of-life outcome indicators, including general health status, physically unhealthy, mentally unhealthy, and functionally limited days. The demographic and medical characteristics studied were age, sex, ethnicity, marital status, education, income, health insurance, obesity, duration of diabetes, and insulin use. These same characteristics were also tested for independent associations with functionally limited days.*

Results: *Ethnicity and gender were not associated with any of the quality-of-life measures among people with diabetes. Those younger than age 65 were more likely to have mentally unhealthy days, but age was not related to the other outcomes. A household income of less than $20,000 was related to poor general health and greater than one week each of physically unhealthy, mentally unhealthy, and functionally limited days. Subjects with a high school education or less, no health insurance, and those not married or cohabiting had at least one poor health-related quality-of-life outcome. Obesity, duration of diabetes of ten or more years, and insulin use were also associated with at least one poor quality-of-life outcome. The only characteristic that was independently related to the number of functionally limited days was income. People with diabetes of working age and with low incomes were more likely to have greater than one week of functionally limited days (aOR = 10.3; 95% CI = 4.9-21.5).*

Conclusions: *Our results suggest an association between poor quality of life and low-socioeconomic status among people with diabetes in North Carolina.*

Background

This study's objective was to determine if there are demographic and/or medical characteristics that can identify North Carolinians with diabetes who are at risk for a poor health-related quality of life. Using general quality-of-life measures, people with diabetes consistently rate their health status worse than those without diabetes.[1-8] Not only is quality of life an important health outcome as a measure of well-being, but people's subjective perceptions of health are also related to more conventional health outcomes such as mortality and healthcare use.[9-11]

As we consider interventions to improve health-related quality of life among people with diabetes, information about which subgroups have a poor quality of life may help us target our resources and interventions more effectively.

Previous research among people with diabetes has helped identify possible demographic and medical characteristics related to physical and mental quality of life. Other investigators have associated age, sex, marital status, education, income, and insurance status with health-related quality of life among people with diabetes.[8,12-19] Many researchers have failed to observe a relation between ethnicity and quality of life among people

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with diabetes.[12,14,17,20,21] However, research using *Healthy Days** surveillance data among a general population sample found that Hispanics and blacks were more likely to have a poor health-related quality of life compared to whites.[1] Other researchers have associated a number of comorbid diseases, such as obesity,[2] cardiovascular disease,[2,16,22] arthritis,[21,22] chronic lung disease,[22] and depression,[20,21,23,24] with poor quality of life among people with diabetes. Diabetes complications, duration of diabetes, and use of insulin are also related to quality of life in most studies.[7,12-17,20,21,25-30]

Nevertheless, prior studies yield conflicting results and may not be generalizable since almost all used clinic-based populations. The only population-based research on quality of life among people with diabetes in the United States was a study by Glasgow et al. using a marketing sample population.[12] Other population-based studies of people with diabetes were done in Europe, where healthcare entitlement is universal and population characteristics differ significantly from the United States.[2-4,7,8,13-15,23] In the clinic-based studies, most researchers used a select group of patients seen at diabetes clinics,[16,17,20-22,24,25,31-33] patients with specific diabetes complications,[26-29] or patients who participated in clinical trials.[30,34,35]

In addition, previous research has used quality-of-life measures that are time and labor intensive and, therefore, not suitable for tracking large population groups. Currently, the Medical Outcomes Study Short-Form General Health Survey is the most widely used generic measure of health-related quality of life in clinical research.[10] This survey consists of physical, social, and role functioning scales as well as measures of mental health, perceptions of overall health, and pain intensity. Although this instrument is extensively used and reliable, it is impractical to use for population surveillance because of its length. In addition, the scales do not provide the kind of concrete measures of health-related quality of life that policy makers need to calculate the associated economic and social costs.

Asking about quality of life in the Behavioral Risk Factor Surveillance System (BRFSS)[9] allows for the collection of continuous, comparable data on large population groups. Likewise, asking for the number of unhealthy days provides a concrete measure of poor quality of life that can be used to quantify costs, thereby allowing employers, legislators, and health and social welfare agencies to understand better the impact of diabetes mellitus on quality of life.

Researchers have used the *Healthy Days* questions from the BRFSS to compare patients with diabetes mellitus to the general population.[1] However, no study has looked for identifiable subgroups of patients with diabetes who are at risk for poor quality of life as defined by *Healthy Days*. By using a state population-based survey with the *Healthy Days* questions, policy makers can quantify the costs associated with poor health-related quality of life and perform future analyses to track changes.

Methods

Design

This cross-sectional study evaluates the associations between multiple demographic and medical characteristics with health-related quality of life among people with diabetes in North Carolina. Our protocol was assessed by the North Carolina Public Health Institutional Review Board and was determined to be exempt from review.

Sample and Setting

Our sample of people with diabetes in North Carolina was from the BRFSS, a state-based, random-digit-dialed telephone survey of civilian, non-institutionalized adults age 18 and older. Response rates in the North Carolina BRFSS, calculated as the number of completed interviews divided by the number of eligible units, ranged from 56.2% in 2001 to 61.7% in 1998. The final BRFSS data were weighted to adjust for sampling probabilities and non-response rates.[34]

We identified adults with diabetes by "yes" responses to the question, "Have you ever been told by your doctor that you have diabetes?" Females with only a history of gestational diabetes were not included in the analyses. Due to the relatively small number of adults with diabetes per year, we combined data from years 1998-2001 (n = 1,035).

Measures

Based on our literature review, we included a number of independent variables thought to be related to poor health-related quality of life. The demographic characteristics included age, sex, ethnicity, marital status, education, income, and insurance status. Ethnicity was dichotomized into white and non-Hispanic versus non-white and/or Hispanic (the majority of whom were English-speaking). The medical characteristics included obesity, duration of diabetes, and use of insulin. Due to the survey's limitations, certain medical comorbidities as well as complications of diabetes could not be included in our analyses.

We used *Healthy Days* to measure health-related quality of life. Earlier analyses of the BRFSS core *Healthy Days* questions in representative surveys of adults show these measures to be internally consistent, accurate identifiers of population groups with poor quality of life and concurrently valid when compared with a self-rated health measure for all adults.[9] For example, a Centers for Disease Control and Prevention (CDC) study using national BRFSS data adjusted for age found a "tenfold difference in *unhealthy days* between adults reporting excellent versus poor general health."[9]

Our study examined four separate outcomes: general health rating, physically unhealthy days, mentally unhealthy days, and number of days with functional limitations due to poor physical

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* To track health-related quality of life among state populations, the CDC developed a measure called *Healthy Days* for its BRFSS. Using four basic questions, this measure asks about a person's self-rated health and evaluates physical health, mental health, and functional health by assessing the number of unhealthy days in the past month.

Table 1.
Demographic, Social, and Health Characteristics of the Sample of Adults with Diabetes (Unweighted number: 1,035)

Characteristic	Unweighted number	Weighted percent
Sex		
Male	373	
Female	662	56
Ethnicity		
White, non-Hispanic	665	68
Non-White or Hispanic	358	
Age		
< 65	594	60
> 65	429	
Marital status		
Married/cohabitating	470	59
Divorced/separated/widowed/single	561	
Annual income		
< $20,000	332	
> $20,000	459	62
Education		
< high school	396	
> college	635	61
Health insurance		
Yes	930	89
No	102	
Obesity		
BMI > 30 kg/m2	544	56
BMI < 30 kg/m2	423	
Duration of Diabetes		
< 10 years	556	61
> 10 years	359	
Insulin Use		
Yes	287	
No	666	70

BMI=Body Mass Index

or mental health. The questions for each of these outcomes were (1) "Would you say that, in general, your health is excellent, very good, good, fair, or poor?" (2) "Now thinking about your physical health, which includes physical illness and injury, for how many days during the past 30 days was your physical health not good?" (3) "Now thinking about your mental health, which includes stress, depression, and problems with emotions, for how many days during the past 30 days was your mental health not good?" and (4) "During the past 30 days, for about how many days did poor physical or mental health keep you from doing your usual activities, such as self-care, work, or recreation?" We then dichotomized the last three of these outcomes based on our examination of the responses, which suggested seven days as an appropriate cutoff. We postulated that one week of unhealthy days would represent a major impact on both the respondent and, for example, the respondent's employer.

Results

Descriptive Data

Table 1 shows the characteristics of adults with diabetes in North Carolina as determined by the BRFSS samples from 1998-2001. Using the weighted data, the majority of the sample are female, white, younger than 65 years, currently married or living with a partner, have household incomes greater than $20,000 per year, completed more than a high school education, have health insurance, are obese, were diagnosed with diabetes less than ten years ago, and do not use insulin.

Our study analyzed the four different health-related quality-of-life outcomes asked by the BRFSS among adults who reported a diagnosis of diabetes (see Table 2). Overall, an equal proportion of adults in North Carolina with diabetes rated their health as excellent, very good, or good (49%) compared to those who rated their health as fair or poor (51%). The overall mean for physically unhealthy days was 9.3 per month, for mentally unhealthy days 4.5 per month, and for functionally limited days 5.7 per

Table 2.
Average Scores for Healthy Days Outcomes among North Carolina Adults with Diabetes

Measure	Percent or Mean number of days	Median number of days	Percent < 7 days
Self-reported health status:			
fair or poor	51%	N/A	N/A
excellent, very good, or good	49%	N/A	N/A
Number of days during the past 30 days that physical health was not good	9.3	1.0	66
Number of days during the past 30 days that mental health was not good	4.5	0	84
Number of days during the past 30 days that poor physical or mental health restricted activities	5.7	0	77

month. However, the unhealthy days outcomes were all greatly skewed, with the median number for each at zero or one day per month. The majority of the sample (range 66-84%) reported seven or fewer unhealthy days for each unhealthy days outcome (physically unhealthy days, mentally unhealthy days, and functionally limited days).

Associations between Demographic and Medical Characteristics with Healthy Days

Table 3 shows the differences in health-related quality of life by the independent variables of sex, ethnicity, age, marital status, income, education, insurance status, obesity, duration of diabetes, and use of insulin. In this table, the subgroups with an asterisk are significantly different (based on Pearson's chi-square at the $p < 0.01$ level). Of the demographic characteristics, socioeconomic variables were associated with the greatest differences in quality of life. Gender and ethnicity were not associated with any of the dichotomized quality-of-life outcomes. Respondents less than age 65 and not currently married or living with a partner were each associated with more than one week of mentally unhealthy days. However, people with diabetes were significantly more likely to have a poor quality of life on all of the outcomes if they had a lower-household income (all p-values < 0.001). The other two socioeconomic characteristics, education and insurance, were also strongly related to a poor quality of life. Those with less education and those with no health insurance were more likely to have a poor quality of life on three of the four outcomes.

All of the medical characteristics we included showed an

Table 3.
Relationship between *Healthy Days* Outcomes and Demographic, Social, and Health Characteristics

	Fair or poor general health			> 7 physically unhealthy days		
Characteristic	**N**	**percent**	**p-value**	**N**	**percent**	**p-value**
Sex						
Male	177	48.1		103	29.6	
Female	363	54.1	0.14	240	36.9	0.06
Ethnicity						
White, non-Hispanic	336	49.7		229	34.6	
Non-white and/or Hispanic	197	54.9	0.21	109	43.6	0.96
Age						
< 65	285	47.8		186	33.4	
> 65	251	57.2	0.02	154	34.5	0.78
Marital status						
Married/cohabitating	225	47.4		146	32.3	
Not married	314	57.4	0.01	196	35.8	0.36
Annual income						
< $20,000	241	73.4*		162	52.8*	
> $20,000	167	36.9	< 0.000	96	21.4	< 0.000
Education						
< high school	396	61.7*		256	41.2*	
> college	142	35.4	< 0.000	86	22.5	< 0 .000
Health insurance						
Yes	474	49.9		293	31.3	
No	63	63.3	0.04	49	51.2*	0.002
Obesity						
Yes	234	55.1		147	37.0	
No	274	50.0	0.20	168	31.4	0.15
Duration of Diabetes						
< 10 years	268	47.8		158	30.1	
> 10 years	211	58.1	0.02	146	40.2	0.01
Insulin Use						
Yes	184	65.1*		130	45.8*	
No	312	46.1	< 0.000	183	28.4	< 0.000

* These subgroups are significantly different (based on Pearson's chi-square at the p < 0.01 level)

association with at least one of the *Healthy Days* outcomes. Obesity was associated with more than one week of functionally limited days. A longer duration of diabetes was associated with more physically limited days. Insulin use was associated with a poor general health rating and greater than one week of physically unhealthy days, in addition to more mentally unhealthy and functionally limited days.

We found no strong independent association between most of the socioeconomic and medical characteristics and functionally limited days. The only characteristic that was independently related to the number of functionally limited days was income. Subjects with an annual household income of less than $20,000 were more likely to have greater than one week of functionally limited days ($p < 0.001$). However, due to an interaction between income and age ($p=0.002$), an income of less than $20,000 showed a stronger association with more than one week of functionally limited days among persons with diabetes who were younger than 65 (aOR=10.3; 95% CI 4.93-21.5) than among those who were 65 and older (aOR=1.9; 95% CI 0.7-5.1).

Conclusions

In this study, the majority of adults with diabetes in North Carolina rate their health-related quality of life as good and report less than a week of physically unhealthy, mentally unhealthy, and functionally limited days. However, our study also identified subgroups with poor quality of life, based on only a few demographic and medical characteristics. The greatest differences were between socioeconomic groups—those of lower socioeconomic status reported more mentally, physically, and functionally unhealthy days and had a lower general health rating. We found that, of the demographic and medical characteristics studied, an annual household income of less than $20,000 was the only one associated with poor quality of life on all of the outcome questions. People with less education and no health insurance were also strongly disposed to be physically unhealthy and likely to report more functionally limited days. Less education was related to a poor health rating and no health insurance to mentally unhealthy days, while low income was the only characteristic independently associated with greater than one week of functionally limited days, especially among those of working age (younger than 65 years of age). The finding of a significant loss of functional days among people with diabetes who have low incomes should be of importance to policy makers since this reflects the number of days people say that they are unable to work or do their usual activities. Further investigations could determine if it is the type of work (e.g., physical labor)—or poor access to healthcare that is most closely associated with a loss of functional days among low-income people with diabetes.

A strong association between low income and poor health-related quality of life is also consistent with the results of other research. Using the Healthy Days measures, a study among the general population found that people with household incomes below the federal poverty guidelines had the lowest quality of life on all outcomes measures, including being more likely to report fair or poor health, having more physically and mentally unhealthy days, and having more functionally limited days.[1] A comprehensive and representative study by Glasgow et al. of health-related quality of life among people with diabetes in the United States, showed a similar association between lower incomes and worse quality of life for each scale of physical, social, and mental health in the Medical Outcomes Study quality-of-life measure.[12] This study of a national sample of diabetic adults was similar to our North Carolina sample, in terms of age range, gender distribution, and health insurance status. However, in the Glasgow et al. sample only 47% of the subjects had more than a high school education, compared to 61% in our North Carolina sample; and the majority of the Glasgow et al. sample had higher incomes than those in our sample of North Carolinians. Nevertheless, both studies found the same associations between less education and low income with a poor health-related quality of life. In addition to these associations, Glasgow et al. found strong, independent associations between more medical comorbidities and more diabetes complications with poor physical and mental quality of life[12]—associations that our study could not assess because of survey limitations. Future surveillance using the BRFSS should include important predictor variables, such as questions regarding chronic disease diagnoses and diabetes complications, on an annual basis.

Our study is not designed to prove that any of the demographic and medical characteristics are a cause of poor health-related quality of life. Nevertheless, important associations can help identify groups based on these demographic and medical characteristics that are likely to be experiencing a poor quality of life and that need to be targeted for interventions. Some of the variation in quality of life by different demographic groups may reflect differences in interpretation of questions. Furthermore, since the BRFSS excludes households without telephones and the institutionalized, it may possibly exclude a portion of the population with a low-socioeconomic status and under-represent severely impaired adults.

Similar to other research on quality of life among people with diabetes, this study includes only those who have been diagnosed and is not designed to include the estimated 30% of people who have diabetes but are unaware of it.[38] The data collected through the BRFSS also relies on self-report, but researchers have found a high agreement between the self-report and medical report of common medical conditions, including diabetes, both in the elderly and other population groups.[39,40] In addition, the overall response rate for the BRFSS in North Carolina was only 56-60%, which could therefore introduce sampling bias; however, the sample is weighted to adjust for different response rates between demographic groups. Among this sample of people with diabetes, less than 5% refused to answer each question relating to the independent variables and outcomes studied, except for household income, which almost 25% did not report. Although those older than 65 were more likely to refuse to report their income level, the proportion of each *Healthy Days* outcome was not statistically significantly different between those who answered their income-level question and those who did not. Therefore, we can say that there was no difference in quality of life between responders and non-responders.

The North Carolina Division of Public Health is interested in quality-of-life surveillance for people with diabetes in order to track health disparities and target its resources. Prior research on health-related quality of life among people with diabetes identified likely associated demographic and medical characteristics. However, these studies, done mostly among clinic populations, yielded conflicting results, and many of them used long, detailed, research tools that are not feasible for surveillance research.

The results of our study are strengthened by the use of a random, population-based, annual state survey and the reliability and validity of the quality-of-life outcome measures. Compared to the research measures used in previous studies, *Healthy Days* is a short, policy-relevant quality-of-life measure. By using surveillance data with easy-to-administer questions regarding quality of life, public health professionals can track how well we are meeting the *Healthy People 2010* goals of increasing the quality and years of life.[41] Since the *Healthy Days* outcomes are included in each state's annual Behavior Risk Factor Surveillance System,[9] studies can also be done of subpopulations with other chronic diseases, such as asthma or arthritis, as well as studies that compare quality of life between people with different diseases and in different states. By measuring the number of days where quality of life is limited due to poor health, *Healthy Days* allows policy makers to calculate the associated economic and social cost of poor quality of life. The results of our study provide information that public health practitioners can use to target resources and interventions to those people with diabetes in North Carolina who are most at risk for a poor quality of life. **NCMedJ**

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ARTICLE

Protecting Workers from Secondhand Smoke in North Carolina

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Abstract

Background: *Exposure to job-related secondhand smoke represents a significant, but entirely preventable occupational health risk to non-smoking workers. This article examines trends in smoke-free workplace policies in North Carolina. We also examine whether workers comply with such policies.*

Methods: *Data from the Census Bureau's Current Population Survey were analyzed from 1992 through 2002. Trends for North Carolina workers are compared with workers nationally, and trends are presented by age, race, gender, and type of worker.*

Results: *North Carolina ranks 35th in the proportion of its workforce reporting a smoke-free place of employment. The proportion of workers reporting such a policy doubled between 1992 and 2002. Females were more likely to report a smoke-free work environment (72.0%, CI +/-2.6) than males (61.2%, CI +/-4.6%). Blue-collar (55.6%, CI +/-5.5) and service workers (61.2%, CI +/-8.4), especially males, were less likely to report a smoke-free worksite than white-collar workers (73.4%, CI +/-2.6). Compliance with a smoke-free policy does not appear to be an issue, only 3.2% of workers statewide reported someone had violated their company's nonsmoking policy.*

Conclusion: *While some progress has been made in North Carolina to protect workers from secondhand smoke, significant disparities exist. Smoke-free policies can make a significant difference in reducing exposure to airborne toxins and their associated diseases, and these protective public health policies have not been shown to reduce business revenues. Much has been done to assure the health and safety of workers through public health policy. However, opportunities to protect North Carolina workers from the health effects of secondhand smoke are limited by a preemptive state law.*

Key Words: *Secondhand smoke, environmental tobacco smoke, occupational status, public health policy, CPS, NCI.*

Introduction

A series of authoritative reports have conclusively demonstrated that exposure to secondhand smoke is a significant health threat to non-smokers, increasing the risk for lung cancer, coronary artery disease, asthma and other lung diseases, and Sudden Infant Death Syndrome.[1-5] New evidence indicates there are health risks for even a brief exposure to secondhand smoke for individuals with preexisting heart disease. In Helena, Montana, a comprehensive local ordinance that banned smoking in all indoor public places, including worksites, was associated with a 40% decline in hospital admissions for acute myocardial infarction during the six months the ordinance was in effect, only to rebound after the ordinance was suspended following a legal challenge.[6] The Helena study prompted the Centers for Disease Control and Prevention to review the literature and to issue a commentary on the public health risks of secondhand smoke, stating, *"All patients at risk of coronary heart disease or with known coronary artery disease should be advised to avoid all indoor environments that permit smoking."*[7]

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The United States workforce has undergone fundamental change in workplace smoking restrictions. Fifteen years ago the United States Congress banned smoking aboard all commercial airlines[8] out of concern for the health of flight attendants who were routinely required to work in the smoking section of the aircraft. At least 11 states* have now enacted comprehensive legislation mandating that most places of employment, including restaurants and/or bars, be smoke-free. These states join hundreds of local communities that have passed totally smoke-free workplace ordinances.[9]

In this important area of occupational health protection, states with historical, economic, and political ties to tobacco, like North Carolina, have traditionally lagged behind other states and the nation.[10] The purpose of this article is to examine trends in smoke-free workplace policies in North Carolina. The data presented are from the Census Bureau's Current Population Survey (CPS).** Trends in the state are compared with trends nationally and among select surrounding states. We also examine the degree to which workers in the state comply with rules that prohibit smoking at their place of employment.

Methods

The CPS is a continuous monthly survey that has been conducted by the Census Bureau for the Bureau of Labor Statistics since 1940, focusing on labor force indicators for the civilian non-institutionalized population of the United States ages 15 and older. In 1992, the National Cancer Institute (NCI) sponsored a 40-item Tobacco Use Supplement to the CPS, which included, among other items, questions about official workplace smoking policies and the nature and characteristics of those policies. The Supplement was conducted over four time periods, 1992-1993, 1995-1996, 1998-1999, 2001-2002. The monthly CPS sample consists of approximately 56,000 eligible housing units in 792 sampling areas. All strata are defined within state boundaries, and the sample is allocated among the states to produce state, Census region and division, and national labor force estimates, keeping the total sample size to a minimum. Response rates to the CPS labor force core questionnaire is about 95% and between 85-89% for the NCI Tobacco Use Supplement.

Worker Eligibility Criteria

Routine labor force questions from the CPS core were used to determine each respondent's employment status and to categorize each worker into a standard occupational group. Because the primary area of interest for this report was the extent of official workplace smoking policies for indoor working environments in North Carolina, additional questions were used to identify eligible respondents. To be included in the analysis, individuals must have been 15 years of age or older and (1) employed either full- or part-time at the time of interview, (2) employed outside the home but not self-employed, (3) not working outdoors or in a motor vehicle, (4) not traveling to different buildings or sites, and (5) not working in someone else's home. Applying these criteria produces 10,773 eligible indoor workers for further analysis.

Definition of Smoke-Free

All eligible respondents were queried, "Does your place of work have an official policy that restricts smoking in any way?" (note: about 2% of subjects responded "don't know" and were excluded from the analyses). Those who responded "yes" were also asked: "Which of these best describes your place of work's smoking policy for indoor public or common areas, such as lobbies, restrooms, and lunch rooms?" and "Which of these best describes your place of work's smoking policy for work areas?" Response choices for each were: "Not allowed in any …" "Allowed in some …" or "Allowed in all …"

Workers who reported that their employer had an official policy that restricted smoking and did not permit smoking in any public or common areas or in the work area, were considered to be working in a smoke-free environment. This definition is identical to that used in other national and state-based reports.[9-13] For compliance, only workers with smoke-free policies were included in the analysis.

Statistical Analysis

Statistical analyses were performed using Statistical Analysis Systems software, version 8.02.[14] Supplement weights, adjusted for overall Supplement non-response and Supplement self-response only, were produced using a special algorithm developed by the Bureau of Labor Statistics.[15] Sudaan was used to compute standard errors and 95% confidence intervals (or margin of error) using the replicate weights that the Census Bureau constructed using Fay's methods.[16]

Results

The percentage of the North Carolina indoor workforce covered by a smoke-free workplace policy has increased over the ten-year period 1992 through 2002 (see Table 1). Less than a third of the state's workforce was smoke-free in 1992-1993, but by 2001-2002, slightly more than two thirds were reporting this level of protection. The trend toward smoke-free worksites

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* States that have enacted comprehensive laws, the date of passage and setting affected: California (restaurants 1995, bars 1998), Maryland (workplaces and restaurants 1995), Delaware (workplaces, restaurants and bars 2002), New York (workplaces, restaurants and bars 2003), Massachusetts (workplaces, restaurants and bars 2004), Utah (restaurants 2005), Florida (restaurants 2003), Connecticut (restaurants 2003, bars 2004), Idaho (restaurants 2004), South Dakota (workplaces 2002) and Maine (restaurants and bars 2004).

** The federal government's primary data source for labor force statistics. These data cover the ten-year period 1992 through 2002.

Table 1.
Comparison of Workplace Policy Trends in North Carolina with Neighboring States and the Nation and State Rank in 2001-2002

Percent of indoor workers 15 years of age and older reporting a smoke-free workplace

State and (rank in 2001-02)	**1992-1993** % (CI)[1]	**1995-1996** % (CI)	**1998-1999** % (CI)	**2001-2002** % (CI)
North Carolina (35)	**30.8 (± 2.1)**	**54.4 (± 2.3)**	**61.0 (± 2.6)**	**67.3 (± 2.5)**
Tennessee (39)	36.0 (± 2.1)	53.0 (± 2.8)	63.0 (± 4.2)	66.1 (± 3.6)
South Carolina (43)	37.7 (± 3.2)	58.3 (± 4.5)	63.8 (± 2.6)	65.4 (±4.3)
Georgia (47)	46.7 (± 3.5)	56.7 (± 4.7)	66.1 (± 2.8)	63.3 (± 3.3)
Virginia (24)	43.7 (± 2.6)	62.2 (± 3.3)	70.6 (± 2.3)	71.2 (± 2.3)
All United States workers	**46.3 (± 0.4)**	**63.4 (± 0.4)**	**69.0 (± 0.4)**	**70.9 (± 0.4)**

CI = 95% confidence interval or margin of error

increased substantially during the initial three-year survey period, increasing 77% between 1992-1993 and 1995-1996, but just 24% over the next six years. As of 2001-2002, North Carolina ranks 35th among all the states in the proportion of its workforce reporting a smoke-free place of employment.

Smoke-free policies vary considerably by age and gender of the worker, with younger workers, particularly males ages 15-24, reporting lower rates of smoke-free policies (40.7% CI +/-12) than middle age male workers age 40-54 (62.0% CI +/-7.4) and older male workers age 55-64 (72.5% CI +/-10.7). Thus, less than 50% of male workers ages 15-24 are likely to be currently covered by a smoke-free policy, the lowest rate of any age group in the state, and this low rate of coverage has not changed in absolute terms since 1995-96. Overall, females are currently more likely to report a smoke-free work environment (72.0% CI +/-2.6) than males (61.2% CI +/-4.6). Rates are similar among blacks and whites throughout the 1992-2002 time period. The rates are slightly lower for Hispanic workers but these differences are not statistically significant.

While consistent progress has been observed in the effort to protect workers from job-related secondhand smoke in the state, some workers are less protected than others (see Table 2). Blue-collar and service workers are considerably less protected than white-collar workers. In 2001-2002, 52.4% (CI +/-5.8) of male blue-collar workers and 47.5% (CI +/-14.2) of male service workers were smoke-free, compared to 73.4% (CI +/-14.2) of all white-collar workers. This difference persisted across all four time periods. Females, regardless of occupational category, reported higher rates of smoke-free policies than males.

Table 2.
Trends in Smoke-Free Policies in North Carolina by Type of Worker

Type of worker	**1992-1993** % (CI)[1]	**1995-1996** % (CI)	**1998-1999** % (CI)	**2001-2002** % (CI)
White-collar	38.3 (+/-2.1)	63.0 (+/-2.8)	68.5 (+/-2.8)	73.4 (+/-2.6)
Blue-collar	18.3 (+/-2.8)	41.6 (+/-5.0)	48.5 (+/-5.4)	55.6 (+/-5.5)
Service	29.5 (+/-4.8)	43.1 (+/-6.2)	48.6 (+/-7.6)	61.2 (+/-8.4)

CI = 95% confidence interval or margin of error.

Note: Throughout the manuscript we refer to three major occupational groups, white-collar, blue-collar and service workers. While no official definition exists for these workers, on the CPS public use data file, the Census Bureau "recodes" some 500 individual occupations into 14 major groups. Examples of white-collar occupations include people employed as managers, accountants, clerical workers, engineers, teachers, physicians, etc., blue-collar workers include carpenters, mechanics, assembly line workers, bus and truck drivers, tailors, etc; and examples of service workers are, food service workers, health technicians, personal and protective services (firefighters, guards, police), etc.

Table 3 provides estimates for smoke-free workers in the state who reported someone had violated their company's smoke-free policy in the two weeks prior to interview by smoking in their work area. Only a small percentage of the state's workforce reported a violation of a smoke-free policy over the six-year time period examined. Furthermore, compliance with such policies appears to be improving, with noncompliance decreasing from less than 5% in 1995-1996 to just 3.2% in 2001-2002, a level of compliance equal to that seen among workers nationally. Blue-collar and service workers report slightly higher rates of noncompliance than white-collar workers, a trend also observed nationally, although none of these differences are statistically significant. Despite the rapid increase in smoke-free workplace policies among workers in the state, in 2001-2002, 96.8% of all workers with such a policy indicated their place of employment was in compliance with that policy.

Discussion

The importance of secondhand smoke as a significant health risk to workers cannot be overstated. Finnish researchers calculated mortality among workers for several major diseases

Table 3.
Compliance with Smoke-Free Workplace Policies among North Carolina Workers Compared to Workers Nationally by Type of Worker and Gender and % of Workers Reporting Someone Violated Workplace Policy in Past Two Weeks.

	1995-1996				1998-1999				2001-2002			
Type of worker/gender	NC %	NC (CI)[1]	US %	US (CI)	NC %	NC (CI)	US %	US (CI)	NC %	NC (CI)	US %	US (CI)
All workers	4.5	(+/-1.3)	5.0	(+/-0.2)	2.6	(+/-1.1)	3.9	(+/-0.2)	3.2	(+/-1.2)	3.2	(+/-0.2)
Male	4.7	(+/-2.4)	6.1	(+/-0.4)	3.2	(+/-1.7)	4.8	(+/-0.3)	3.2	(+/-2.2)	3.9	(+/-0.3)
Female	4.3	(+/-1.3)	4.1	(+/-0.2)	2.3	(+/-1.2)	3.2	(+/-0.3)	3.3	(+/-1.4)	2.7	(+/-0.2)
White-collar	5.2	(+/-1.4)	4.2	(+/-0.2)	2.5	(+/-1.3)	3.1	(+/-0.2)	2.3	(+/-1.2)	2.5	(+/-0.2)
Service	5.8	(+/-5.2)	7.2	(+/-0.9)	3.2	(+/-3.5)	6.1	(+/-0.8)	7.0	(+/-3.3)	5.3	(+/-0.7)
Blue-collar	1.9	(+/-1.5)	7.3	(+/-0.8)	3.0	(+/-2.5)	6.1	(+/-0.7)	4.4	(+/-3.7)	5.4	(+/-0.6)

CI = 95% confidence interval or margin of error.

related to secondhand smoke and estimated that such exposures were responsible for 2.8% of all lung cancer deaths, 4.5% of deaths from asthma, and 3.4% of all coronary heart disease deaths.[17] Other investigators have demonstrated that food service workers experience a lung cancer death rate that is 50 percent higher than the general population even after controlling for active smoking.[18] More recently, the Centers for Disease Control and Prevention has estimated that secondhand smoke is a cause of 38,000 premature deaths annually in the United States, the majority from cancer and heart disease,[19] although millions more are made ill and lose work from asthma, pneumonia, bronchitis and other respiratory problems.[4]

When smoking is permitted in indoor environments, the quality of the indoor air quickly becomes unhealthy, not only for workers, but patrons and visitors alike. When smoking is eliminated, improvements in air quality are almost immediate, even in heavily polluted bars and restaurants. Air quality researcher James Repace recently measured the levels of particle-bound polycyclic aromatic hydrocarbons (PPAH) and fine particle respirable suspended air pollutants (RSP) in eight hospitality venues in Delaware just prior to and several weeks after a statewide clean indoor air law was implemented.[20] PPAH levels in the eight venues prior to implementation of the statewide ban averaged five times the level found in outdoor air, while the average level of RSP was 15 times the level allowed in outdoor air under the United States National Ambient Air Quality Standards (NAAQS). Implementation of the law was associated with a 90-95% reduction in both RSP and PPAH levels. Similar results have been observed elsewhere.[21,22] Repace calculated that to bring a typical bar with average smoking prevalence into compliance with the NAAQS for fine particle air pollutants would require more than 80 air changes per hour.[22]

In North Carolina, opportunities to protect workers from the health effects of secondhand smoke through public health policy are limited by a preemptive law. In 1993, the state legislature passed a law that required state-controlled buildings to set aside 20% of their space for smoking and prohibited local regulatory boards from enacting stronger provisions unless the legislation was enacted before the state law would take effect in October of that year.[23] A total of 105 local ordinances were in effect by the October date, 89 of which had been fast tracked to beat the deadline. A legal challenge to one ordinance, contending that boards of health are not elected officials and do not have the authority to rule on this particular issue, was eventually appealed to the North Carolina District Court. The subsequent ruling invalidated almost all of the 89 newly enacted ordinances,[24] forcing most communities to suspend legal enforcement of their ordinances.

Some progress has been made within the state to protect workers from the health effects of secondhand smoke through voluntary efforts, but such efforts have created significant differences in coverage between different categories of workers. The local Health Directors Association initiated an aggressive statewide education campaign encouraging local governments and others to adopt smoke-free policies in 1993,[25] and North Carolina Project ASSIST began educational campaigns to encourage businesses to adopt voluntary policies.[26] As a result, the proportion of the state's workforce reporting a smoke-free place of employment increased from three-in-ten workers in 1992-1993 to nearly seven-in-ten workers by 2001-2002, with most of the increase occurring during the time of the state-sponsored educational campaign.

However, significant disparities exist. While more than seven-in-ten white-collar workers in the state work in smoke-free settings, blue-collar and service workers lag significantly behind, and blue-collar workers are more likely than other workers to be exposed to other hazardous agents in the workplace. The smoke-free rate among service workers in North Carolina is similar to the rate reported by service workers nationally in 2001-2002, although male service workers in the state report significantly lower rates of smoke-free policies than other workers (less than 50% are smoke-free). Many of these workers are employed in the food service sector of the economy. A recent study of 38 major occupations showed food service workers were the least protected from job-related secondhand smoke. Just 28% of waiters/waitresses and 13% of bartenders report working under a smoke-free workplace policy.[27] According to the Bureau of Labor Statistics, 275,000 North Carolinians were employed in restaurants and bars in August 2004 compared to 160,000 at the beginning of 1990, an increase of 70%, making it one of the more significant and fastest growing segments of the state's workforce.[28] More than 50% of these workers are women. Given the low level of smoke-free policy coverage among service workers in the state and nationally, it is likely that a large proportion of the quarter-million bar and restaurant workers in North Carolina are also at risk from job-related secondhand smoke.

There is evidence that suggests immediate improvements in the health status of bar and restaurant workers after implementation of a smoke-free law. Eisener et al.[29] in a study of 53 California bartenders, documented improvements in pulmonary function and respiratory symptoms one month after a statewide smoke-free law went into effect. Sargent et al. observed a 40% reduction in hospital admissions for acute myocardial infarctions in Helena, Montana following implementation of a smoke-free ordinance that included bars and restaurants.[6] The elimination of secondhand smoke from all hospitality venues, such as bars and restaurants, could have a significant impact on the health of this large and growing segment of the state's workforce.

Smoke-free policies do not hurt business revenue, even in restaurants and other hospitality venues. Recently published economic analyses in California, New York, and elsewhere have clearly demonstrated that smoke-free laws are essentially revenue neutral, that is, they neither increase nor decrease revenue when implemented.[30-35] In 2003, Scollo and colleagues[36] reviewed 97 studies on the economic impact of smoke-free policies, including studies funded by the tobacco industry. None of the 60 independently funded studies found any significant, long-term economic effects associated with smoking bans in restaurants and bars. Of the 27 studies that controlled for other economic factors and used objective measures to assess impact, none showed a negative effect. Zagat, the world's leading provider of survey-based consumer dining behavior, found that 72% of 110,000 American restaurant-goers surveyed for its 2005 poll indicated their eating-out habits would not change if smoke-free policies were put into effect in restaurants, while 26% said they would eat out more often, versus only 3% who said they would eat out less often.[37]

The findings of this study are based on a series of cross sectional surveys conducted by the US Census Bureau for its Current Population Survey (CPS) and covering the period 1992 through 2002. Information on official worksite smoking policies is based on responses obtained from employees and not worksite managers or business owners. Data derived from workers are likely more accurate than a survey consisting of responses from workplace managers or owners for several reasons. First, almost all surveys of worksites published to date,[11] exclude small businesses from their sampling frame, yet, according to the Census Bureau, small companies (<50 employees) employ 42% of all workers and make up more than 95% of all businesses in the US. Thus, worksite surveys provide an incomplete picture of worksite smoking policies. Second, worksite surveys typically rely on a response from a single individual, usually a company official, who responds for the entire company. In the COMMIT trial consisting of 11 communities of varying size in North America, Glasgow et al,[38] reported that individual workers reported rates of smoke-free policies that were lower than those reported by management-level representatives. Finally, the CPS has an excellent track record for obtaining accurate worksite and employment data. Since 1940 the CPS has been the federal government's main data source for monthly labor force statistics.

The primary purpose of this paper was to focus on differences in smoke-free policies by examining a number of demographic and employment variables as a means of highlighting which workers are currently not protected from the dangers of secondhand smoke in North Carolina. Multivariate analysis could provide some insight regarding which factors are independently associated with workplace smoking policy but such analysis is beyond the scope of this report. Variables such as age, gender, type of worker, work site and smoking status could serve as confounders of specific trends reported in this study. Previously published data demonstrate that smokers report significantly lower rates of smoke-free policies than nonsmokers.[11] Smokers tend to be younger and less educated than nonsmokers and blue-collar and service workers report significantly higher cigarette use rates than white-collar workers.

Conclusions

Second hand smoke is a well-established health hazard. While some progress has been made in North Carolina to protect workers from secondhand smoke, significant disparities exist. Smoke-free policies can make a significant difference in reducing exposure to airborne toxins and their associated diseases and these protective public health policies have not been shown to reduce business revenues. Much has been done to assure the health and safety of workers through public health policy. However, opportunities to protect North Carolina workers from the health effects of secondhand smoke are limited by a preemptive state law. **NCMedJ**

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> *"Visionary clinical leaders have demonstrated innovative ways to improve the financial margins of their practices, improve access to timely care for their patients and communities, and deliver higher quality care for patients with chronic disease."*

INTRODUCTION

Policy Forum:
Innovations in Primary Care Practice

The July/August 2002 issue of the *North Carolina Medical Journal* gave topical focus to "The Place of Primary Care." The papers in that issue of the Journal provided a general overview of the evolving role primary care plays in the ever-changing American healthcare sector. The last paper in that issue, by Warren P. Newton, MD, MPH, Professor and Chair of the Department of Family Medicine at the University of North Carolina School of Medicine, raised questions about the attractiveness of medicine as a profession (primary care practice in particular) in an age of increasing pressure from managed care and governmental insurance programs, as well as at a time of increasing commercialization of medical science and practice. These pressures and added complexities may be making these fields less attractive to future medical school applicants and graduates.

Now, three years later, we have invited Dr. Newton and several colleagues from across the state who practice (or study) primary care to describe some of the recent developments in this field that are enabling practitioners to better serve their patients' primary care needs, while at the same time assuring their own personal, professional, and financial goals. Most of these papers were generated from discussions taking place in a fall 2004 conference on "innovations in primary care practice" named in honor of the late Robert Huntley, MD.*

These papers describe six specific categories of developments in the organization and practice of primary care. Although these ideas are often described as "innovations" in this field, they are not new ideas for the most part. Rather, it is the recent attention they have received as strategies for improving quality of care and assuring the professional and financial viability of primary care practice that makes them important.

These six categories of developments include: (1) efforts to downscale the size and complexity of practice organization with an emphasis on low-overhead operations; (2) the infusion of electronic health records in primary care practice; (3) the use of disease management protocols for the major categories of chronic conditions seen in primary care practice; (4) the use of *Advanced Access* scheduling as a way of increasing the efficiency of small practice organizations; (5) community-wide, collaborative care delivery models to meet the increasing burden of caring for the uninsured and underserved; and (6) the use of electronic communication with patients via e-mail and other uses of the Internet. There is no doubt that each of these developments reflects the changing nature of available technology and the contemporary pressures on primary care practice organizations. They also signal new directions in how primary care practitioners relate to their patients as well as the potential for significant improvement in the effectiveness and quality of some aspects of care.

Other information contained in this issue of the Journal describes the supply and distribution of primary care practitioners in our state and the important trends in this regard.

As always, we hope that the discussion of these issues will elicit comments and observations from our more than 25,000 readers.

Gordon H. DeFriese, PhD
Editor-in-Chief and Publisher

Kristie Weisner Thompson, MA
Managing Editor

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* Dr. Huntley was a faculty member at the University of North Carolina at Chapel Hill in the 1950s and then served as Professor and Chair of the Department of Family Medicine at Georgetown University for 19 years before retiring to Chapel Hill.

ISSUE BRIEF

New Developments in Primary Care Practice

Warren P. Newton, MD, MPH, C. Annette DuBard, MD, and Thomas H. Wroth, MD, MPH

The great paradox of modern American medicine is the coexistence of stunning achievement in biomedical knowledge and technology, alongside our failure to meet the basic healthcare needs of a substantial proportion of the population. As the bridge between technical advances in medicine and the real lives of patients, primary care physicians find themselves stretched thin by patient demand for greater responsiveness to urgent care needs, lack of time to deliver preventive services, and the increasing complexity of chronic disease management. Communities in North Carolina and throughout the country are facing a relentless escalation of healthcare costs, with an alarming rise in the proportion of the population without health insurance. Simultaneously, the physicians serving these communities face increasing costs and decreasing reimbursement, with mounting pressure to see more patients in less time, or to limit the types of patients they care for, in order for their practices to survive.[1]

"...physicians serving these communities face increasing costs and decreasing reimbursement, with mounting pressure to see more patients and less time, or to limit the types of patients they care for, in order for their practices to survive."

The Aim of this Issue of the Journal

In response to these challenges, primary care is rapidly evolving, as healthcare providers explore new ways of responding to patient needs while also making their practices more efficient and effective. These innovations are the foci of this issue of the *North Carolina Medical Journal*.

Revisiting the history of general practice in North Carolina offers insight into contemporary primary care delivery, and allows us to examine whether the structure of primary care that has evolved in our communities is adequately equipped to address the needs of the population being served. Our own review of this history suggests that primary care practice requires substantial systematic change to remain viable and to provide adequate access to quality healthcare. Against the background of this historical overview, we will present ways in which practices across the state are rising to the challenge of improving access and quality while decreasing costs, and discuss implications for future strategic initiatives, policies, and research.

It is well-established that community-based primary care practices play a key structural role in the care of the population. Kerr White, T. Franklin Williams, and Bernard Greenberg first established this with their classic 1961 paper on "The Ecology of Medical Care," derived from their work here in North Carolina, which demonstrated that the vast majority of patient care takes place in community-based outpatient practices, substantially distinct from care received in hospitals and academic

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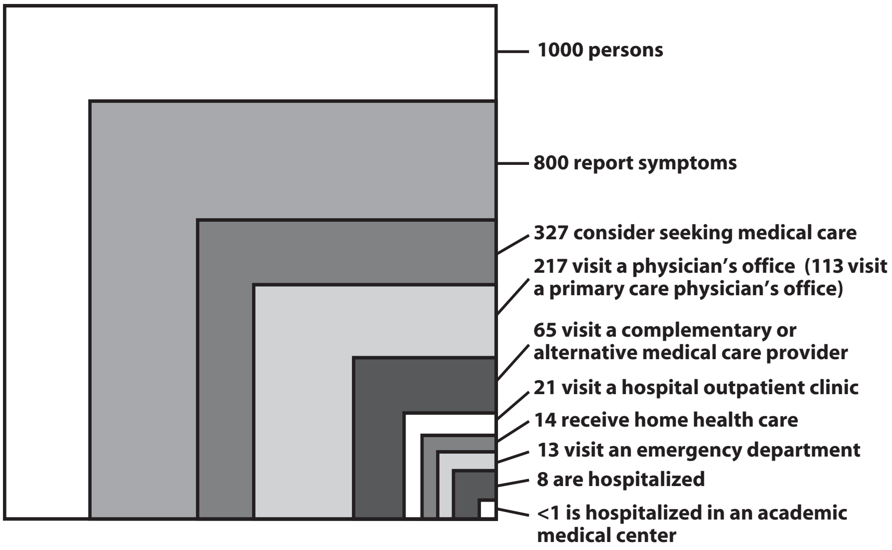
Figure 1.
Results of a Reanalysis of the Monthly Prevalence of Illness in the Community and the Roles of Various Sources of Healthcare



Each box represents a subgroup of the largest box, which comprises 1000 persons.
Data are for persons of all ages.
Source: Green, et al., 2001.[3]

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health centers.[2] Larry Green more recently updated and confirmed this conclusion (see Figure 1).[3]

It is further evident that the strength of the organization of primary care has a major impact on the health of the population. Barbara Starfield conducted a series of studies in the early 1990s to measure the integration and impact of primary care systems around the world, and found that countries where primary care is most firmly established as the foundation of the care delivery system have not only the best health outcomes for the population, but the least expensive care.[4-9] Within the United States, counties with more primary care providers have lower mortality rates.[10] Similarly, states with higher ratios of specialists to the population have both higher healthcare expenses and lower-quality care for the Medicare population, while states with more generalists have lower spending and use more effective care.[11] The structure and processes of community-based primary care practice in North Carolina, then, warrant a closer look.

Looking Back: A History of Community Practice in North Carolina

Today's community-based primary care practices have evolved from a model that dates back at least a half-century. In 1952, there were just over 2,000 general practitioners in North Carolina, with a ratio of approximately 5,000 patients per primary care physician.[12] The health status of North Carolinians was poor at the time: 40% of whites and 60% of blacks were found unfit for the military draft during the World War II—the highest percentage of draft rejections of any state in the country. Leading causes of death included cancer, stroke, and heart attack; but deaths from tuberculosis, accidents, and premature births were also much more common.[13]

In 1953, 75% of North Carolina physicians were in solo practices. Most primary care physicians offered hospital care and obstetrics, and one-in-ten performed major surgeries. Most physicians practiced out of small offices—often in a drug store or in a practice facility attached to their home—offering preventive care and treating respiratory infections, injuries, cardiovascular and infectious diseases, and other conditions. Fifty-two percent offered walk-in care, sometimes without appointment systems. Office staff was minimal, with perhaps a single nurse or assistant, and less than half of practices had their own x-ray and electrocardiogram (EKG) equipment. Record-keeping was sporadic; 11% did not keep clinical records and 47% kept notes that consisted only of the diagnosis or treatment.[14]

Community clinicians in 1953 worked 50 hours-a-week seeing patients in the office, not including on-call and after-hours work. Most had office hours on Saturdays, and a remarkable 11% also kept Sunday hours. In addition, most doctors visited patients in the hospital and made house calls. Fees were low, about $3 per visit, contributing to an annual salary of about $16,000.[14]

The population of North Carolina has nearly doubled in the last 50 years. While the number of family physicians today is only slightly more than the number of general practitioners in the 1950s, the addition of internists, pediatricians, and obstetricians to the primary care ranks has netted a ratio of about 1,200 patients to each primary care practitioner.[15] As Table 1 shows, the mortality of influenza/pneumonia, non-vehicular accidents, premature births, and tuberculosis have all decreased substantially over the past half-century. Deaths due to cancer have increased dramatically, as have deaths due to chronic lung disease, chronic diabetes, and Alzheimer's disease.[16] This explosion of chronic disease has had a large impact not only on mortality, but on the distribution of demand for patient care. While preventive care visits are still common, the proportion of visits for chronic conditions, such as cardiovascular disease, diabetes, and musculoskeletal disorders, has risen considerably (see Figure 2).[17]

The organization of primary care practice has also changed dramatically. Solo practices, which once accounted for three-quarters of all community practices, have largely been replaced by group practices. While health insurance only covered about 12% of patients in 1950, 73% of patients today are covered by Blue Cross Blue Shield, Medicare, Medicaid, or health maintenance organizations.[18] As a consequence of changing needs of

Table 1.
Leading Causes of Death in North Carolina, 1952 and 2002
The past half-century has witnessed a disappearance of premature births and tuberculosis as leading causes of death, while cancer and chronic diseases have risen in dominance.

1952	Deaths per 100,000	2002	Deaths per 100,000
Heart disease	251	Heart disease▼	222
Vascular lesions affecting CNS	98	Cancer▲	194
Malignant neoplasms	80	Cerebrovascular disease▼	63
Influenza and pneumonia	31	Chronic lower respiratory diseases▲	44
Accidents (except motor vehicle)	30	Diabetes mellitus▲	27
Motor vehicle accidents	30	All other intentional injuries▼	24
Premature births	22	Alzheimer's disease▲	24
Nephritis and nephrosis	17	Influenza and pneumonia▼	23
Tuberculosis	15	Motor vehicle injuries▼	20
Diseases of arteries	14	Nephritis and nephrosis	17

▼Conditions for which mortality rates have decreased ▲Conditions for which mortality rates have increased

Sources: Division of Epidemiology Biennial Report, NC State Board of Public Health, 1952; and NC State Center for Health Statistics, Detailed Mortality Statistics, 2002.

the population, the dramatic development of office-based technology, and the spread of insurance reimbursement, staffing ratios have gone up dramatically. The ratio of one nurse or assistant to one physician in the 1950s increased to an average ratio of 4:1 or 5:1 by 2004. The resulting increase in overhead is a key feature of the business model of modern primary care. Today's community clinicians have cut their office hours down to about 44 hours-a-week or less, with weekend hours much less extensive and house calls exceptional. The number of patients seen each week has dropped from an average of 170 to 95. Fees have risen to a mean of $71 per office visit,[19] while the median salary of all primary care physicians is now $153,231[20]—both representing dramatic increases far beyond inflation.

What are the lessons of this history? First, the primary care practices of the past were designed for short, problem-focused visits that addressed acute infectious disease, trauma, and well-person care. Consequently, practices were organized around rapid triage for relatively simple problems, with short appointments emphasizing diagnostic tests, brief treatments, and education. Most of the care delivered was provided by the doctor. In contrast, primary care practices of the future need to provide chronic disease management in addition to acute care and more comprehensive preventive services. In order to do chronic care well, Wagner and colleagues at Group Health Cooperative of Puget Sound have argued for an emphasis on patient self-management support, planned regular visits with care-giving teams, linkages to community resources, and evidence-based clinical decision support,[21-24] all of which require system redesign on an organizational level, rather than merely motivating behavioral change on the part of individual providers. It must be recognized, however, that the role of primary care is not limited to chronic disease. A key element of primary care's contribution to the health of the population and to cost control is its multiple missions—to provide preventive services and urgent care as well as chronic care.

Second, the traditional business model for primary care is failing. Public demand and the broad penetration of health insurance (compared with the 1950s) has allowed a great expansion of practice costs related to staff and clinician salaries, spurred by increases in office technology and the need to capture reimbursement from a complex array of payers. The last decade has seen great additional increases in overhead costs, in terms of staff salaries, Health Insurance Portability and Accountability Act (HIPPA) and other regulatory compliance, and now electronic health records. Reimbursement has not kept up with these expenses, and sectors of practice that were previously critical to financial viability, such as office laboratories, have been tightly restricted. Primary care practices have always had to attend closely to overhead costs; now they must rethink their overhead radically and look for innovative ways to maximize clinical efficiencies through technology and the reorganization of care systems.

Looking Around: A Broken Primary Care System

It is important to understand that many aspects of our current primary care system—and thus the bulwark of the health of the population—are broken. Despite dramatic economic growth since 1990, North Carolinians are finding it increasingly difficult to access regular and continuous primary healthcare services. According to the 2004 North Carolina Behavioral Risk Factor Surveillance System, almost one-in-five adults in North Carolina lack health insurance, with rates of insurance coverage much lower among racial and ethnic minorities. Twelve percent of insured adults and 51% of uninsured adults report not having

> *"...practices across the state are rising to the challenge of improving access and quality while decreasing costs..."*

a personal physician or other healthcare provider. Approximately 17% of all North Carolina adults report that they could not get needed medical care at some point during the last 12 months due to cost.[25,26] Concomitantly, the health status of the population is worsening. Those without health insurance or a usual source of care receive fewer preventive services[27] and experience higher mortality rates and worse clinical outcomes for chronic conditions.[28]

The national Institute of Medicine (IOM) has argued persuasively that the quality of American healthcare falls far short of expectation.[29,30] While much attention has been given to patient safety and quality of care in inpatient settings, there is ample evidence of a quality chasm in primary care as well. In a recent random sample, only slightly more than half of adults received recommended care for prevention, acute episodes, or treatment of chronic conditions.[31] Similarly, more than half of patients with diabetes,[32] hypertension,[33] high cholesterol,[34] congestive heart failure,[35] chronic atrial fibrillation,[36] asthma,[37] depression,[38] and tobacco addiction[39] are managed inadequately.[40]

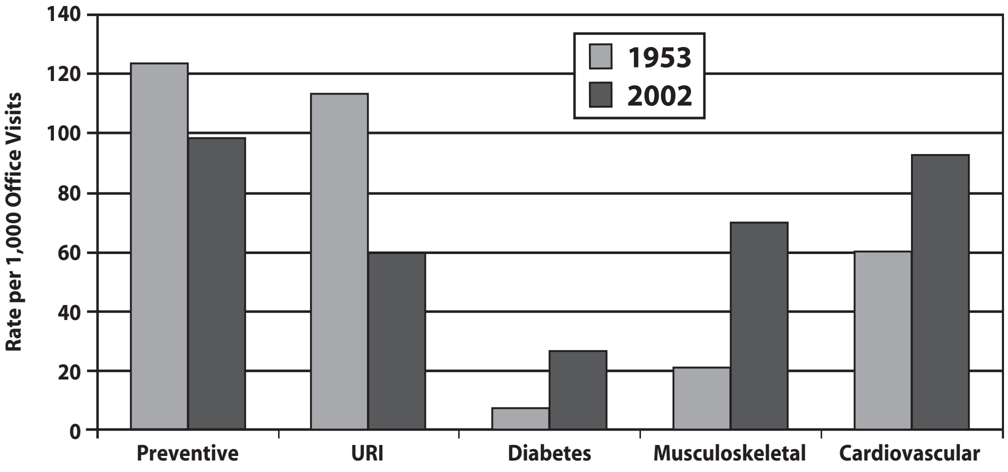
Nationwide, disparities in healthcare access and quality related to race, ethnicity, and socioeconomic status are pervasive. Disparities have been well documented in preventive, acute, and chronic care across many clinical conditions; and across many care settings, including primary care.[41] In North Carolina, African Americans have persistently higher death rates from heart disease, stroke, and diabetes than whites;[42] conditions which are largely preventable with early detection of risk factors and good chronic disease management. Disparities may be attributable, in part, to differential access to quality primary care. A recent study showed that among Medicare patients, 80% of visits for African American patients in this country represent care provided by only 22% of physicians. Physicians caring for African American patients are less likely to be board-certified, and less likely to have access to specialty consultation, diagnostic imaging, and arrangements for non-emergency hospital admissions.[43]

As concerning as these trends are, there is reason to believe that conditions will worsen. While advances in medical technology, such as organ transplantation, thrombolytic therapy, or anti-HIV pharmaceuticals receive wide publicity and acclaim, the prevalence of key health conditions, such as diabetes, hypertension, high cholesterol, obesity, and sexually transmitted disease, continues to rise.[44-46] Furthermore, the healthcare safety net itself is in danger. Often unrecognized is that primary care practices form a huge component of the safety net for the poor and uninsured. Nationally, nearly two-thirds of the uninsured report a private practice physician as their regular source of care,[47] a far greater number than traditional "safety net" institutions such as academic health centers, community health centers, and county health departments. As primary care practices fight for survival, there will be a tendency to jettison patients with a relatively less desirable source of reimbursement—the uninsured or, increasingly, Medicare and Medicaid.

Looking Ahead: Innovations in Primary Care

During the last few years, the leading professional organizations in family medicine,[48] general internal medicine,[49] and pediatrics[50,51] have performed substantial studies of what the future of their disciplines will hold. The Future of Family Medicine project[48]—a broad scope effort which involved all family medicine professional organizations, conducted extensive

Figure 2.
Office Visits[1] for Common Diagnoses in North Carolina, 1953 vs. 2002



[1] Preventive visits include well child care, well adult care, prenatal care. URI includes upper respiratory infection, pharyngitis, bronchitis, sinusitis. Musculoskeletal includes arthropathy, spinal disorders, rheumatism. Cardiovascular includes coronary heart disease, hypertension, congestive heart failure, hypercholesterolemia.

Sources: Peterson et al, An analytical study of NC general practice 1953-1954. J Med Educ, 1956; and Woodwell et al, National Ambulatory Medical Care Survey: 2002 summary, CDC.

survey research, obtained substantial participation from employers and insurers, and tested its economic model—has attempted to define a "New Model of Practice"—including the scope, philosophy, organization, and business model of practice. Table 2 contrasts the New Model of Practice to Traditional Practice.

Practices that include all features of the "New Model of Practice" do not yet exist—nor is there consensus that all elements of the new model are necessary. There have been, however, great efforts to develop and test new models of primary care that respond to the changing needs of the population and the demands placed on practices. This special issue of the *North Carolina Medical Journal* highlights examples of recent developments in the delivery of primary care from our own state that show promise in advancing access to quality care or enhancing the financial viability of community practices. Our experience is that many of the innovators are working in relative isolation, often below the radar of academic medical centers traditionally focused on improving the efficacy of care. We believe that broader networking and public discourse will help move the process along. It is the intent of this Journal issue to spur dialogue, not about whether primary care needs fundamental change, but rather how to do it in such a way that access and quality of care are improved while ensuring a viable primary care delivery system.

It is important to set some bounds on the discussion. A premise of this issue is that it is unrealistic to look to individual physicians alone to rectify the pervasive issues of access and quality in primary care. Work from the Duke University Department of Community and Family Medicine has illustrated quite clearly the impossibility of incorporating all evidence-based preventive and chronic care guidelines into our current modes of practice. To fully achieve current recommendations for an average panel of 2,500 patients, a physician would have to dedicate 7.4 hours per working day to preventive services alone (to the exclusion of acute and chronic care).[52] As emphasized in the IOM Quality Chasm Report, "Trying harder will not work. Changing care systems will."[29]

A second premise of this issue is that our focus is limited to office-based primary care in community settings. Dentistry and public health have been largely excluded from the American concept of primary care for at least two generations, and the marketplace has further "carved out" a large component of mental healthcare in recent years. The rapid spread of hospitalists, especially in urban centers, also has potential to fundamentally alter relationships between primary care practices, hospitals, and communities. Finally, entities outside of primary care, notably large businesses and insurers, are increasingly developing programs of disease management that overlap with initiatives

Table 2.
Traditional versus New Model of Practice

Traditional model	New model
Systems often disrupt the patient-physician relationship	Systems support continuous healing relationships
Care is provided to both sexes and all ages; includes all stages of the individual and family life cycles in continuous, healing relationships	Care is provided to both sexes and all ages; includes all stages of the individual and family life cycles in continuous, healing relationships
Physician is center stage	Patient is center stage
Unnecessary barriers to access by patients	Advanced Access by patients
Care is mostly reactive	Care is both responsive and prospective
Care is often fragmented	Care is integrated
Paper medical record	Electronic health record
Unpredictable package of services is offered	Commitment to providing directly and/or coordinating a defined basket of services
Individual patient oriented	Individual and community oriented
Communication with practice is synchronous (in person and by telephone)	Communication with practice is both synchronous and asynchronous (e-mail, Web portal, voicemail)
Quality and safety can be assumed	Processes are in place for ongoing measurement and improvement of quality and safety
Physician is the main source of care	Multidisciplinary team is the source of care
Individual physician-patient visits	Individual and group visits involving several patients and members of the healthcare team
Consumes knowledge	Generates new knowledge through practice-based research
Experience-based	Evidence-based
Haphazard chronic disease management	Purposeful, organized chronic disease management
Struggles financially, undercapitalized	Positive financial margin, adequately capitalized

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presented in these articles. Though rarely acknowledged, the implications of these trends are substantial, and have been only partially evaluated. We recognize, but cannot address fully, the need for further dialogue about the role of practices in these larger issues of public health promotion, prevention, and disease management.

Addressing the Business Model: Low-Overhead Models of Practice

In recent years, much attention has been given to the rapid spread of practices developed to counter the failing business model of traditional primary care. Examples include hospitalist practices, in which the hospital bears the vast majority of costs of staff and systems, exclusive nursing home practices, and niche practices limited to home care. In this issue, Dr. Brian Forrest's practice provides a representative example of the concept of dramatically reduced overhead extended to traditional primary care office practice.[53] Traditional primary care practices have among the highest overhead rates of any office-based medical practice—often exceeding 50-60%. Dr. Forrest and others have been able to demonstrate the practical consequences of reducing overhead below 25% of total costs: appointment lengths of 30 minutes, with greater time to address prevention and chronic disease, improved patient satisfaction, and the opportunity to see people who can not afford traditional care. The expense break-even point of three-to-five patients per day is remarkable, and Dr. Forrest's attention to the sources of overhead, from staffing to facility maintenance, is instructive to anyone working in a traditional environment. Given the rapid escalation of copays and deductibles, the experience of Dr. Forrest's patients is instructive: they pay less out-of-pocket for a history and physical exam, as well as standard and screening tests than would be required for copays under many insurance companies. It is important to note that Forrest and others do not yet offer data about overall cost and quality of care over time. Still, the experience of his practice and others like it raises the question of the incremental value of oversight and quality interventions that insurers provide—how much does it cost and how much is it worth?

"...it is unrealistic to look to individual physicians alone to rectify the pervasive issues of access and quality in primary care."

Low-overhead practices are not yet for everyone, however. While Forrest and others have been successful in specific settings, with favorable demographics and a charismatic clinical leader, other primary care providers attempting to adopt the model have failed. It is important to learn what factors influence success, and how such practices can be integrated into a larger local health systems, including hospitals and specialty care. Similarly, it will be important to develop the model further with more explicit attention to chronic disease management and care outcomes. The most important priority, however, is to explore the viability of the model among more disadvantaged populations. Dr. Steven Crane describes early experience with low-overhead practices targeting indigent patients, and discusses challenges to implementing this model in underserved communities.[54]

Advanced Access Scheduling: Doing Today's Work Today

Advanced Access, also known as Open Access, refers to a way of organizing a practice to allow much improved access to care. The basic premise is that patients should be able to get an appointment the same day that care is needed. This requires a fundamentally different approach to patient scheduling—practices must anticipate demand to assure that enough open slots are available for same-day requests. The transition to Advanced Access is challenging—requiring substantial changes to clinician templates, front-desk routines, and telephone protocols, with a difficult period of "working down the backlog" in which both previously scheduled appointments and same-day appointments are being seen.[55,56] Successful practices report a significant reduction of missed appointments, improved financial performance, and significant improvements in patient and physician satisfaction. In this issue of the Journal, Drs. John Anderson and Carlos Sotelango provide a case study of the transition to Advanced Access in a family medicine practice, with an illustration of the use of metrics and iterative process improvement methods key to successful implementation.[57] Dr. Greg Randolph's commentary addresses potential advantages and problems in extending the Advanced Access model to subspecialty practice.[58]

Several unanswered questions remain, however, about the feasibility of Advanced Access scheduling in varied settings. First, how robust is the business model? How long do financial benefits last? Advanced Access requires specific and potentially costly infrastructure—can the practice environment afford it? Will local insurers pay for combined services, such as preventive and acute care, provided at the same visit? Such features, while appreciated by physicians and patients alike, are not sustainable without reimbursement. A second issue is the incorporation of chronic disease care into Advanced Access. Patient-driven appointment scheduling may improve patient satisfaction, but patients with chronic disease and other conditions need regularly scheduled visits—whether or not the patient takes the initiative to ask for them. We may need to move beyond Advanced Access to a concept of organized access, to incorporate both patient-demanded access and practice-initiated visits for focused chronic disease care.

Disease Management in the Primary Care Setting

Recognition that the majority of patients with chronic illness do not receive optimal treatment has motivated the redesign of primary care around improved chronic disease management in recent years. The chronic care model, as envisioned by Edward Wagner and colleagues at Group Health Cooperative of Puget Sound, posits that higher-quality care necessitates "system reform in which informed, activated patients interact with prepared, proactive practice teams."[23] Innovation in chronic care disease management has six interrelated components: support for more effective patient self-management beyond traditional didactic patient education; clinical information systems to include patient registries and treatment planning reports, delivery system redesign with coordination of multidisciplinary caregivers; clinician decision support through evidence-based practice tools; healthcare organizational support for chronic disease improvement; and integration of community resources.[59]

Several practice models for improving chronic disease management have emerged in recent years, traditionally focusing on high-cost diseases such as diabetes, congestive heart failure, and asthma. Many disease-specific chronic care management initiatives have been shown to improve clinical outcomes and reduce healthcare costs or lower the use of more costly healthcare services.[24,60,61] Successful models can be found in a wide variety of practice settings, including integrated delivery systems (such as Group Health Cooperative of Puget Sound in Washington, or Kaiser Permanente of Northern California), private practices, and community health centers.[23] Such initiatives typically emphasize patient self-management support, and may involve case management or interdisciplinary team approaches, group visits, or planned disease-focused visits, reminder systems and physician performance feedback, and enhanced clinical decision support through technology.[23,62-65]

Despite these promising examples, chronic care model components have not been widely adapted into individual practice settings. Internal and external obstacles to practice redesign, related to time and money, present major challenges to community practices. Additionally, a focus on a single chronic disease state may be both counter-intuitive and counter-productive in community practice. Primary care patients typically arrive with multiple concerns unrelated to their chronic disease and often have multiple co-morbidities that influence care and outcomes, such as coexisting disease, poverty and underinsurance, and language difficulties or illiteracy. Unlike targeted disease management programs, family physicians are faced with the management, on average, of more than three problems per encounter (with an average of 4.6 problems per encounter for diabetic patients).[66] It is important to recognize, then, that tailoring disease management programs to patients seen by community-based primary care practitioners, rather than by specialty groups or academic centers, will require further research and refinement.[67]

For this issue of the Journal, Drs. Thomas Wroth and Joseph Boals have provided a commentary[68] that focuses on improvement of asthma in a community pediatric practice, and illustrates how a rapid cycle quality improvement approach can significantly improve both process and outcome measures of quality. Dr. Samuel Weir reviews the experience of Sandhills Pediatrics and describes the broader lessons learned for developing disease management programs in primary care.[69]

Electronic Health Records

The paper medical record utilized by the vast majority of primary care providers has many disadvantages, including illegibility, inaccessibility to multiple providers of care at the time and place needed, and segmentation with multiple volumes and multiple storage sites. Comprehensive electronic health records (EHR) include not only the clinical record (with problems, medication lists, health maintenance information, reminder systems, and population health improvement capacity), but also scheduling systems and support for billing and electronic communication with insurers, pharmacies, and patients. Electronic health records hold great promise for improving both quality of care and clinical efficiency.[70,71]

Other countries have implemented highly successful national programs to promote EHR use. In Australia, 70% of general practitioners used computers in their consulting rooms in 2000 compared to 15% in 1997. In England, 98% of general practitioners have access to EHR; nearly all use it for prescription refills, and 30% report that their practices are paperless.[72] There are signs that similar transitions are coming in the United States. The American Academy of Family Physicians (AAFP)and its Center for Health Information Technology has led a national initiative to promote electronic health records, leading to a dramatic change in the market for EHRs, including falling costs and market recognition that transition costs are substantial, national efforts to develop standards for EHRs among vendors, and the Center for Medicare and Medicaid Services' initiatives regarding the nature of the continuity record and the development of pay for performance reimbursement. The AAFP currently estimates that 12% of their members use EHRs, and that this will rise to 50% within two years. The use of EHR is beginning to grow in other specialties as well.

It is important to note that the comprehensiveness of the computerized record is key to its cost-effectiveness. Replacing dictation cost and filing clerks reduces the expense structure in the practice; facilitating Advanced Access scheduling and pay for performance premiums also add income. As a part of the Future of Family Medicine initiative, the Lewin group was commissioned to assess the economic feasibility of a "New Model Practice." In an economic analysis of the new model of practice compared with best available estimates for current private practices, the EHR accounted for the single greatest positive change to clinician compensation, and most of the income gain that made the new model practice financially vigorous.[73]

It is also important to understand that current technology is clearly transitional; there is a great divide between office-based systems (and their vendors) and large hospital-based systems of care. Substantial organizational, regulatory and technical barriers to bridging this gap exist. Early efforts to raise the technical standards of communication between office and hospital systems have been seen, but it will be impossible to fully track outcomes without easy-to-use interfaces between offices and many other sources of data relevant to patient care, such as hospitals, nursing homes, pharmacies, insurers, and health departments.

The front-end costs of implementing an electronic health record present an insurmountable barrier to many community practices, despite the promise of long-term cost savings for most practices and an eventual decrease in total United States healthcare costs with widespread application of this kind of information technology.[73] The national Institute of Medicine has argued that government and large private purchasers of healthcare should provide incentives to practices to make such changes, and such initiatives are becoming more common.[62]

Dr. Karen Smith's commentary in this issue of the Journal[74] describes the transition to an EHR in her practice, in a relatively poor, largely African-American rural community. It is clear that the transition to EHR is a major event in the lifecycle of a practice, and that the costs are large, both in direct expenses and in organizational efforts. Dr. Smith currently serves as the President of the North Carolina Academy of Family Physicians, and she has made adoption of EHRs the focus of her presidential efforts across the state. Dr. Edward Ermini provides further perspective on the development of EHRs and the creation of a national health information network.[75]

Electronic Communication with Patients and Payers

Rapid advances in information technology now allow integration of the electronic health record with common practice management activities and billing systems, including electronic communication with payers, leading to considerable reduction in practice administrative costs. In a similar way, communication with patients via e-mail offers an attractive way to enhance patient-centered care and to improve access and timeliness of interventions. E-mail communication between patients and providers allows for closer surveillance of disease status or response to therapy, tracking of the receipt of clinical preventive services or consultative care, and rapid feedback of test results.

Applying such technology, however, incurs substantial costs to the clinical practice and to the individual practitioner. The acquisition of equipment that can make it possible for physicians and office staff to interact through e-mail with patients from multiple locations, and perhaps through wireless connectivity, requires the investment of resources and the acquisition of minimal skills in the use of such technology. Perhaps more importantly, it remains unclear how physicians can be reimbursed for the time required to respond to and document patient-initiated e-mail correspondence. Similar issues arose as communication with patients via telephone expanded dramatically.

Dr. Spencer's commentary in this issue of the Journal[76] describes the initial experience of establishing a web-based interface with patients in a family medicine setting. His report makes it clear that setting up e-mail communication is much more involved than just having e-mail contact with patients. In addition to privacy issues, many different functions must be served by the interface, such as arranging appointments, referrals, and pharmacy refills, which are most effectively addressed by non-physician staff. Dr Komives's serves as the Senior Medical Director for Network Services at Blue Cross and Blue Shield of North Carolina. Her commentary discusses advances in electronic communication between clinicians and patients.[77]

New Delivery Models for Community-Based Care

Beyond practice-based clinical and administrative initiatives, an increasing number of primary care providers are participating in external initiatives to improve comprehensive disease management or reduce barriers to care in their communities. Individual practices, especially solo or small group practices and rural or community health centers, often lack sufficient internal resources to conduct major quality improvement initiatives or evaluate and adapt new innovations for their practice settings. In recent years, federal and state agencies have developed programs through which health centers or practices can participate in collaborative networks addressing specific issues in patient care. The intent is to build strategic partnerships and develop infrastructure and expertise for the incorporation of new evidence-based models of care into clinical practice. The federal Bureau of Primary Health Care collaboratives, targeting community health centers serving underserved populations, have focused on preventive services and chronic disease management (cancer screening, diabetes, depression, asthma, and cardiovascular diseases) as well as center operation (Advanced Access and patient flow redesign).[78] Similarly, the state-based North Carolina Chronic Disease Management Collaborative has assisted private and not-for-profit primary care practices in implementing comprehensive diabetes and cardiovascular disease management models, achieving substantial improvements in evidence-based clinical processes and clinical outcomes since January of 2003.[79]

An extension of these ideas has led to the development of regional networks involving all primary care clinicians, county health departments and hospitals in particular geographic regions. The stimulus for these initiatives has come from the North Carolina Medicaid Program in the North Carolina Department of Health and Human Services (NC DHHS). Over the last ten years, the Division of Medical Assistance in the NC DHHS has developed models of regionalized care focused on quality improvement and cost control. Currently, 3,000 physicians throughout North Carolina are participating in the Community Care of North Carolina (CCNC) initiative. This program provides community infrastructure and management tools to allow providers to more effectively implement evidence-based clinical care and more efficiently utilize community resources. With the involvement of all providers in a region, these networks provide an opportunity for substantial changes in the organization of care in a community, such as increased after-hours care availability in private offices and centralized immunization programs at the local health department. An external evaluation of the overall community care model by Mercer estimated approximately $120 million of savings to Medicaid as the result of community-based population management.[80] A savings of $4.6 million in savings were realized between 2000-2002 from the asthma and diabetes disease management programs alone.[81,82] CCNC programs have demonstrated clearly that it is possible to improve patient care and decrease costs.

Dr. Allen Dobson's commentary in this issue of the Journal[83] describes the development of the CCNC pilot program in Cabarrus County, underscoring the new organizational structures necessary to re-organize care in a community, the challenges to organizing care in this way and the early outcomes in that county. Dr. Charles Willson, President-Elect of the North Carolina Medical Society, describes the development of a similar CCNC model in Pitt County.[84] CCNC programs are now being implemented in every county in North Carolina.

The Outlook for Primary Care

Community-based primary care clinical practice appears to be at a crossroads in its history, resulting from the simultaneous demands of a rapidly increasing population of patients in need of timely acute, preventive, and chronic care; and the pressure to operate within ever narrower bounds of financial accountability and cost constraint. Add to these pressures the growing expectation that physicians will provide the very best, evidence-based diagnostic and therapeutic interventions, and one has a recipe for extreme frustration among primary care specialties whose financial margins are already minimal. Despite the commitment of primary care physicians to the provision of high-quality care to their patients, deficiencies in healthcare access and quality are widespread and pervasive, and the long-term viability of current practice models may be in question. Hence, innovative ideas about how to redesign certain basic aspects of primary care practice, and how to combine the resources of healthcare providers at the community level, are worthy of serious examination.

In this issue of the Journal, several contributing authors have offered illustrations of recent developments addressing the organizational aspects of primary care practice. Examples range from narrowly focused, practice-based improvements in patient flow or communication, to comprehensive, clinical quality improvement initiatives, to sweeping community-wide reorganization of care. What these innovations share is a recognition of the critical need for fundamental changes in primary care, and a commitment to better serve patients and communities.

While visionary clinical leaders are critical to the successful negotiation of current challenges to primary care, primary care practices do not shoulder the responsibility for addressing the needs of the population alone. There is a great need for health research to move beyond the traditional questions of efficacy and effectiveness to questions of population health impact, which requires attention to the development, dissemination, implementation, and maintenance of improved practice arrangements. Active planning for the diffusion of valid research findings into routine clinical practice is necessary to close the gap between the academic generation of knowledge and the clinical care of the patient.[85,86] Conversely, it has been said that "to obtain more evidence-based practice, we need more practice-based evidence."[87] Until a solid evidence base exists for clinical and administrative primary care practice innovations, progress toward the goals of improved quality and access to care for communities, and improved operational margins for practices, is likely to be slow and sporadic.

Policymakers and other stakeholders in health system costs, such as employers, hospitals, private insurers, Medicare, and Medicaid, also have an interest in improving primary care systems. Creating a favorable business case for innovation in primary care requires that the long-term cost savings that result from improved preventive and chronic care accrue to the organization paying for the improvements.[24] Any substantial innovation in healthcare practice requires an initial investment of time and money. Clinical information systems, which play a central role in streamlining administrative efficiencies and providing a framework for improved preventive services delivery, chronic disease management, and practice-based continuous quality improvement, are particularly expensive and difficult to implement for many practices. Community practices need a financial environment that helps them to implement positive change. Arguably, third-party payers and other stakeholders who invest in primary care practice innovation, by offsetting start-up costs or rewarding superior performance with increased reimbursement rates, will reap the rewards through improved health status of the population served and decreased dependence on more costly care for avoidable complications.

Conclusions

Community practices today are the direct descendants of general practice in the 1940s and 1950s, although the health and healthcare problems faced by today's communities are quite different. Primary care must change radically to survive the financial pressures of today's healthcare environment while addressing widespread systematic deficiencies in healthcare access and quality. Visionary clinical leaders have demonstrated innovative ways to improve the financial margins of their practices, improve access to timely care for their patients and communities, and deliver higher quality care for patients with chronic disease. Refinement and diffusion of such innovations will require greater investments of both research and capital, with the active and creative engagement of all of us who desire better health for our communities. **NCMedJ**

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Low-Overhead Practice Models and the Uninsured:

Harnessing the Power of Small Scale to Address Large Unmet Health Needs

Steven D. Crane, MD

Despite a decade of extraordinary economic growth and low unemployment, fewer Americans had health insurance in 2000 than at the beginning of the decade. One third of working North Carolinians (2.5 million people) between the ages of 18 and 64 are not covered by health insurance.[1] Minorities are much less likely to have insurance; 40% of Hispanics and 20% of African Americans lack insurance compared to 12% of whites. Furthermore, lower-income Americans are more likely to be uninsured; 30% of those making less than $25,000/year, compared with 8% of those making more than $75,000, lack insurance. Insurance makes a difference. Those without insurance seek needed care less often, are less likely to receive preventive services, and have poorer health outcomes.[2] About 18,000 Americans die each year of treatable diseases because they don't have healthcare coverage.[3] Most of the uninsured are employed full-time, and nearly one fourth work for firms with more than 500 employees.[4] Two thirds have household incomes of $25,000 or more [140% of the federal poverty guidline (FPG)].

Private physicians provide 75% of ambulatory care for uninsured patients.[5] Given that substantial system-wide health reform is unlikely to occur in the foreseeable future, the private sector will likely remain an important part of the healthcare safety net. Nevertheless, financial pressures are eroding charity care in the private sector. Primary care physicians widely report that managed care/Medicare changes have substantially increased overhead in outpatient practices, reducing time with patients and increasing physician dissatisfaction.[6] The number of United States-trained medical students choosing careers in primary care has steadily declined for the last five years.[7] Although there are likely multiple reasons for this decline, the perception that primary care is a less satisfying medical career is probably an important one.

Examples of Low-Overhead Solo Practices

Gordon Moore, MD, has demonstrated that a primary care practice can dramatically lower costs by "going solo," hiring no staff, and using technology and lean systems to manage a practice's "non-physician" tasks.[8] This allows longer, more meaningful interactions with patients, improved ability to address their chronic needs, while maintaining a salary in excess of $150,000 and averaging only 12 patient visits per day (or about half the daily volume for most family physicians). Innovative use of electronic medical records, communication technology, and Advanced Access scheduling[*] allows patients unparalleled access to their primary care physician, improving the quality of their care, and enhancing professional satisfaction. Closer to home, Dr. Brian Forrest has demonstrated similar results from a practice opened in April 2002. Patients are charged a flat office visit of $45. Lab tests are charged based on cost and yield the practice a small net profit of $15 per test. The practice nets $165,000 per year with a practice volume of 15 patients a day/44 weeks a year. Both of these practice examples share a

> *"Although this practice model may be very appealing, physicians will encounter many barriers to actually opening such a practice."*

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[*] Advanced Access scheduling is a patient-scheduling model that emphasizes the provider seeing patients on the same day the patient calls for an appointment.

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low-volume, low-overhead model approach, but differ in that Dr. Moore accepts insurance whereas Dr. Forrest accepts only cash payments for services and allows patients with insurance to file their own claims for reimbursement if they wish. Both practices are located in urban areas.

Dr. Kate Sloss of Bat Cave, North Carolina has established a high-volume, low-overhead model in an isolated rural community. Although she employs three staff members (to Moore's none and Forrest's one), her overhead is still substantially below Medical Group Management Association benchmarks[9] for family physicians and enables her to see 15% of her patients on a sliding-fee basis ($10 per visit) and a large proportion of Medicaid and Medicare patients, with less than 15% commercial or management care coverage. She achieves these cost reductions from a lower rent structure through a community church, very low capital costs through donated or used equipment and furniture, and administrative overhead that is paid through lab revenue from a local provider group with which she is affiliated.

Each of these practices shares some very important features. First, they are solo practices providing personalized service to patients with Advanced Access scheduling. Each reports high levels of patient satisfaction, due to Advanced Access scheduling, and higher physician satisfaction, because they are able to focus more of their attention on taking care of patients' needs and less on managing complex organizations. Second, precisely because these practices have lower overhead, they report profitability at volumes or in locations that more traditional practices would find difficult. Finally, although each practice approaches the revenue side of the practice differently, the revenue is sufficient, given the practice model, for the physician to enjoy a competitive net income.

Will Providers Who Use Low-Overhead Models Continue to Provide Quality Care to the Uninsured?

Low-overhead practice models could play an important role in addressing the failings and gaps in the present system of primary care for the uninsured. As noted above, two thirds of families without health insurance have incomes greater than $25,000 (or 140% above FPG) and potentially could pay the cost of primary care if it were more reasonably priced, as it may be through achieved low-overhead practices. Because one third of all adults aged 18 to 64 in North Carolina do not have health insurance, this population represents a great untapped market for primary care in nearly every community. Physicians choosing to establish these types of practices could choose to locate nearly anywhere and quickly become profitable.

While it may be inevitable that these types of practices will become more commonplace as experience with the model grows, it is not at all clear if the practices will serve the needs of the uninsured or if they will produce the type of quality and breadth of services called for by the Future of Family Medicine Project.[10] Practitioners in low-overhead practices may very well either continue to provide care to the insured population, enjoying higher incomes with less stressful work styles, or to those uninsured with higher incomes who can afford higher out-of-pocket fees for "concierge" type service.[11] It is also unclear if solo practitioners will perform any better with regard to quality, safety, or evidence-based practice standards than those in more traditional practice models. It is quite likely that without the peer oversight and role-modeling, which may occur in group practices, practitioners may perform less well in these areas.

Barriers to Implementing a Low-Overhead Model

Although this practice model may be very appealing, physicians will encounter many barriers to actually opening such a practice. First, as in any practice, there are a myriad of details and tasks that need to be successfully completed before opening the doors. These include developing a business plan, securing working capital, finding a location, negotiating a lease or building purchase agreement, finding equipment and supplies, setting up accounting and financial procedures, and developing an array of necessary forms, to name a few. Family physicians just graduating from residency, or even those who have previously practiced in a group where such details are managed by others, may lack the confidence, experience, or entrepreneurial spirit to start such a solo practice. Second, because this practice model is innovative, banks may be reluctant to extend business loans to someone wishing to start such a practice. Finally, although the idea of having more professional control may be appealing, many may fear becoming professionally isolated. Medical training is typically done in large organizations, and a physician's previous patient care experiences are likely always to have been part of a larger group.

For the low-overhead practice model to meet the needs of low-income patients or isolated communities, it will need to accommodate those who have public-funded insurance, such as Medicare and Medicaid. For instance, Dr. Forrest's practice accepts no insurance and charges a flat rate of $45 per visit. This may be both affordable and a bargain for moderate-income patients, but neither to low-income patients who have Medicaid or Medicare and no physician. Under present Medicare and Medicaid rules, Dr. Forrest couldn't easily begin taking such insurance and continue serving his uninsured clients at a lower rate. Sliding-fee scales for low-income patients and cash discounts may be acceptable ways to accommodate both payment systems into a low-overhead practice, but would probably require further clarification if this model is to become more widespread. Although accepting Medicare and Medicaid would add some complexity and cost to a low-overhead practice, it would nevertheless add some robustness to the model by allowing a more diverse and medically needy patient population.

Access to Specialty Care

Even if these practices could help improve access to primary care for a substantial portion of the uninsured population, lack of health insurance still limits access to more expensive specialty or inpatient services. If a person requires expensive inpatient or specialty care to return to work (or to health) they face a "Sophie's Choice" of getting the care and facing financial ruin, or not getting the care and facing worse health. Strategies that just address the affordability of primary care neglect this critical aspect of access for the uninsured. Uninsured families are likely to remain one illness or injury away from financial ruin if they require such care in order to return to health. According to bankruptcy experts, medical bills contribute to about one-in-five personal bankruptcies, and the states with the highest filing rates tend to have larger-than-average populations of uninsured.[12]

Benefits in Creating Networks

A network of semi-autonomous, low-overhead practices specifically targeting high-need areas and populations could harness the promise of this low-overhead model in addressing the larger goals and needs of the healthcare system. A network could help reduce costs by allowing for group purchase arrangements, sharing of management expertise, and providing start-up know-how and capital. These highly innovative practitioners could also share their solutions to the daily practice tasks, thereby improving efficiency for all in a shorter time frame. A network could help provide professional support and accountability by reporting clinical outcomes for chronic conditions and preventive care, raising the general standard of care in such practices. The lessons learned from this practice model in improving access, patient and physician satisfaction, lowering costs, and clinical outcomes could lead to wider system improvements, if there was an efficient mechanism for monitoring and reporting these innovations.

A network of such practices potentially in partnership with third-party payers could also spur the development of an innovative insurance product that coupled high-deductible catastrophic coverage (generally available at about half the premium of traditional preferred provider organization policies) with a prepaid primary care allowance. Such a primary care prepayment structure of even $15 per month could allow these low-overhead practices to achieve similar revenue and utilization rates, but allow primary care to be even more accessible while giving working families substantial protection from ruinous medical costs. This insurance product could help small businesses extend employer-based coverage for primary care at a much lower cost than is presently available even through group purchase arrangements.

Improving access, reducing racial and economic disparities in health status, and improving patient outcomes should be high priorities of healthcare reform. Efforts to expand health coverage or expand subsidized healthcare centers are expensive and unlikely to be undertaken in a climate of other pressing national concerns. Although other individual practitioners may adopt a similar low-cost practice model, as demonstrated by the experience of Drs. Moore and Forrest, unless the model specifically targets underserved populations in the network context, health outcome improvements will be sporadic. And unless there is a mechanism to share the risk of catastrophic illness, the uninsured will remain excluded from the benefits of expensive care that can restore health and function.

Success of this type of practice could encourage the use of this model to serve unmet needs in many communities. Demonstrating that low cost and sustainability, coupled with accountability to achieve measurable outcomes, may hasten the development of such networks elsewhere using locally available resources. **NCMedJ**

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Access Healthcare:
A Model to Provide Improved Access to High-Quality and Affordable Healthcare

Brian R. Forrest, MD

The Access Healthcare model is based on a combination of new and vintage approaches to patient care that work together to provide reasonable solutions to some of the current problems in the healthcare system. The hypothesis of the Access Healthcare model is that if practices can decrease overhead and collect payments at the time of service (i.e., eliminating practice-based insurance billing), then they can reduce fees and increase revenue.

I performed an evaluation of several existing North Carolina family medicine practices and then opened a practice based on a model that would address some of the problems that had been observed. This commentary describes the Access Healthcare model and discusses what has been learned from it.

Background

The Access Healthcare model began as an observational study of existing practice models in the piedmont and triad areas of North Carolina. This particular evaluation began five years ago (2000) and involved several different practices and more than 50 providers. Various types of offices were studied, including a large group practice, a small group practice, and a multi-specialty group practice. The main aspects observed were patient flow, time spent in the waiting room, billing, patient check-in and check-out, verification of insurance, and DNKAs (number of patients who did not keep their appointment). For 42 of the providers, the average charge was $93 per patient visit, the average collection was $39 per patient visit, and the total average overhead was $50 per patient visit. Even though this is an average, it represents an $11 loss per patient seen. Additional study over a 16-month period and review of other innovative approaches from articles in *Family Practice Management, Family Practice News, American Medical Association News*, local newspapers, and magazines, helped me conceptualize the Access Healthcare model.

For three and a half years, the Access Healthcare practice (located in Apex, North Carolina) has provided continuity care for more than 2,000 patients. Practice overhead is consistent at 25%. Charges/collections average $65 per patient. The net practice profit is $48 per patient.

The $65 average is made up of the $45 office visit added to the average lab and supply cost of about $20 per patient. This means that the supplies and labs are paying the overhad and the office visit charge is basically the net profit for each provider. This makes it possible to charge less, see fewer patients, and still net a higher reimbursement per encounter than most providers due to the reduced overhead and higher collections. Also, it only takes about three to four patients per day to break-even (and pay overhead costs) with this model.

The Access Healthcare Model Key Concepts

Patient Cost and Charges. At Access Healthcare, costs are less than half what they are in other practice settings, which results in patient charges being significantly lower. Since practice costs are lower, these savings can be passed on to the patient. Cost reductions come primarily from reduced overhead, which normally accounts for 50-60% of a "traditional" practice's costs. Patients understand and appreciate the shared cost savings and are, therefore, more likely to return and to "spread the word." Word of mouth from satisfied patients represents the largest new patient referral base for the practice.

Collections. With patients expected to pay the full balance at the time of service, collection rates are two times that of other practices.[1] The net result of collecting the payment sooner and reducing the costs associated with collecting the revenue is a collection rate of more than 99% after three and a half years.

Office Visit Length. The true joy in practicing medicine is spending time with patients and helping them with their health problems. In most practices, the high volume of patients that must be seen reduces the time a clinician can spend with each patient. The Access Healthcare model helps optimize patient

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encounters by increasing the amount of time the provider can spend with each patient. Being able to spend enough time with the doctor is the top reason that most patients give for returning to the practice. People are willing to spend money on something they value, and they value time with the doctor. This is truly a win-win situation for both the doctor and the patient.

Patient Satisfaction. If patient demand is a barometer for patient satisfaction, then patients are very satisfied with this model of care. The practice averages 15 new patients per week, even when no advertising is taking place. Anecdotal evidence also gives us reason to believe the patients are satisfied. In many informal encounters in the town where the practice is located, patients report a high level of satisfaction and persons who have never been to the practice report that they have heard very positive things about Access Healthcare.

The Access Healthcare Model: Implementation

In April 2002, I opened the Access Healthcare Practice in Apex, North Carolina. Apex is a mix of suburban and rural, well-insured and uninsured, and self-employed and under-employed. Within a two-mile radius of the Access Healthcare office are million dollar houses and the local community health center—affluent and indigent. This population mix is reflected very evenly in the practice. Roughly 30% of the patients served in this practice have no insurance at all. Fifty percent have traditional prescription and copay coverage. Another 20% are catastrophically insured with high deductibles or hospital-only coverage.

Decreasing Overhead. Decreasing overhead is crucial to making Access Healthcare viable. Staff size is usually the largest burden for practice overhead. The Access Healthcare practice has one staff person per provider rather than the normal 4.6 per provider, which is the national average.[2] Cross training and investment in each employee is crucial, and keeping turnover low is a must. Each medical office assistant is responsible for scheduling, check in/out, phones, referrals, chaperoning exams, and setting up basic tests like urinalysis and streptococci tests for the provider.

The provider has responsibilities, which are not typical in other practices, such as providing their own phlebotomy, giving injections, and returning and making patient phone calls with lab results. While these activities reduce costs, they also contribute to high patient satisfaction, as the patients are not "handed-off" to others, and they receive lab results very quickly.

Operational costs have also been reduced. Since there is no insurance to file, no billing equipment or software is necessary. Only one computer is needed for scheduling, accounting, and word processing. Due to lower patient volume, minimal inventory is required so there is no concern for wasted storage space or expired medications.

Utility costs are kept low by turning off lights that are not in areas being used and by operating the thermostat on a timer. Easy listening radio run over a wireless intercom for background music saves hundreds of dollars per year over "Muzac" type services.

The Access Healthcare practice even provides its own janitorial services. All duties are split among employees (including the physician). Many practices pay $10,000-$15,000 per year on these services. Access Healthcare employees are asked if they would rather have that amount divided and added to salaries for 15 minutes of work per day or hire someone to do it. Everyone always answers the same way.

Technology can cut costs too. A four-line phone system that uses wireless technology is utilized so the traditional key system with hard-wired lines is not needed. This saved about $7,000 in initial phone costs and has required no maintenance. This system also has an advanced digital answering system that can triage calls and page the provider, so there is no need for an operator or an answering service.

Setting Fees. After analyzing the cost and charge ratios from the practices studied, a flat office-visit fee was initially set at $40 per patient visit (now $45). Whether a patient is in the office for five minutes or 50 minutes, the basic charge is the same for visits with Current Procedural Terminology (CPT)® codes 99211-99215.* The average office visit at the Access Healthcare practice is 30 minutes. The model works because the average visit at a primary care practice is a code 99213 (a 30-minute visit with a problem-focused history and exam and a low-complexity medical decision). Over time, if the practice gets $45 for both a 90-minute physical and a 20-minute visit, this will equate to the average charge for a code 99213.

> *"The true joy in practicing medicine is spending time with patients and helping them with their health problems."*

The Access Healthcare practice charges patients an additional fee for lab tests (based on cost), but pays the lab company directly for the tests. Payment-in-full to the lab companies is certain because Access Healthcare is able to pay companies without rejecting claims due to incorrect ICD-9 codes or diagnosis/CPT mismatch. Lab companies are able to pass on some savings they

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* Clinicians use the CPT series of codes 99211-99215 to describe the five levels of intensity for evaluation and management services provided in office or other out-patient settings for established patients. For example, a 99211 could be a five-minute visit with a nurse, and a 99215 would be an extensive evaluation and physical exam of multiple medical problems that could take an hour or longer.

realize from not incurring the expenses of billing patients or insurance companies, and their payment is guaranteed. For these reasons, discounts may be as much as 50-90% off list price, which means most patients pay an average of $20-25 for lab tests that would have cost more than $100 if the lab company billed the patient or the insurance company directly.

Scheduling patients. Advanced Access scheduling is used at Access Healthcare. This is beneficial in several ways. For the practice, Advanced Access scheduling cuts lost productivity and revenue from "DNKAs." Advanced Access scheduling also increases the practice's revenue by attracting patients that might otherwise go to urgent care or to the emergency department for non-emergent care. Patients appreciate being able to see their primary care provider on a "same-day" basis when needed, especially when going to an urgent care or emergency department can be much more costly for them. This increases patient satisfaction and patient loyalty to the practice. Many patients who need brief encounters such as flu shots and blood draws appreciate seeing the physician and having minimal wait times for these services.

The scheduling template is filled by scheduling eight to ten patients a day for appointments and leaving the rest of the day for same day call-in or walk-in patients. Normally, same day call-in/walk-in patients fill DNKA patient slots. This arrangement allows each full-time provider to treat 15-16 patients each day—a lighter patient load than for providers in a traditional practice. This means a less hectic office. It makes it easier to maintain privacy, cuts the risk exposure for medical mistakes and malpractice, and allows time for adequate documentation during the workday rather than dictating at the end of the schedule.

House Calls. Access Healthcare has gone back to yesteryear by reinstating house calls. This can be done without the contractual restrictions for charges that exist in insurance agreements. It is a joyful way to practice medicine, and physicians around the country are going back to it. House calls are great for homebound patients who are unable to get other physicians to come out to their house. The Access Healthcare practice charges a $150-cash rate for house calls.

Patient Billing. The Access Healthcare model makes it easy for patients to know what their bill will be and increases the underinsureds' ability to pay at time of service. One reason for this is that all charges are clearly identified on an *a la carte* sign in the waiting room.

However, a major portion of the patients have health insurance. When the practice opened, it was anticipated that 90% of patients would be uninsured. However, as the word of mouth about Advanced Access and hour-long office visits spread, patients who could submit their own insurance and get reimbursed (preferred provider organizations, State Employees, etc.) began to fill the practice. These patients now represent the majority (about 65%) of the practice.

Many insurance co-payments for urgent care visits are $50 now—more than a code 99215 at Access Healthcare—and some plans' office-visit co-payments are $35 or $40, which is very close to the office-visit charge at Access Healthcare. For most plans, patients can simply submit their Access Healthcare encounter form/receipt, and their insurance company will reimburse them (less their respective copay for out of network providers). While most physicians say they wait months on reimbursement from insurance companies, most Access Healthcare patients report receiving reimbursement within a few weeks. In the current healthcare system, this is due to the fact that physicians have surrendered their power to insurers by signing contracts. However, patients, who are the clients of the insurer, have the real power. If claims were denied or delayed to patients who filed, those patients would likely pick another insurer or pressure their employer to do so.

> *"Most patients have a very positive reaction to this ... Insured patients value increased access and longer visits ... Uninsured patients are ... charged a fraction of what they are charged at an office that accepts insurance."*

Medicare. The Balanced Budget Act of 1997 gives physicians and Medicare patients the freedom to privately contract outside the Medicare system. If a physician opts-out of Medicare, he or she agrees to bill patients directly and forgo any payments from Medicare. Once out, the physician may not submit claims to Medicare for any Medicare patients for a two-year period. Since Access Healthcare has never taken Medicare, the practice can treat Medicare patients as long as Medicare patients sign a private contract with the physician/practice stating that no charges incurred at Access Healthcare can be billed by the practice or by the patient to Medicare.

Patient Reaction. Most patients have a very positive reaction to this practice model. Insured patients value increased access and longer visits more than the inconvenience of filing their own insurance. Uninsured patients are also very receptive to this model. They are charged a fraction of what they are charged at an office that accepts insurance. Uninsured patients at traditional practices are often paying more for healthcare than anyone else, when they should be the ones getting discount care. This occurs since practices that file insurance have to charge the uninsured the same or higher rates due to insurance contracts and increased overhead.

Outcomes: Retention of patients has been outstanding with greater than 98% of all patients keeping Access Healthcare as their primary care provider after three years. There only have been around 15 hospitalizations out of this patient population exceeding 2,000 over last three years, despite the fact that many patients have multi-system diseases and 10% are more than 65 years of age. Because of the time spent with patients, providers can practice with good continuity and within current treatment guidelines. The practice participated in a study being conducted by Wake Forest University based on chart audits, which found that, for diabetes and hypertension management, the Access Healthcare practice is in the upper echelon of practices' adherence to current recommended standards.

On several occasions, estimates of the "normal-visit cost" for an insurance-accepting practice have been done, and it has been determined that insurance companies saved approximately $25,000 per month on average and that the insured (as a group) have paid $400 to $500 per month in higher out-of-network copays. The uninsured (as a group) saved $5,000 to $10,000 per month in out-of-pocket expenses over what they might have paid at a conventional practice.

Conclusion

We have learned several lessons. From the beginning, the Access Healthcare practice should have clearly explained and marketed the fact that insured patients could file their own claims and receive reimbursement for treatment at the practice. Many patients are surprised to find out that if they send in the encounter form they get a check back in a couple of weeks. The practice would have benefited from more thorough market research (e.g., local demographics, major employers, etc.) as well.

There are potential drawbacks to this model. One potential drawback is working with insured patients who need out-of-network referrals. This can be a hassle when services require prior approval from an "in-network" primary care provider. For some patients, the co-pay may be higher for an out-of-network provider, and this is the biggest reason for patient attrition, though attrition has been very low. Having a small staff means there is less reserve if illness or turnover occurs. However, the practice is fortunate to have many well-trained volunteers who can step in when needed.

Access Healthcare has been fiscally sound from day one and has never taken out loans for any operating expense. All start-up costs were taken care of through savings accumulated for nine months prior to opening. Expansion plans are under consideration with the potential for several new Wake County locations. The providers at the Access Healthcare practice hope that other physicians will adopt innovative practice models to improve their satisfaction, bottom line, and, most of all, patient care in the coming years. **NCMedJ**

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Creating a National Health Information Network:

The Importance of Individual Provider Participation

Edward B. Ermini, MD

Paper kills when it is used to compose medical records, according to Newt Gingrich.[1] He is not alone in voicing that opinion. Powerful leaders including Hillary Rodham Clinton, Patrick J. Kennedy, William H. Frist, and President George W. Bush agree that the current paper charting system used by most medical offices is a problem that needs to be corrected. Our government is currently creating a National Health Information Network (NHIN) that will connect physicians, patients, labs, and hospitals securely and seamlessly. The NHIN will make it easier to evaluate and improve the quality of healthcare delivery systems. Patients will be able to view and supplement their medical record over the Internet and interact with components of the network. Clinicians will be able to manage disease more efficiently, resulting in fewer medical errors and mistakes. The success of this network will depend upon whether medical groups of eight or fewer providers participate, since these groups deliver the largest proportion of healthcare in the United States.

> *"The success of this network will depend upon whether medical groups of eight or fewer providers participate, since these groups deliver the largest proportion of healthcare in the United States."*

The concept of the "paperless office" has been discussed for more than 20 years, and it is an idea that has been slow to materialize. Many early adopters of electronic medical record (EMR) systems have had bad experiences. A combination of technology that was difficult to use and providers resistant to changing their ways has kept the digital office from reaching widespread use. Early EMR systems offered little in the way of compatibility with other systems, often relying on proprietary software that required frequent upgrades and revisions. It has been said that 50% of EMR installations have failed, and experts attribute those failures to a lack of planning, training, and ongoing support through the transition and afterward. Vendors were focused on sales, and physicians had unrealistic expectations about the ease of transition. The workflow changes that were needed in order for the systems to work were never implemented, leading to failure and lost revenue. Most providers now acknowledge that computerized medical records will play a role in the future, but many feel compelled to wait as long as possible to adopt them. There is reluctance to put forth the money and effort now because more powerful systems and financial incentives will likely be available in the future.

Early adopters of EMR systems often saw computers as an efficient way to generate complete office notes that would meet the documentation criteria created by government regulations. Although many offices were able to store records electronically, notes had to be printed or faxed when other providers needed information. Electronic communication between providers was hindered by proprietary software that was incompatible with programs developed by other vendors. With less than 20% of practices utilizing electronic records, it was unlikely that other offices would have the capability to accept digital data if it were made available.

Creating Data Transfer Standards

In order to achieve interconnectivity between physician offices, our government realized that data transfer standards were necessary. In other areas of commerce such as transportation, telecommunications, and banking, the government has set the national standards in order to let developers know how to design their products. The goal was to make medical records available to providers through processes similar to those used by

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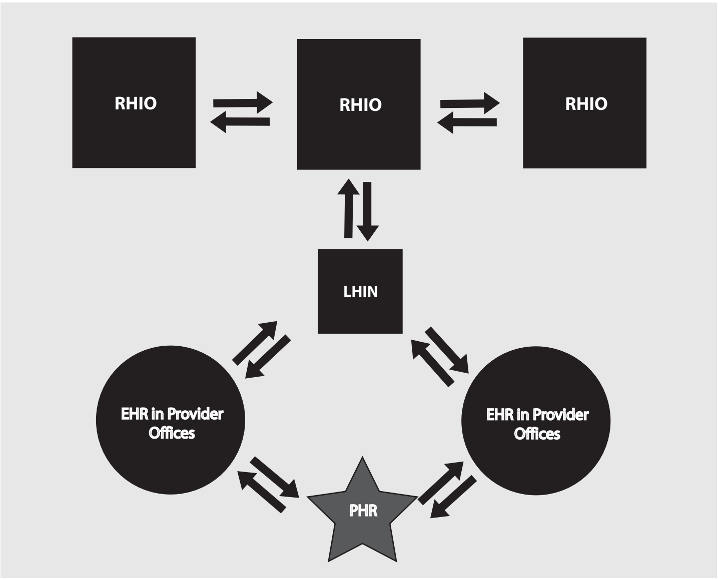
banks to share account information for automatic teller machines.

Organizations like Health Level 7® (HL7) have been working for years on data transfer standards. Most vendors distributing sophisticated software packages use versions of these standards already. In 2004, Secretary of Health and Human Services Tommy Thompson announced the creation of the Office of the National Coordinator for Health Information Technology (ONCHIT), and named David J. Brailer, MD, PhD, to the position. The coordinator is responsible for promoting widespread use of the NHIN by 2010. One of Dr. Brailer's first tasks was to create the Commission for the Certification of Electronic Medical Record Systems. This summer, the first vendors will receive certification. Certification means that the system will be able to exchange data at a minimal level between other certified systems. It opens the way for a National Health Information Network.

The basic components of the Health Information Network will be the electronic health record (EHR) and the personal health record (PHR). The EHR will be created in provider offices or hospitals and will generate and store clinical encounter information. For the first time in history, patients will participate in the creation of their own medical records through the PHR. Elements of the PHR will be imported into the EHR during a clinical visit. The complete EHR will be portable and available through the National Health Information Network with necessary safeguards to protect patient privacy.

The NHIN will be composed of Local Health Information Networks (LHIN) and Regional Health Information Networks (RHIO) linked via the Internet (see Figure 1). Health information will not be stored in one massive central data storage area. Instead, a partnership between patients, hospitals, and providers will allow the National Health Information Network to exist. RHIOs are now emerging in several parts of the country as a way of promoting the development of LHINs. For example, a North Carolina RHIO is being proposed by the North Carolina Healthcare Information and Communications Alliance (NCHICA) and will likely stimulate health infrastructure development in our state.

Figure 1.
National Health Information Network



The Advantages of a National Health Information Network

There are tremendous advantages for clinicians if a National Health Information Network is created. By using a certified EHR system, a healthcare provider should be able to obtain current medication lists, drug allergy information, demographics, labs, and x-rays instantly through the Internet. These data elements can then be automatically incorporated into an accurate medical record. After the office visit, prescriptions can be checked against formularies and then sent directly to pharmacies. Referring physicians will be able to check the progress of a patient's visit to a specialist without having to wait for the notes to be delivered. Records will be available instantaneously, and the faxing and copying that goes on now in most offices will become a thing of the past. The number of clean insurance claims should go up, and rejections by payers will become less common. When one considers the amount of time the average office spends tracking down labs and x-rays, checking insurance and demographic information, and creating a chart for a new patient, the advantages become apparent. Further financial benefits will come from reduced chart storage costs, payroll and transcription savings, and easier compliance with government regulations. Billing and scheduling components are also available in most commercial systems. Quality outcome measures will also be easier to evaluate with a computerized database. EHR systems will also help prevent medical errors by providing decision support capabilities that check for errors and remind clinicians to perform certain tasks. Links to libraries, disease registries, and "best practice" recommendations also will be available.

Conversion Challenges Faced by Clinicians

The backbone of the NHIN will be the private physicians in small medical groups. The migration from paper to electronic records for this group requires unique financial and technical challenges. Without access to large information technology (IT) budgets and network technical support, any system they adopt must be inexpensive, secure, and reliable. The conversion from paper to electronic medical records will take more than the purchase of hardware and software to be successful. Since most clinicians were trained at a time where computers were not an essential part of medical documentation, the advantages of office automation may not be recognized and appropriately exploited. Education, technical assistance, and a change in the way clinicians organize their workflow will be important components of any successful effort to create a useful National Health Information Network.

It is unlikely that significant health information technology adoption will occur in small medical groups without some type of financial incentive. Current proposals to stimulate IT adoption include payments of three to six dollars per patient visit[2] and lower co-pays for patients visiting offices with electronic records systems. Less attractive incentives may come as reduced fees for those practices without computerized records. Market forces generated from patients, insurances companies, and industry are also expected to encourage IT adoption. One reason for these market forces is the amount of money the NHIN is expected to trim from the healthcare budget of the United States. It is estimated that a functioning network could save insurers $112 billion per year in the ambulatory care setting alone.[3]

> *"It is estimated that a functioning network could save insurers $112 billion per year in the ambulatory care setting alone."*

There are several ways of providing inexpensive systems to small clinician groups. The Application Service Provider (ASP) model allows clinicians to use a computer in their office to link to a large server hosted at a secure, remote location via the Internet. The ASP maintains the server, updates the programs, and maintains IT support in exchange for a low fee from the clinician. Groups needing more control than an ASP allows may opt for purchasing their own server and programs. This approach carries the responsibility and expense of providing upgrades, support, and security. Small groups usually lack the financial and technical resources to properly maintain this type of network. Larger groups of physicians or even clinician co-operative groups can band together to purchase "enterprise" versions of software that allow the organization to act as its own ASP. Legal counsel is recommended for these ventures since federal laws could be inadvertently violated if the network were used as a vehicle for creating referrals, price-fixing, or gaining financial advantage.

Options for Electronic Health Record Systems

Not all existing EHR systems are expensive. One of the best EHR systems, VistA, is available for a minimal charge from the government. With millions of taxpayer dollars, the VistA system was developed for the Veterans Administration (VA). In 2004, Secretary Thompson announced that it would be made available to the public.[4] Current versions of VistA are written in a language called MUMPS, which is not widely used by programming specialists. The VA is upgrading the VistA system in stages. Groups like OpenVistA™ have tried to convert VistA to a LINUX-based product in order to allow easier implementation by the medical community. The government is also creating a version of the software called VistA-Office EHR, which will soon be available for private use. All of these are expected to be compatible with the NHIN. Also worth mentioning is *open*EHR®, an international project under development by a team of volunteer programmers. If successful, it will provide a sophisticated software system accessible to any healthcare provider on earth.

Of course, the big question about all of these free systems is the level of support available. Sources for training and maintenance will have to be provided before any of these will attain widespread acceptance by small medical practices.

Patient Safety and Healthcare Quality

The report "*To Err is Human*"[5] pointed out that there were frequent errors in hospitals causing adverse events. It also illustrated the need to have a reliable source of data for assessing performance in the medical community. Although the numbers so widely quoted from this report were obtained by extrapolating a relatively small number of actual hospital cases, it has produced many good ideas for quality improvement. The American Hospital Association and the American Medical Association have embraced the *100,000 Lives Campaign*[6] recently launched by the Institute for Health Improvement. In North Carolina, the Medical Review of North Carolina, Area Health Education Centers, North Carolina Medical Society, North Carolina Medical Board, North Carolina Institute of Medicine, and North Carolina Healthcare Information and Communications Alliance, Inc., as well as various specialty organizations are all instituting programs to improve quality through health information technology. Clearly, electronic health record systems figure to play prominently in future solutions for improving healthcare quality.

The development of the NHIN may be the most important breakthrough to affect the medical profession in decades, and it may occur with little physician input. Ironically, it is the reluctance of physicians to adopt information technology systems that is slowing the creation of the NHIN. At some point in the future, payers and patients will demand that physicians utilize the NHIN. There will be a "tipping point," where providers must link up to the network in order to stay competitive in their fields. When that occurs, the NHIN will become essential in the practice of medicine. **NCMedJ**

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6 Institute for Health Improvement, 100,000 Lives Campaign. Available at: http://www.ihi.org/IHI/Programs/Campaign/Campaign.htm. Accessed June 6, 2005.

Additional Resources

North Carolina Healthcare Information and Communications Alliance, Inc.
http://www.nchica.org/

American Health Information Management Association
http://www.ahima.org/

American Medical Society
http://www.ama-assn.org/

North Carolina Medical Society
http://www.ncmedsoc.org/

American Academy of Family Physicians
http://www.aafp.org/

ModernPhysician.com
http://modernphysician.com/

Office of the National Coordinator for Health Information Technology
http://www.hhs.gov/healthit/

Connecting for HealthSM
http://www.connectingforhealth.org/

Healthcare Information Management Systems Society
http://www.himss.org

Health Level 7®
http://www.hl7.org/

***open*EHR®**
http://www.openehr.org

OpenVistA™
http://www.pacifichui.org/openvista/

Transformation of a Dinosaur:

Revising Healthcare Documentation

Karen L. Smith, MD

Healthcare in America is entering a new phase. Electronic health records (EHRs) will eventually replace the paper records we have used for years. Healthcare consumers are demanding cost-effective services and high-level quality. To meet these demands and survive in this high-cost industry, we must find ways to make healthcare delivery more efficient and cost effective. Physician organizations recognize that this change must occur in every entity which provides medical services. Physician offices, outpatient facilities, and hospitals should have the capability to communicate in an efficient manner. Using ERs would facilitate more effective communication. Modernizing the health records is also a way to improve patient safety and healthcare quality. With electronic health records, the complete patient record is reduced to computerized format. This complex information would be maintained in a secure database, yet be readily available at the time of need. The following account provides an example of how an electronic health record could make it easier for healthcare providers to provide time-sensitive healthcare to patients.

> *"With electronic health records, the complete patient record is reduced to computerized format."*

How an Electronic Health Record Could Save a Life

Mr. Joe is a 59-year-old man who is employed as a small engine repairman at a local plant. He and his wife were eagerly awaiting the news of their first grandson from their daughter in Iowa. His daughter and son-in-law began their law careers five years ago and had attempted to conceive for at least three years. The news finally came, so the grandparents took the first flight out. Mrs. Joe noted that her husband was having difficulty keeping pace as they walked steadily toward the gate. Once on the plane, he slept the entire six hours. They were greeted by their son-in-law, who whisked them to the hospital to see the baby. Just as they exited the nursery, Mr. Joe collapsed. He was rushed to the emergency room and eventually admitted to the coronary care unit. His family learned that his heart was enlarged, but he did not have a heart attack. In all the excitement, Mrs. Joe suddenly remembered that her husband had a rare condition, which his mother also had. She could not remember the name, but knew his mother was on prolonged steroid therapy, until she entered remission. Mrs. Joe decided she would call her family physician to obtain this important information. Since it was Saturday, she was concerned she may not be able to reach her doctor, especially at 2:00 am. Even if Mr. Joe's physician answered the call, he may have to provide answers to her questions based on memory (unless he had an electronic health record).

From memory alone, Mr. Joe's physician will not be able to disclose his latest lab results, vital signs, body weight, last electrocardiogram (EKG) reading, last chest x-ray results, or even the last date he was seen. The physician may or may not remember the historical information about Mr. Joe's mother. The physician then must decide if he should awaken his spouse, get dressed, and go into his solo practice to retrieve Mr. Joe's records. This is a frustrating dilemma for physicians. How many times has his own individual and family life been interrupted due to this ethical dilemma? He makes the same choice he has made many times in the past—to retrieve this information now in order to prevent a delay in therapy. Upon arrival to his office, he must locate the paper chart, which is not in its correct place. He searches the front office, the billing staff, and, finally, his own desk. The chart is found on his desk with a message from Mrs. Joe regarding the need for a prescription refill prior to travel. He opens the chart only to discover the last clinical note has not been filed since these reports must come in from the transcriptionist. The physician now searches his pocket for the number given to him by the telephone answering service. It is 4:00 am before he can call the Iowa hospital. When he calls, the physician learns that Mr. Joe had an abrupt change in his condition 15 minutes ago.

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This scenario may have proceeded differently if the physician's records were readily accessible. Electronic health records would allow the physician to review each patient's chart without leaving the home. The physician could turn on the computer wait five minutes for the system to warm up, make the call to Iowa, and answer questions with confidence. He could share the EKG, labs, and chest x-ray results with the Iowa physicians. These results could even be faxed to Iowa for review and comparison. Mr. Joe's family physician could also confirm the date and time all prescription refills were sent to the pharmacy, and he could confirm Mrs. Joe's report by acknowledging that her husband has a condition called sarcoidosis with cardiac manifestations. According to the chart, Mr. Joe responded to a three-month course of prednisone three years ago with no further exacerbations since that time. Mr. Joe's prior episode responded rapidly once a bolus dosage and subsequent dosages were given to him. He did well and was discharged to his home five days later. The Iowa physicians would appreciate this information, and Mr. Joe's physician could be back asleep by 2:30 am.

Since the advent of electronic health records entered the healthcare scene, the choice to implement or defer use remains with the individual physician. The average Joe really can not persuade his or her doctor to adopt electronic health records. The average Joe actually represents the doctor, his family, the patient, and all others who play a role in his or her daily well-being. Let's face it, if we find ourselves in medical crisis, one of the first individuals called will be our family physician to provide the trusted information. Due to the state of healthcare in North Carolina, family physicians are responsible for many lives, and providing quality healthcare is paramount in that responsibility. This responsibility has been accepted by the profession as part of the discipline's transition, noted in the Future of Family Medicine,[1] which states, "Family physicians are committed to fostering health and integrating healthcare for the whole person by humanizing medicine and providing science-based, high-quality care. To remain true to this statement of identity, while continuing to meet the needs of patients and society in a changing healthcare environment, family medicine must promote innovation in the delivery of clinical services and in the education of clinicians." Chief among the multifaceted responsibility of providing patient-centered care, will be ensuring that every citizen has a medical home and that physicians use tools such as electronic health records.

Electronic Health Records Have Advantages for Patients and Healthcare Providers

The benefits of electronic records are noted beyond the standard access to clinical information. The record is documentation of every encounter the patient has with the physician's office. This includes a request for records from the patient's insurer or consulting physician. The individual's billing and financial information can be accessed in the same format in order to verify existence of healthcare coverage. The record is also used to track preventive health information (i.e., need for mammogram, pap smears, prostate or colon screening). Documentation of this nature helps reduce potential duplication of services and unnecessary testing, which, in turn, may help to reduce the healthcare financial costs that are now spiraling out of control.

A physician's professional and family life can be enhanced with organized and efficient documentation. Electronic health records would allow the physician to reduce after-hours time spent completing and reviewing records. This time is often taken away from personal family time, which can disrupt spousal and family relations. The doctor may even be neglecting his/her own personal health needs due to lack of time in the business day. Physicians who utilize time-management strategies with strict requirements for patient care schedules and controlled access after hours are sometimes criticized. The technique is effective for separating personal and professional life, but fails to solve the problem of limited time. Inefficiencies of the traditional medical practice have stripped valuable hours from the daily schedule. Electronic health records are a way to recover badly needed time for the physician and his/her staff.

What's the Hold Up?

This is a no brainer. So what is the delay? Implementation of electronic records requires commitment by the individual doctor, practice, or hospital group. The physician must bear this expensive financial endeavor. In addition, time is required to teach the physician and staff how to use their selected system. The practice must dedicate time and money in order to gain time in the long run. Medical practices that pursue this challenge would benefit from incentive payments to assist with the financial aspect. Insurers (both patient care and medical malpractice carriers) should recognize practices that utilize electronic health records with increased payments and decreased premiums, respectively.

An electronic health record is merely a component of a larger plan to transform healthcare to a discipline that can respond to the needs of the public. Every person should have access to high-quality, equitable care. Every person should be able to identify their own physician and be assured that the physician has adequate resources to care for their needs. The implementation of electronic health records is beyond the individual doctor. It will require the support of the entire community. **NCMedJ**

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Application of Quality-Improvement Methods in a Community Practice:

The Sandhills Pediatrics Asthma Initiative

Thomas H. Wroth, MD, MPH, and Joseph C. Boals IV, MD

Asthma is the third leading cause of preventable hospitalization in North Carolina and frequently leads to school absence, parental work absenteeism, and childhood disability.[1] Although there is evidence that appropriate use of controller medicines and self management education improves outcomes in children with asthma, a recent national study demonstrated that most individuals with asthma do not receive recommended care.[2] While disease management programs have been developed to improve care for those with chronic diseases, such as asthma, their interventions often fail to be integrated into care provided in primary care practices. Community practices are ideally situated to lead disease management efforts, but face barriers such as lack of time, poor reimbursement, lack of available staff, and inadequate information technology.[3] Although barriers do exist, effective methodologies have been used to improve care in busy practices, such as measuring performance and providing feedback, and using Plan-Do-Study-Act (PDSA)[4] cycles to test improvement strategies. *Plan* includes initial problem identification, probable causes of the problem, potential solutions and data needed to evaluate them, and improvement goals. *Do* involves implementing a solution and collecting the data needed to evaluate the impact of the solution. *Study* requires further data analysis to develop conclusions—what happened when we made that change? *Action* involves either further study or action that comes out of the data analysis. In this commentary, we describe one pediatric practice's experience using quality improvement methods to improve asthma care.

The Practice

Sandhills Pediatrics is a rural, private practice in Southern Pines, North Carolina with approximately 37,000 patient visits per year. The practice is staffed by six pediatricians (five full-time and one part-time) and two pediatric nurse practitioners. The payer mix includes 50% Medicaid, and the practice is enrolled in AccessCare, one of North Carolina's Medicaid managed care networks. AccessCare provides case management services to Medicaid recipients and also supports practice-based quality improvement for asthma. At the start of the project in 1998, the practice estimated that they cared for approximately 1,400 children with asthma. That year, 19 of these children were hospitalized, and 216 were seen in the emergency department with the primary diagnosis for asthma. The aim of the project was to improve outcomes in asthma care, including reducing emergency department visits and hospitalizations due to asthma.

Organizing and Collecting Baseline Data

A practice team was initially formed consisting of all providers and several nurses. The practice team adopted the 1997 clinical practice guidelines from the National Heart,

> *"While disease management programs have been developed to improve care for those with chronic diseases, such as asthma, their interventions often fail to be integrated into care provided in primary care practices."*

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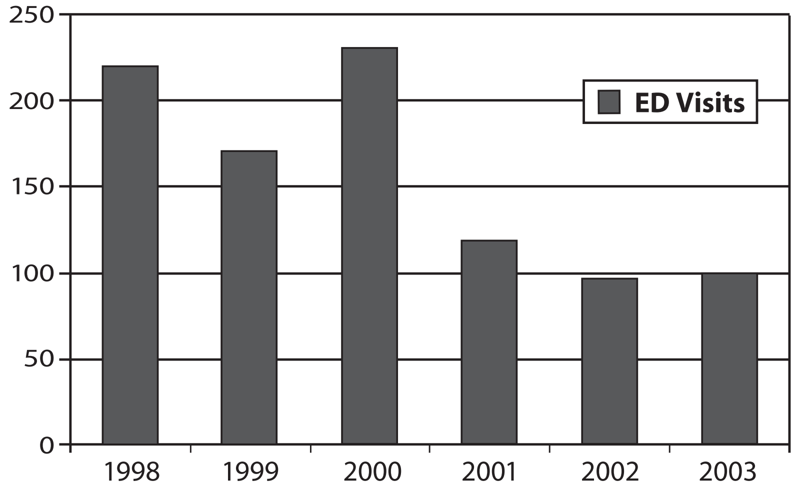
Figure 1.
Emergency Department Visits, 1998-2003



Lung, and Blood Institute's (NHLBI) Asthma Education and Prevention Program (NAEPP)[5] to improve care. A case manager from the Medicaid managed care program assisted the team with performing chart audits and reporting performance data. Based on the results of a baseline chart audit, the practice team focused on improving four measures: staging patients as severe-persistent, moderate-persistent, mild-persistent, or mild-intermittent asthma; providing spacers and peak flow meters ("hardware"); using a written action plan; and ensuring that those with persistent asthma were prescribed long-term control medications.

At the beginning of the project, a chart audit was performed on children enrolled in the AccessCare program. The audit found that less than 10% of the charts had documented staging, a written action plan, spacers and peak flow meters, or that long-term control medications were prescribed. It was clear that there was substantial variation among providers in how they cared for their patients with asthma.

Educating the Team

The first phase of the intervention involved educating the practice team about the NHLBI guidelines and the potential impact of following the guidelines on the practice population. The practice team and AccessCare staff developed written action plans with embedded asthma guidelines. AccessCare provided patients with the education booklet called *One Minute Asthma*.[6] The practice team met approximately once a month, with most meetings being unscheduled and informal. After several months, a follow-up chart audit was performed. While there was improvement in the use of long-term control medications, spacers, and peak flow meters, fewer than 20% of children were staged and given action plans. The practice team postulated that physicians were not staging patients and using action plans because there was not enough time during the visit.

Strategies to Improve Care

In an effort to overcome time constraints that limited the provider's ability to provide complete asthma care, the team created "standing orders" so that other team members could provide certain aspects of care. Nurses were given the responsibility for teaching patients how to use peak flow meters and how to fill out a portion of the action plan. In order to facilitate the staging of patients, the action plan form was revised to include a staging tool. One of the other strategies used by the team was to provide the performance data to both the providers and the practice. The performance data of individual physicians were also displayed, creating a "healthy" competition among providers. The next round of chart audits indicated that practice behavior had begun to change. Greater than 80% of the charts audited had documentation of staging, use of action plans, prescribed long-term control medications when appropriate, and use of peak flow meters and spacers.

Outcomes

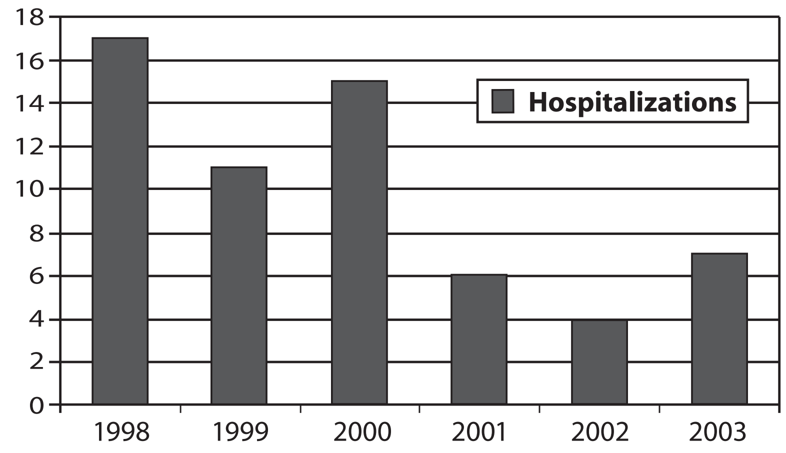
Pediatric asthma emergency department visits and hospital admissions were tracked yearly from 1998 to 2003. Data were obtained on Sandhills Pediatrics' patients, age two-to-17 years with the primary or secondary diagnosis of asthma. Over the project time period, there was a 48% reduction in emergency department visits and a 62% reduction in hospital admissions for asthma (see Figures 1 and 2).

Summary

This case study demonstrates the use of quality improvement methods to improve asthma care in a busy community practice. The practice used disease-management strategies, such as population identification, self-management education, and performance measurement and feedback. The practice then applied several practice-based quality improvement methods, such as PDSA cycles, to improve care. From 1998 to 2003, process measures, such as staging of asthmatics, use of long-term control medications, use of peak flow meters and spacers, and use of action plans, improved. There was also a substantial decrease in emergency department use and hospitalizations among patients with asthma.

Although there have been several studies demonstrating the efficacy of disease management strategies, most lack generalizability to community practices.[7] Often, interventions are so intensive and cumbersome, that they are unlikely to be replicated in primary care settings. Researchers have been unable to determine which components of the interventions are most effective and replicable. Furthermore, many studies of disease management strategies enroll participants who lack the co-morbidities seen in

Figure 2.
Asthma Hospitalizations, 1998-2003



community practice. There are also few studies of disadvantaged populations that face other barriers to care, such as lack of transportation, poor access to specialists, and medical illiteracy.

In this case study, there were several unique factors that enabled the practice to improve care for this population. The AccessCare case manager who worked with the practice not only provided data and feedback to the practice team, but also served as an improvement "coach," often pushing the team and facilitating many of the improvement efforts. AccessCare's approach is in contrast to many of the commercial disease management companies' "carve out" models that do not sufficiently involve providers or practices in their interventions. The other necessary ingredient for success in this project was organizational leadership and support. The leaders of the practice saw beyond the usual metrics of patient visit counts and relative value units (RVUs) to embrace the concept of population health: the notion that practices are not only responsible for providing acute, episodic care in the office, but also for improving health outcomes in the community in which they serve. Other important factors included ensuring a basic agreement among providers on the need for improvement and frequent communication about the goals of the project. Although the champions of the project tried to minimize formal meeting time, there was frequent informal communication between team members. In the future, there is a need to develop other approaches to stimulate these endeavors in community practices, such as "pay for performance" programs, continuing education credit, and tying maintenance of board certification to quality improvement initiatives. **NCMedJ**

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Disease Management in Primary Care:
Rapid Cycle Quality Improvement of Asthma Care

Samuel S. Weir, MD

What can we learn from the Sandhills Pediatrics' asthma care experience?[1]

The first lesson is that primary care-based disease management programs can dramatically improve outcomes of care. Not surprisingly, an organized, explicitly designed approach to caring for special populations leads to improved outcomes of care. Sandhills Pediatrics successfully *carved into* their practice "a systematic, population-based approach to identify persons at risk, intervene with specific programs of care, and measure clinical and other outcomes."[2]

> *"The Sandhills experience can teach the rest of us the key ingredients and how to organize them to improve population outcomes in primary care."*

This is an important lesson because in the mid to late 1990s many in the managed care community lost faith in practicing physicians doing what Sandhills Pediatrics has done. Managed care executives turned to *carve out* solutions from emerging disease management vendors. These vendors developed programs that bypassed the traditional healthcare delivery system and used externally based case managers or other resources to reduce costs and improve outcomes related to chronic diseases.[3]

It's clear that a specifically designed disease management program can improve outcomes for those with chronic disease. But how do we carve these successful programs into existing practices? Viewed from the perspective of operations research, Sandhills Pediatrics becomes a laboratory with very important lessons for the rest of us. The Sandhills experience can teach the rest of us the key ingredients and how to organize them to improve population outcomes in primary care.

Leadership

The first and arguably most important ingredient is leadership. Leadership must be persistent and able to defuse nearly certain initial resistance to build an effective team of colleagues and office staff. The image to get in your mind here is that of the Energizer Bunny®—leadership that keeps going and going and going.

Organizational Support

A second crucial ingredient for successful disease management is organizational support. Notice that Sandhills has been involved in several improvement initiatives around preventive care, access, oral rehydration, and attention deficit disorder. Clearly this is an 'early adopter' medical practice! In each of these efforts, the practice had the support of a larger organization helping them improve their practice. Practices need a guide, a support network, and a larger context in which to view their work. In this case, Dr. Boals had the support of the AccessCare network of practices. AccessCare is a non-profit organization committed to improving quality of care and reducing costs of care for state Medicaid beneficiaries.[4] Other third-party payers might take notice of this innovative approach to working with practices to improve quality and reduce costs of care.

Measuring Practice Performance

A third vital ingredient to build a successful disease management program is measurement of practice performance. As with Sandhills pediatrics, this can involve time-consuming chart reviews. In their case, an AccessCare staff member did the chart reviews. Identifying a non-clinician member of the staff who can be trained to do the chart reviews on an ongoing basis may be a way for practices to achieve this.

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Hand-in-hand with a commitment to measure practice performance is the courage to face the results squarely. Many clinicians feel challenged and threatened when they begin to see this kind of data and will question the measurement strategy and the data quality rather than begin to look for ways to improve. A measurement plan that is simple and transparent can quiet the critics and refocus attention on performance improvement.

Team Approach

A fourth necessary ingredient to building a successful practice-based disease management program is a team approach to care. I don't think it is an accident that Drs. Wroth and Boals described significant improvement after the nurses in his practice began to participate in asthma care by 'automatically' doing peak flow measurements and writing action plans for patients with a diagnosis of asthma. This expansion of the nursing role within a practice is a common theme of successful disease management programs. Prerequisites to this include a practice culture that is open to learning new skills and applying those skills in expanded roles within the practice.

Focus on Process

A final ingredient to building successful carve-in disease management programs is a focus on the process of care. What happens when a patient with asthma visits the practice? Who is going to do what? Where? When? With what resources?

These ingredients: leadership, organizational support, measurement of practice performance, a team approach to care, and a focus on the process of care have been identified as common elements of successful clinical microsystems in studies done across the United States.[5] How should these ingredients be combined? The recipe for successful disease management in primary care practices calls for the proper mixing of these ingredients over time.

Rapid cycle quality improvement combines these ingredients in repeated cycles of planning, doing, studying, and acting (PDSA) cycles.[6] *Planning* includes initial problem identification, probable causes of the problem, potential solutions and data needed to evaluate them, and improvement goals. *Doing* involves implementing a solution and collecting the data needed to evaluate the impact of the solution. *Studying* requires further data analysis to develop conclusions—what happened when we made that change? *Action* involves either further study or action that comes out of the data analysis. Rapid cycle quality improvement leads back to a better understanding of the problem and more planning.[7]

This cyclical process of improvement was well-illustrated in commentary by Drs. Wroth and Boals. Their first cycle of improvement involved physician and nurse education and the provision of pre-printed action plans and patient education materials. They began planning for a second cycle of improvement by increasing education, making peak flows and filling out action plans 'automatic' within the practice, and reporting individual clinician outcomes. These steps led to a dramatic improvement in outcomes. A third cycle of improvement led them to create an evening asthma clinic for 'well-asthma' visits once a month.

Unfortunately, Sandhills Pediatrics and its remarkable improvements in asthma care remain the exception rather than the norm. The task for many of us is to emulate their efforts in our own practices across the state. **NCMedJ**

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Implementing Advanced Access in a Family Medicine Practice:

A New Paradigm in Primary Care

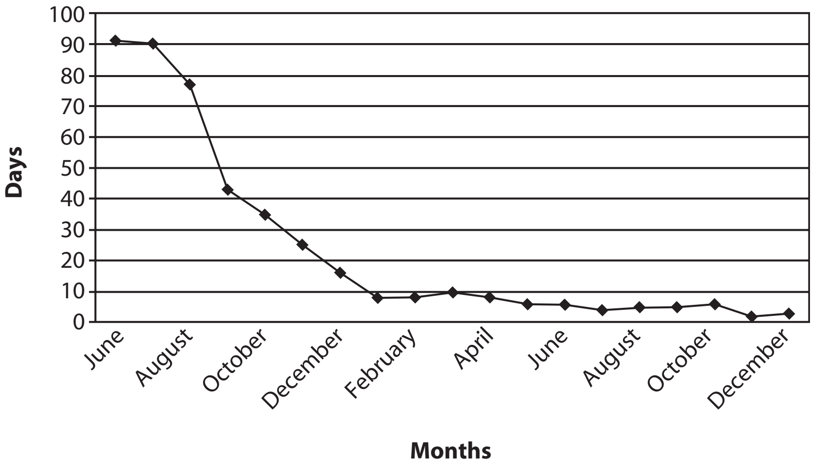
John B. Anderson, MD, and Carlos A. Sotolongo, MD

Triangle Family Practice is a family medicine group that has been part of the Duke University Health System since 1995. There are eight physicians and three physician assistants/nurse practitioners in the group that is located in suburban Durham. Growth in this area of Durham has resulted in a significant influx of new patients to the practice. In 2001, the practice was seeing almost 300 new patients a month. The wait for an annual physical appointment was an average of 90 days, with one provider booked out to 180 days (see Figure 1). Patients were unhappy because they were unable to see their usual provider, the staff was dissatisfied at having to continually bargain with patients over appointments, and the providers were struggling to keep up with the demand. Everyone realized that something had to be done, as this had become an untenable situation.

We became aware of the concepts and principles of Advanced Access scheduling after attending an Institute for Healthcare Improvement meeting and realized that this approach could address the issues we were having at Triangle. Advanced Access is based on the premise of doing "today's work today" and that it is not necessary to make patients wait, either for appointments or while they are in the office. The old paradigm is that we can create capacity in today's schedule by pushing work into the future.[1] The result is that all the routine or non-urgent requests are scheduled out for weeks hoping to make space for those patients who need to be seen today. Our schedules end up full with last months work, and patients have to convince the staff they are sick enough to be seen today. Patients are often unable to see their usual provider, they have to wait for preventive and chronic illness care, and they routinely miss appointments that are scheduled weeks and months into the future. The practice's financial performance suffers because of the high no-show rate and the large number of low-acuity visits. Patient and staff satisfaction are also poor as a result of the constant haggling for appointments and inefficiencies in the office.

The decision was made to use Triangle Family Practice and Butner-Creedmoor Family Medicine as pilot practices prior to implementing Advanced Access across all the practices that make up Duke's primary care network, Duke University Affiliated Physicians (DUAP). What follows is a description of how we implemented these concepts at Triangle from the spring of 2001 until spring of 2002. The group participated in a Breakthrough Learning Series Collaborative sponsored by the Institute for Healthcare Improvement on Advanced Access and

Figure 1.
Wait Time for Physical Appointment (Practice Average): Third Next Available, June 2001-December 2002



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Office Efficiency with other primary care practices from around the country. The collaborative approach was helpful in that we learned from expert faculty, but also were able to share experiences and strategies with other practices.

Implementing Advanced Access Scheduling

The challenge that confronted Triangle was how to take the "high-leverage" changes, outlined elsewhere in this Journal and in the literature, and apply them to their own situation.[1,2] The decision was made early in the process to close the practice to new patients so as to allow the providers to work down their "backlog" of patients that were scheduled out into the future. This process can take anywhere from six weeks to six months, but is a crucial step in the process of creating capacity to see patients on a same-day basis. We also began to examine several long-standing policies regarding the way our schedules were managed. There were rules in place as to how many physicals could be scheduled in a day and multiple appointment types structured in an attempt to "manage" the demand from patients for visits. Providers were scheduled as "walk-in" doctors so they could see acute care patients. Scheduling providers on a walk-in basis disrupts continuity and further restricts the physician's availability to see his or her own patients. In addition, the practice had no idea of what the demand for appointments was and no idea of what individual provider panel sizes might be.

> *"Patients were unhappy because they were unable to see their usual provider, the staff was dissatisfied at having to continually bargain with patients over appointments, and the providers were struggling to keep up with the demand."*

Involving Staff and Providers in the Process

The practice created an internal team that participated in the collaborative. The team met on a weekly basis to plan the necessary changes and to analyze the data collected to measure the impact of these changes. They began to measure their demand for appointments so as to compare it with their capacity to see patients. They also tracked their no-show rate, their cycle time (how long it takes a patient to move through the office), and their patient and staff satisfaction. We use the third-next available appointment for a physical as our measure of access with the goal being able to get this down to same day availability. As mentioned earlier, Triangle's was out to 90 days. One of the biggest challenges faced by Triangle's team was convincing the staff and providers of the need to change and adopt this new approach. This was accomplished by involving them in the process, and sharing the data from the practice and testing changes prior to their implementation.

The practice was able to create significant capacity in their schedule by reducing their appointment types to two, 15, and 30 minutes. The scheduling rules, such as only four physicals per day, were removed, and the primary question staff had to answer when patients requested an appointment was whether the patient's provider was in the office that day. Once providers began to see their own patients, more could be done at each visit, and patients did not have to be seen as often. We began to employ a concept called "max-packing," which entailed doing as much as possible for patients when they are in the office and not having them return for another appointment. This frees up the future schedule and raises the acuity level of that visit. Care teams were created in the practice that also included schedulers and medical record personnel. These teams would "huddle" each morning before patients were scheduled to plan the day's work, synchronizing patient information with the appropriate provider. The care teams were geographically co-located to help facilitate real-time communication between nurses, providers, and schedulers on the phone with patients. As appointment availability increased, the need for phone triage decreased, and those nurses could be given other tasks in the office.[3]

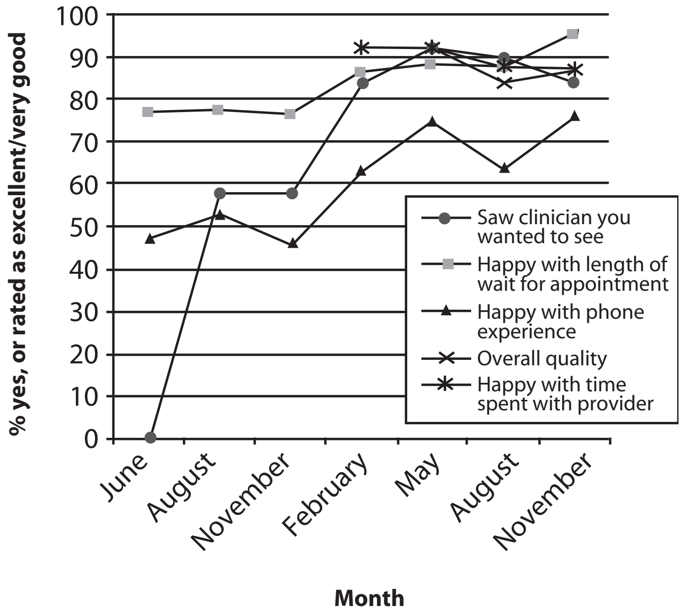
Making Adjustments

Once the practice was able to collect and understand its demand for appointments data, over-paneled providers could shift some of their patients to other providers. We learned that Mondays and Fridays are high-demand days, so we were able to "shape" the demand and book return appointments at less busy times. Patients who needed to return for follow-up were given appointments, but because we had availability, we did not have to schedule patients for "just in case you're not better" appointments. The practice also developed contingency plans for when providers were on vacation or at times of high demand for appointments. There were some concessions made with the scheduling of physicals due to the high demand for some of our female providers. We did limit this number to six-a-day, and they were scheduled on the hour so as not to occur back to back.

Conclusion

As a result of implementing Advanced Access, the practice can now measure its availability in terms of one-to-two days.

Figure 2.
Patient Satisfaction, June 2001-December 2002



Patient satisfaction has improved dramatically (see Figure 2), the staff finds this a much more satisfying place to work, and the providers feel less stressed and better able to take care of patients. The practice has enjoyed financial success and has been able to grow its market share. The changes associated with Advanced Access cannot be implemented without significant work and effort, but the resulting success has positioned the practice to respond to the changing landscape that lies ahead for primary care medicine. **NCMedJ**

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Where Next for Advanced Access:

Will It Be Embraced by Specialties?

Greg D. Randolph, MD, MPH

A Brief History of Advanced Access

Advanced Access, sometimes referred to as Open Access (see page 199), is a set of principles designed to help practices reduce waiting times for appointments and reduce office-waiting times, two common access barriers in healthcare today. The Advanced Access approach to practice management and scheduling was originally developed by Mark Murray, MD, MPA, and Catherine Tantau, RN, at Kaiser Permanente in the early 1990s.[1] Many if not all of the strategies were derived from the experience of other industries[2]—though cleverly adapted to healthcare.

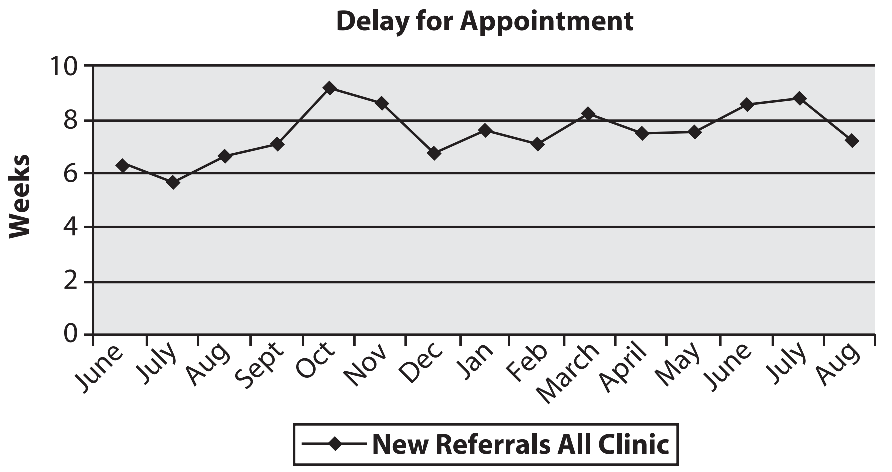
In the mid-1990s, Murray and Tantau began a partnership with the Institute for Healthcare Improvement (IHI), a nonprofit organization devoted to the spread of improvements in healthcare. Together with the IHI, Murray and Tantau have been involved in spreading Advanced Access to thousands of practices, primarily in primary care settings.[3,4] The improvements in care documented by Triangle Family Practices in this issue are important drivers of the increasing appeal of this approach in primary care.

More recently, the IHI, the Veterans Health Administration, and the National Health Service in the United Kingdom have developed methods for widespread dissemination of Advanced Access to thousands of practices. These large scale efforts have included specialty settings. However, adoption of Advanced Access by specialty practices has been slow and generally limited to a small number of organizations and geographic areas.

Access Problems in Specialties

There is certainly a need for attention to reduce delays for specialty care. Local data from the University of North Carolina Chapel Hill Pediatric Subspecialty Clinics (see Figure 1) is typical of the delays for new referrals to many specialties. Unfortunately, it is quite common for new specialty referrals to reside on waiting lists that are several months long.

Figure 1.
Delays for Appointments for New Referrals from the UNC-Chapel Hill Pediatric Subspecialty Clinics, June 2003-August 2004



There are several potential causes for these delays. One is the increasing concern about national shortages in the pediatric subspecialties.[6] There may be local shortages among some adult specialties too, even though the national supply appears adequate. Waste and inefficiency in many subspecialty clinics are another potential cause.[3] In addition, just as in primary care settings, there is a common mindset in specialty settings that it is okay for patients to wait—more alarming, waiting is often viewed as

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an indication that "we are the best."[7] As long as waiting is viewed as acceptable or even desirable, there will be a major barrier to redesigning practice systems to allow more timely care.

Principles of Advanced Access Are Generalizable

There is no reason to believe that principles of Advanced Access (see Table 1) cannot be applied to specialty settings. They are applicable to industries outside healthcare like Wal-Mart, General Motors, and Starbucks (where these principles were first applied), so why not to specialty care? Indeed, through the IHI's Pursuing Perfection project, Cincinnati Children's Hospital is successfully applying these principles to pediatric subspecialties.[8] Similarly, the Veterans Health Administration has had success spreading these principles to adult specialties.[9]

> *"Advanced Access, sometimes referred to as Open Access, is a set of principles designed to help practices reduce waiting times for appointments and reduce office-waiting times, two common access barriers in healthcare today."*

Specialty clinics can reduce appointment backlog, reduce appointment types, and manage bottlenecks just as primary care practices can. However, with increasing experience in specialty clinics, we are learning where some of these principles need to be applied slightly differently. For example, to balance demand and supply, specialty clinics need to address the number of new patients subspecialty clinicians are assigned (based on current numbers managed, full-time equivalents, expertise, etc.) rather than panel size (as in primary care). In addition, in order to reduce demand, primary-specialty partnerships are very important for specialists (e.g., to establish referral criteria and to design systems to promote prompt return to the primary care setting).

Table 1.
Advanced Access Principles

Principle	Examples
Balance appointment supply with patient demand	• Predict appointment supply by accounting for holidays, vacations and non-clinical work • Predict patient demand for appointments by collecting appointment data
Work down the backlog (waiting list)	• Distinguish between "good" (planned care) and "bad" (delayed care) backlog • Measure the extent of the backlog and make a plan for reducing it, including a start and end date
Reduce appointment types	• Reduce number of appointment types • Standardize appointment lengths (e.g., consider 30-minute appointments for all visits)
Plan for contingencies	• Increase capacity at peak times • Plan for predictable seasonal increases in appointment demand
Reduce future patient demand	• Maximize activity at appointments to reduce future demand • Extend intervals for return appointments
Manage the bottlenecks	• Identify bottlenecks in clinic flow • Drive unnecessary work away from the bottlenecks
Synchronize patient, provider, and information	• First AM and PM appointments start on time • Patient registration done by phone if confirming patient appointment
Predict and anticipate patient needs at the time of the appointment	• Use regular "huddles" to anticipate and plan for contingencies in schedule • Use notepads, whiteboards, flag systems, etc. to communicate during the day
Optimize rooms and equipment	• Use "open rooming" to maximize flexibility • Standardize supplies in all rooms and have stocked at all times
Use continuous flow strategies	• Do this moment's work now (e.g. dictate immediately after visits) • Use scheduled pauses to apply continuous flow approach to non-appointment activities (e.g. returning phone calls)

What's Ahead?

In the near future, it is reasonable to expect that the demand for specialty access improvements will accelerate. The growing body of research that suggests that Advanced Access decreases no-show rates, improves patient satisfaction, improves staff satisfaction, increases physician productivity, and increases revenues in primary care will likely accelerate the spread of this approach among primary care practices in the United States.[4,10-15] As more primary care practices adopt Advanced Access, these practices and their patients will begin to turn their attention to timely access for specialty care. Indeed, we have already witnessed this phenomenon in some areas of the country. In addition, market forces will likely apply pressure to specialty practices to improve patient satisfaction—reducing delays for specialty care will be an important way to address these market forces.

As the experience with Advanced Access increases in specialty settings (through the experiences of "early adopters"), the feasibility and the advantages of this approach will become clearer to a greater number of potential adopters in specialty settings.[16] The spread of Advanced Access to specialty practices could reach in to the thousands within the next five years, based on the experience of primary care we have witnessed. However, spread will ultimately depend on a small number of "early-adopter" practices to try and succeed with this relatively new innovation in healthcare scheduling and practice management. A number of groups, including the IHI and The Center for Children's Healthcare Improvement, are trying to assure this indeed does occur. **NCMedJ**

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Community Care of North Carolina:
Saving State Money and Improving Patient Care

Charles F. Willson, MD

It was a morning in January, flu season, and I was already a half a dozen patients behind as I entered the exam room and saw Heather lying in her mother's lap, tugging for air.

Heather was a frequent flyer at our office, well known to the doctors and staff for her bad asthma. At age four, she knew the fearful regimen of subcutaneous epinephrine injections given every 15 minutes until the wheezing broke or, even worse, an admission to the hospital for intravenous (IV) aminophylline. Usually her grandmother brought her, but today it was her mother, a thin young woman who looked older than her years.

Heather was in respiratory distress, nares flaring, deep intercostal retractions, tugging with her neck muscles with each breath. I quickly counted her respirations, 64 per minute. Worst of all, she looked tired, barely lifting her head from her mother's breast to look at me. The nurse had already laid out the epinephrine and syringes. I gave the first epinephrine injection subcutaneously with little resistance from Heather. Instead of waiting to see if she improved, I left the room to call the hospital for a bed for Heather. The second and third injections brought little improvement and a lot of tachycardia. As I handed her a set of admissions orders, I explained to Heather's mother that she would need to be admitted to hospital for IV therapy and a chest x-ray. She nodded in agreement.

> *"...the only way to curb the spiraling cost of healthcare in our country is to prevent that which is preventable and catch the rest in its earliest stages through a well-planned system of primary care with access for all the people..."*

Off I went into the next exam room. Around lunchtime, I received a call from the emergency department (ED). Heather had been sent there from the admissions office. She was being admitted to the pediatric intensive care unit (ICU). Off I went to the hospital. Heather had just reached the ICU when I got there. Her blood gases showed significant carbon dioxide retention. With the help of the anesthesiologist, we had her intubated, taking the load of breathing off that thin little frame.

That afternoon, I learned that Heather and her mom had walked the two miles to my office in sub-freezing temperatures. Instead of going directly to the hospital, her mother had walked her home to get her pajamas. As I listened to the story in disbelief, the social worker related that Heather's mom was a heroin addict and perhaps it was more than pajamas she went home for. Clearly, a healthcare delivery system that relied on the parent to decide when to come to the office, how to get there, and how to follow the treatment plan was not meeting the needs of Heather and her two brothers.

The Old Model

The primary care model I learned in medical school and residency in the seventies and practiced in the eighties and nineties could best be described as "snap shot" medicine. We saw the patient briefly in the office, made a diagnosis, and, most often, wrote a prescription. Getting the prescription filled, taking the medicine, and returning for follow-up, if things weren't going better, were left to the patient. Little attempt was made to find out if the patient could afford the medicine, understood the instructions, or could comply with the treatment regimen. If things didn't go well or if the patient didn't return for follow-up, it was probably

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his or her own fault. We didn't even have a system of identifying who hadn't shown up for their appointment each day. Was no news, good news? Few physicians had resources or systems to follow their patients over time or to determine the outcomes of their patient care in the aggregate. Physicians had no data comparing their practices with their peers'. The default standard was "medico-legal." If you didn't get sued, you were probably doing "okay."

The New Model

In Crossing the Quality Chasm,[1] the Institute of Medicine of the National Academies outlined the desired characteristics of a new model for healthcare delivery in our country:

- Care is based on a continuous healing relationship.
- Care is customized according to patient needs and values.
- The patient is the source of control.
- Knowledge is shared and information flows freely.
- Decision-making is evidence-based.
- Safety is a system priority.
- Transparency is necessary.
- Waste is continuously decreased.
- Cooperation among clinicians is a priority.

In the late eighties and nineties when health maintenance organizations (HMOs) arrived in North Carolina, many healthcare leaders thought the HMOs would bring system improvements. The upside for a pediatric generalist was that well-child care finally became a covered benefit. The downside was that the reimbursement rates were a percentage of your usual charge or, even more worrisome, a capitation rate associated with patient risk level (How could I be responsible for my patients' costs and outcomes? We all knew patients weren't very compliant.). Some insurers actually gave us performance data, comparing us with other pediatricians in their network. These data were often linked with financial withholds and highly suspicious of being another way of further decreasing reimbursement. There was little effort to enhance my ability to care for my patient.

Physicians in practice needed a new model that would supply the resources necessary to provide a "continuous healing relationship." We needed practical education on how to implement "evidence-based" best practices. We needed an office-based computer system that could track and aggregate our clinical information. We needed believable, practice-specific utilization data from the insurers. Most of all, we needed specially trained office personnel (case managers) who could be our eyes, ears, and arms to follow our most medically and socially complex patients once they left the office.

The Medical Home

While the medical model is founded on the physician-patient relationship, the community-based primary care model is based on the medical home. A medical home is a well-planned primary care practice that strives to meet the broad spectrum of healthcare needs of its patients from simple acute illnesses to preventive health maintenance visits through referrals to specialists for complex and chronic conditions. Using evidence-based disease management protocols and knowledge of where additional services can be accessed in the community, the region, the state, and even the nation, the physicians and staff of the medical home can advise the patient on what services are needed or recommended for any given medical question or complaint. Over time, a "continuous healing relationship" is developed. By catching illness early and encouraging healthy lifestyle changes, the medical home brings great value and comfort to its patients during periods of illness and stress in their lives. In Community Care of North Carolina (previously called Carolina Access II/III), our medical home model is made powerful thanks to the enhanced resources the primary care physicians are given to help manage their patients. These resources are disease management protocols, case managers, and practice-specific utilization data. Many healthcare leaders refer to our model as an "enhanced primary care case management model (E-PCCM)."

A Brief History of Carolina Access

During the early 1990s, North Carolina Medicaid Director Barbara Matula created a partnership with primary care physicians called Carolina Access. She wanted improved rates of well-child care (HealthChecks) and decreased unnecessary use of the emergency department as a source of primary care. By committing to be on-call 24 hours-a-day, seven days-a-week, 365 days-a-year for their Medicaid patients, the primary care practice would receive a case management stipend of $2.50 per member per month. Triage nurses at the local ED would call the patient's on-call physician and describe the patient's complaint, condition, and vital signs. If the Medicaid patient was stable and could be safely seen in their medical home, the patient would be referred there. In the first year, Carolina Access decreased ED charges by 10%. Unfortunately, the Health Care Financing Administration [HCFA, now the Center for Medicare and Mediciad Services (CMS)] that had given a waiver to North Carolina to implement Carolina Access, took away this option with the Emergency Medical Treatment and Active Labor Act (EMTALA)* in 1995. EMTALA regulations erected major barriers to triaging patients back to their primary care offices.

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* "In 1986, Congress enacted EMTALA to ensure public access to emergency services regardless of ability to pay. Section 1867 of the Social Security Act imposes specific obligations on Medicare-participating hospitals that offer emergency services to provide a medical screening examination (MSE) when a request is made for examination or treatment for an emergency medical condition (EMC), including active labor, regardless of an individual's ability to pay. Hospitals are then required to provide stabilizing treatment for patients with EMCs. If a hospital is unable to stabilize a patient within its capability, or if the patient requests, an appropriate transfer should be implemented." Available at http://www.cms.hhs.gov/providers/emtala/default.asp. Accessed June 13, 2005.

Carolina Access II

By 1996, with North Carolina Medicaid costs again skyrocketing at double-digit yearly growth figures, the North Carolina legislators were again looking for a cost containment mechanism. Commercial HMOs told legislators they could save the state 10% in the first year, if legislators would turn the North Carolina Medicaid program over to the HMO industry. For a $2.5 billion program, that was an attractive offer. Another option, offered by a group of large hospitals in North Carolina with high Medicaid usage, was to form a consortium to take over Medicaid. Both the HMO- and the hospital-consortium plans included 15-20% overhead costs, while North Carolina Medicaid only cost the Division of Medical Assistance (DMA) 4% in overhead. Converting to a program with higher overhead would mean there would be less money for direct patient care and services.

Recognizing that physician orders, prescriptions, and treatment plans generate more than 70% of Medicaid costs, then Secretary of the North Carolina Department of Health and Human Services H. David Bruton, MD, proposed a direct partnership between Medicaid providers in the communities and the state Division of Medical Assistance. His recipe for success was rewarding physicians for working harder and smarter. Medicaid programs in other states had low-participation rates by physicians due to reimbursement rates that didn't cover the office expense of seeing the Medicaid patient. Why not enlist physician participation by rewarding them with a $2.50 per member per month case management fee and paying them a fee schedule that more than covered costs (95-100% of Medicare rates)? Nine pilot sites were funded across the state. The enhancement of Carolina Access into disease and case management was named Carolina Access II.

A Brief History of the Community Care Plan of Pitt County

In June 1996, Secretary Bruton presented his vision of a physician-led healthcare system to a meeting of our local physician organization, Eastern Carolina Health Organization (ECHO). He explained that the healthcare middle men brought little value, but extracted 15-20% of the healthcare dollar. He called for a partnership between physicians and the state to bring improved access to care, measurable quality, and cost-effectiveness. His goal was to decrease yearly cost increases for Medicaid from the 15-20% level down to 8% by the fiscal year 2000. He asked that local provider groups submit proposals to his office on how to accomplish his goals. In January 1997, our Physicians Hospitals Organization (PHO), University Medical Center Health (UMC Health), submitted a detailed proposal for a county-wide partnership of the physicians, hospital, health department, and department of social services to manage the care of Medicaid patients in Pitt County. Cabarrus County, under the leadership of L. Allen Dobson, Jr., MD, submitted a similar model. My practice, Greenville Pediatric Services, had been invited to join a large statewide pediatric group model (AccessCare), but we declined. To be an effective alternative to the HMO model, we needed projects that covered all Medicaid patients in the area. While 70% of Medicaid patients are children, they generate only 30% of the costs. Adults and disabled patients comprise 30% of Medicaid patients, but they generate 70% of the costs. For this reason, we speculated that the pediatric network would not be inclusive enough to control total Medicaid costs. Secretary Bruton agreed, designating our more inclusive, county-wide model as Carolina Access III. Carolina Access II included other pilots that cared for only portions of the Medicaid population.

Financing the Pilot Programs

Administrative costs for the pilots were funded by an additional $2.50 per member per month. Our fiscal entity receiving these funds was the local PHO. A project coordinator, a part-time medical director (me), and case managers were hired. A steering committee was empowered by the PHO to run the pilot. The steering committee was loosely constituted, with each partner being represented (i.e., physicians, hospital, health department, and department of social services). Decisions are by consensus. Over the last six years, I recall only one formal vote by the steering committee, and it was unanimous. Care management committees were formed to identify the clinical issues that should be addressed, as well as to implement best practices developed by the statewide medical directors group.

With the Carolina Access roots into decreasing unnecessary ED utilization, our first challenge was to encourage our patients to use their medical homes as the first contact for care. In partnership with the hospital, a nurse advice phone line (HealthDirect) was developed. Every Carolina Access family, received a refrigerator magnet with the office phone number and the HealthDirect nurse advice-line number. Also, we created a community pediatric after-hours clinic that was staffed by a pediatrician (either from private practice or the medical school) and several residents. This after-hours clinic operates from 6:00 pm to 10:00 pm every night of the year, including weekends and holidays. With these two initiatives, we decreased ED visits by Medicaid patients under age 21 by 17% in our first year (fiscal year 1999). Importantly, our parents and patients appreciated the convenience of these alternatives to the long waits in the ED.

The Physician Champion

Much of the success of Carolina Access can be directly traced to physician involvement at all levels. Each pilot program in Carolina Access II/III had a medical director committed to the vision of a primary care-directed, evidence-based healthcare delivery system for North Carolina Medicaid patients as articulated by Secretary Bruton. Medical directors meet every two months to review statewide data and discuss innovative programs initiated at the pilot level. At the practice level, we try to identify a physician champion who will attend our local care management meetings and be the catalyst to implement disease management initiatives in his or her practice. As our county-wide model has evolved into a regional network, we have realized the need for a physician champion in each medical community. This physician champion receives a small stipend for a few hours of work each month (e.g., arranging and attending local steering committee meetings and interpreting the utilization data provided to individual practices). Physicians across North Carolina should feel an ownership in the success of Community Care of North Carolina.

Disease Management

Disease management tools were developed by a statewide medical directors group. Utilization data gleaned from charges showed that the North Carolina Medicaid program had high costs for pediatric asthma patients from ED use and hospitalization. In 1995, the national Institute of Medicine published guidelines[2] for management of children with asthma, so we felt we could adapt those guidelines for our use and get physician buy-in fairly easily. The results were impressive. Over the first four years of the program, utilization data showed we saved $27.5 million in reduced ED and hospital charges to North Carolina Medicaid. Diabetes management was the second disease tackled. Congestive heart failure is now being addressed through a more top-down approach. Several networks have initiated other disease management initiatives based on need and enthusiasm for tackling a perceived clinical problem. Buncombe County developed a Depression in Adults Initiative. In Pitt County, we are addressing attention deficit hyperactivity disorder and children with complex and chronic disease.

Case Management

In AccessCare, each pediatric practice has a case manager on site to assist in patient education and to overcome complex barriers to the successful implementation of the treatment plan. In our county-wide model, we've found great value in assigning our case managers to a primary care practice, but housing the case managers in a central location where they can learn from each other and cover each other's patients during holidays and vacations. We employ one case manager for every 3,300 patients, with each case manager actively following 100 to 200 patients at a given time. Referrals for case management are made directly by the practicing physicians, as well as by high-risk/high-cost patients identified by utilization data. Patients who frequently utilize the ED also receive calls from our case managers to assess reasons for the ED visit and schedule follow-up with the medical home.

Other case managers exist throughout the healthcare system. Our case managers often take referrals and then hand off the active management to other case managers located at health departments, departments of social services, mental health centers, early intervention programs, and the Children's Development Services Agencies. With these precious resources, we cannot afford to overlap services.

Implementing Evidence-Based Practice

Why do physician offices change how they practice? Every physician I know wants to practice the best medicine he/she can, and generally thinks they are. A physician won't change because Chuck Willson says he or she needs to, and especially not when a faceless bureaucrat in Raleigh or Washington, DC tells them to. Typically, physician offices will change if they can see opportunities for improvement. We've learned that practice-specific data will identify opportunities for a practice to improve. For example, when I told one Pitt County practice that their ED rate was four times the county average, the practice joined the community after-hours clinic consortium. Within a few months, their ED rate was better than the county average. While utilization data from claims are instructive and often compelling, we perform chart audits in the practices to assess compliance with disease management initiatives. We found early on that ED visits for asthma are correlated with a practice's asthma guideline compliance and office hours on weekends. When I first audited my own charts, I found that fewer than 50% of my asthma patients were staged or had a peak flow management plan as recommended by NIH guidelines. What a rude awakening for a physician champion!

Community Care of North Carolina

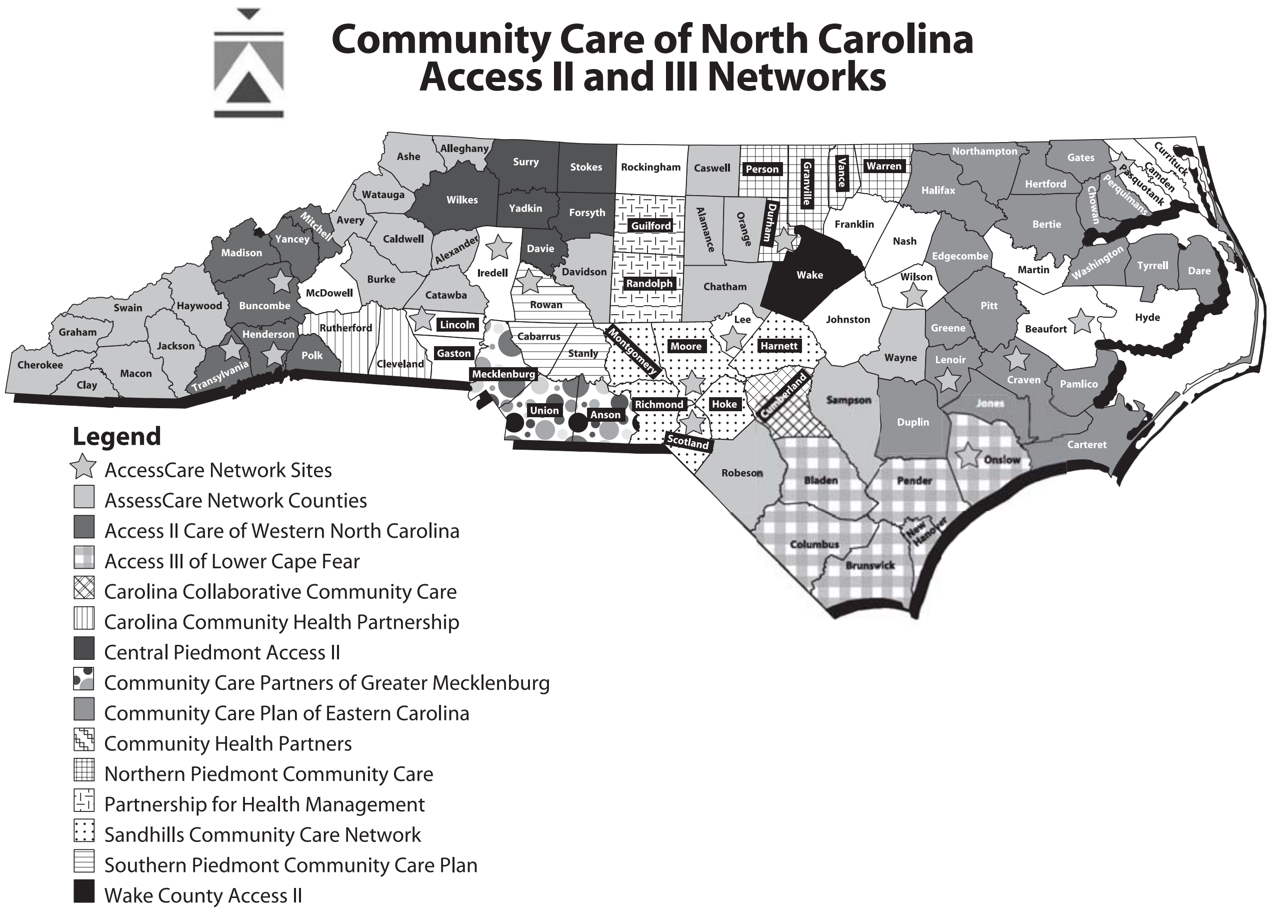
When Secretary Carmen Hooker Odom took over the North Carolina Department of Health and Human Services in 2000 after Governor Easley's re-election, she renamed Carolina Access as Community Care of North Carolina (CCNC). She also deemed the county-wide model as the preferred model and asked that it be implemented statewide by 2006. The Pitt County CCNC model became the Community Care Plan of Eastern Carolina (CCPEC). We help counties develop local partnerships for implementation of the enhanced primary care case management model. Since community healthcare is dependent on local resources, we recruit a physician champion as clinical director and form a local steering committee with representatives from the hospital (if there is one), health department, and department of social services. The local steering committee hires a project director and the case managers with funds being passed through our fiscal entity (now AccessEast, a not-for-profit corporation that evolved out of the PHO). CCPEC is now operating in 16 counties across eastern North Carolina (see map).

The Value of a Primary Care Network

Community Care of North Carolina works because it provides a network of enhanced primary care medical homes for North Carolina Medicaid patients. These enhancements are financial, data, and disease/case management. High-quality care is being delivered in a timely fashion in the least costly setting. Once the statewide network is complete, opportunities will exist to look at specialist care for North Carolina Medicaid patients with the same goals of improving access to care, measuring utilization and quality, and enhancing cost-effectiveness.

Conclusion

To achieve best outcomes for the individual patient, a primary care medical home empowered with disease management and



case management resources provides the "continuous healing relationship" envisioned by the national Institute of Medicine. A community network of these enhanced medical homes, linked into a regional network, can really start to deliver improved care for entire populations of patients, whether aggregated by insurance coverage (or lack of) or by disease processes. These networks become a platform to launch new and innovative care management programs.

As I think about Heather, my hope is that under our new CCNC model, she would have been in case management, her transportation issues identified, her mother's drug addiction addressed, and a pediatric ICU admission with intubation could have been avoided. Once our practices have mastered the evidence-based care of disease, my hope is that we, as primary care physicians, can turn our attention to the genetic and lifestyle issues that lead to disease. Primary care physicians need to assess the health and risk factors of their patients and give them a map to sustained good health until age finally intervenes with a peaceful death. I dream that the medical homes of the future will provide "prospective care" as outlined by R. Sanders Williams, MD, Dean of the Duke University School of Medicine, at a 2004 United States Department of Health and Human Services symposium in Baltimore. Truly, the only way to curb the spiraling cost of healthcare in our country is to prevent that which is preventable and catch the rest in its earliest stages through a well-planned system of primary care with access for all the people of our state and nation.[3] Community Care of North Carolina is a major step in that direction. **NCMedJ**

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Cabarrus County:

A Study of Collaboration

L. Allen Dobson Jr., MD, and Torlen L. Wade, MSPH

While recent attention has been paid to office-based interventions to improve care, innovations in population-based healthcare have had an arguably larger impact on the health of the population. The experience of healthcare providers and community organizations in Cabarrus County, one of the original Community Care of North Carolina (CCNC or Medicaid Access III) pilots and early Healthy Community Access Program (HCAP) federal grantees, demonstrates two important innovations in population-based healthcare: primary care case management of the Medicaid population and integration and collaboration of safety net providers to care for the uninsured. CCNC, now expanded to cover the majority of the state, has had remarkable success statewide by ensuring a medical home for every Medicaid recipient, fostering community-wide collaboration around improved systems of care and employing disease management strategies to improve care. These principles applied statewide have resulted in remarkable improvements in asthma care, decreased hospitalizations, and a resultant savings of $124 million for state fiscal year 2004 for women and children covered by Medicaid.[1] HCAP grants and the Project Access model of Buncombe County have been used to improve volunteerism and coordination of care for the uninsured. Although every community is different in terms of resources and stages of healthcare systems development, this description of Cabarrus County's experience may define principles and elements of successful provider collaboration and system change.

History

Cabarrus County has a long history of excellent medical care; often beyond that expected in a community of its size. From the early days when textiles dominated the local economy, Northeast Medical Center (then Cabarrus Memorial Hospital) had a close tie to the textile industry and, in particular, with Cannon Mills. Charles A. Cannon served as Chairman of the Board of Directors of Cabarrus Memorial Hospital and was an early champion of high-quality healthcare. This close relationship continues today as the Cannon Foundation and Charitable Trusts supports the hospital and many worthwhile health-related projects. One early example was the medical education affiliation with Duke University supported by the Cannon Charitable Trusts, which improved physician continuing medical education and helped recruit many of the early specialists to the community. In the 1980s and early 1990s, in response to rising healthcare costs, there were attempts at healthcare integration through development of a health maintenance organization (HMO) and other managed care endeavors. Although these initiatives were not successful over the long term, they did set the necessary groundwork and provided valuable experience among physicians and other healthcare providers for working together.

Background of Collaboration

Cabarrus County and its many healthcare providers and agencies had a number of successful collaborations prior to more formally organizing as Cabarrus Community Care Plan, Inc. (CCCP) to locally manage Medicaid recipients and to coordinate the care of the uninsured. Some notable examples of early collaboration include:

- The *Community Free Clinic*, founded in 1994 by two retired physicians, Drs. George Liles and David Lockhart, receives wide community and provider support and plays a significant role in CCCP by providing a site for eligibility determination, medical care, and pharmacy services for the uninsured.
- The Cabarrus Family Medicine Residency Program, a collaborative venture between Northeast Medical Center, its medical staff, and the physicians of Cabarrus Family Medicine, was developed in 1996 to increase the supply of primary care physicians in Cabarrus County and rural communities in North Carolina.

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- The Logan Community Family Resource Center was a 1997 collaborative effort between municipal, health, law enforcement, and local government to provide needed services to the medically at-risk, minority population of the Logan community.
- Cabarrus Human Services Center opened in 1998 and includes Piedmont Behavioral Healthcare (mental health agency), Cabarrus Health Alliance (health department), and the department of social services under one roof. Co-location of these agencies has promoted access to care and ease of service.

> *"One of the keys to CCCP's success was the inclusive nature of the organization. While keeping the key providers of care at the center of the organization, there was balanced decision-making and building of trust among the entire medical community."*

Other notable community organizations that resulted from community collaboration include: Healthy Cabarrus (1998), Mental Health Association of Cabarrus County (1998), Latino Advocacy Council (1999), Parish Nurse Program (1997), Medical Assistance Enrollment Network (1995), and others.

Organization

In 1998, the community informally organized and applied to become one of the first Access III Medicaid pilots. Access III networks were defined as full-county initiatives that included the majority of physicians providing Medicaid services, the local hospital, the health department, and the department of social services. The goals of the network were to:

- Work directly with those community providers who have been caring for Cabarrus County's Medicaid recipients.
- Build a public and private partnership where community providers can work together to cooperatively plan for meeting patients' needs and where existing resources can be used most efficiently.
- Put in place local systems and supports that are needed to achieve long-term improvements in quality, cost, and access for Medicaid recipients; including implementing evidenced-based practice, disease management, case management, high-cost service management, and feedback and accountability.

In 2000, after a community needs assessment identified unmet medical needs for the uninsured, Healthy Cabarrus convened a task force to apply for the new federal HCAP grants available to communities to improve care for the uninsured. This application and the subsequent award became the pivotal point in the formal organization of Cabarrus Community Care Plan, Inc., a 501(c)3 (not-for-profit) corporation.

From the beginning, CCCP's governance structure included both providers of care and community organizations. A large Board of Directors represented physicians, the hospital, mental health, the health department, social services, free clinic, schools, dentists, and other community agency/organization representatives. A smaller executive committee provided day-to-day oversight. As with each CCNC network, Medicaid provided a $2.50 per member per month fee to the network to provide for management support. The HCAP grant provided needed project assistance in developing and delivering care to the poor uninsured. The network hired "care managers" who had a broad responsibility in assisting providers and patients. Another key function of the network was development of a Medical Management Committee, representing the major primary care practices charged with being the medical home for patients. Their role was development and implementation of disease management and utilization management initiatives at the practice and community level. In Cabarrus, that function fell to an already established disease management group at Northeast Medical Center. CCCP's role was to support and coordinate existing resources, rather than develop new infrastructure. One of the keys to CCCP's success was the inclusive nature of the organization. While keeping the key providers of care at the center of the organization, there was balanced decision-making and building of trust among the entire medical community.

Ongoing Projects

In addition to projects implemented as part of statewide Medicaid disease management efforts, CCCP was able to pilot new initiatives for the state and also work on local initiatives. Examples of statewide projects include asthma disease management, diabetes disease management, Prescription Advantage List (more cost effective prescribing), emergency department utilization reduction, and high-cost/high-risk case management.

CCCP was also part of initial pilot programs for the dental screening and fluoride varnish project in the zero-to-three-year-old Medicaid population, therapy services utilization management, poly-pharmacy in the nursing home project (which reduced and improved medication use among nursing home patients), and the current depression and mental health integration initiatives.

Examples of local projects include a community-wide attention deficit disorder (ADD)/attention deficit hyperactivity disorder (ADHD) management project tracking 1,481 students with ADD/ADHD; expansion of the dental care system for the poor and uninsured; and the HCAP grant, which funded the community-wide system for care of the uninsured. Through the HCAP program, 1,400 uninsured individuals received care in 2004, representing more than $2 million dollars in free physician services, and $1.2 million in free medication.

Notable Results

Although each of the above projects has shown improvements based on community and practice report cards, the most significant community results have been with regard to diabetes. Practice-based disease management for diabetes in Cabarrus County was initially championed by Dr. Doug Kelling, a local internist. His early work led to the development of a disease management center supported by NEMC. The Disease Management Center established a diabetes registry that tracks over 6,000 diabetic patients. The data measurements include hemoglobin A1C, low-density lipoprotein cholesterol, blood pressure, eye exams, aspirin, ACE inhibitor use, and monofilament exams. Patients are followed in the registry regardless of insurance type or extent of coverage. These data, in addition to practice improvement data, are collected and allow evaluation of care of the uninsured and Medicaid recipients compared to the privately insured population.[2]

The bankruptcy and subsequent closure of the largest employer in Cabarrus County, Pillowtex, created the largest layoff in North Carolina history. The increasing uninsured population combined with ongoing medical needs of former Pillowtex employees, and a growing Latino population for which disease management data indicated a lack of adequate access to care, significantly exceeded the community's ability to provide care. In response to this, CCCP led the effort to open and secure funding for a new Community Health Center

CCCP's efforts in managing the Medicaid population have resulted in significant cost savings for the state and local community. This is clearly the most significant success to-date. Despite having a higher than average per patient cost in 2001, CCCP was able to show an overall decrease in per patient Medicaid cost over the next three years of 5% (or $18.4 million). This measure best approximates utilization and is compared to a 10% increase for the state over the same period. Based on state estimates, total Medicaid expenditures in Cabarrus County, likewise, were less than would be expected over the same period and resulted in a savings of more than $1.01 million in local tax revenue.[3] Continued improvement is expected as CCCP begins management activities for the aged and disabled populations covered by Medicaid and other populations.

Lessons Learned

There are some basic principles that can be drawn from the Cabarrus experience as well as experiences in other CCNC communities.

- Community ownership is a *must* if these efforts are to be effective.
- A "medical home" for every patient remains the backbone for improving healthcare quality and access.
- You can't do it alone. Partnership, inclusiveness, and collaboration are keys to success.
- You must develop and support systems that change care at the practice and community levels.
- Physician leadership of the care improvement process is essential for long-term success.
- You have to measure outcomes. You get what you measure, but it is important to start measuring *something*, even if it is a single measure.
- Early success builds trust and makes future initiatives easier.
- Lasting change will take time and reinforcement.

Improvements in care quality, access, and savings seem to be additive (i.e., the totality of care improvement at the community level seems to be greater than the individual initiatives).

The promise of a more integrated community health system based on a primary care medical home and collaborative systems of care at the local level is attainable and should help prove the value of further development of the Community Care of North Carolina program. **NCMedJ**

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RAP
RAP 610
RAP 12
RAP 11

Clinician-Patient E-mail Communication:

Challenges for Reimbursement

Eugenie M. Komives, MD

I inadvertently entered the world of electronic communication with patients in my former practice when a staff member suggested putting some of my business cards in the exam rooms. I was not aware that she had used the version with my e-mail address on them until I started receiving unsolicited e-mail from patients. Most of the patients who proactively chose to communicate with me via e-mail did so appropriately—they asked general questions, needed prescription refills, and/or had non-urgent problems. I removed the business cards before the volume of users got "out-of-hand," and the experiment came to a natural end when I left the practice for a job at Blue Cross and Blue Shield of North Carolina as Medical Director for the State Health Plan.

Why Should Electronic Consultations Be Reimbursed?

The core question regarding the issue of electronic clinician-patient communication that both patients and insurers should answer is, "Why should I start paying for something I used to get for free?" Electronic clinician-patient communication offers a number of advantages. For the patient, the advantages might be enhanced convenience (e.g., avoiding a long wait on the telephone, multiple phone transfers, uncertainty as to whether the prescription was called into the pharmacy, and/or making un-necessary trips to the clinician). I certainly would be willing to pay a fee for the convenience, and I suspect I am not unique in this regard.

"Why should I start paying for something I used to get for free?"

A different set of reasons might prompt insurers to consider reimbursing clinicians for this service. Payers are more likely to value innovations that reduce healthcare costs, improve the quality of care for members with chronic disease (regardless of whether or not costs are reduced or stable), and improve member satisfaction for the service offered.

Technology Links Patients, Providers, Payers, and Pharmacies

Research has found that many patients value these services and are willing to pay at least a nominal amount of money for their availability.[1,2] Thus far, at least one study explores the value proposition for electronic clinician-patient communication services from the insurers perspective.[3] This study involves a product called RelayHealth® and was conducted by Stanford University and the University of California–Berkeley.

RelayHealth® is a secure, Web-based, Health Insurance Portability and Accountability Act (HIPAA)-ready platform that can facilitate electronic clinician-patient interaction. RelayHealth® includes an algorithm-driven clinical interview process called a webVisit®, which facilitates electronic communication between patients, healthcare professionals, payers, and pharmacies. Through this type of program, patients can consult their clinicians with specific questions or requests, and clinicians can respond with the assistance of medically-reviewed, guideline-based content and can even attach patient education materials from an online library. Other patient-oriented features include prescription renewal, appointment scheduling, obtaining lab results or referrals, and access to self-care information. Possibilities for clinicians include: a program that coordinates referrals, triages patient messages, broadcasts preventive reminders, and sends appointment reminders and lab results. The program is also able to determine the patient's insurance status and can submit claims to participating insurers.

Stanford University and the University of California–Berkeley performed a pilot study with RelayHealth®, Blue Shield of California, ConnectiCare, and several large self-insured employers affiliated with Pacific Business Group on Health (using Aetna as a third party administrator).[3] The pilot was designed to answer the following questions:

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- What is the impact of the availability of RelayHealth® webVisit® services on healthcare utilization and costs?
- How do patients respond to the opportunity to communicate with their clinicians online in this manner?
- How do clinicians respond to the opportunity to deliver non-urgent care online using these tools?

The program was conducted between April 2001 and May 2002. Physicians were reimbursed $25 per webVisit® (other communication was not reimbursed), and the patients had copayments of $0-$10 per webVisit® consultation. Two hundred eighty-two physicians and 3,688 patients agreed to participate in the study. A control group matched for baseline demographic characteristics, including access to the Internet, was selected. Analysis of available claims information found that office visit costs decreased by $1.92 per patient per month, and total medical costs decreased by $3.69 per patient per month. The cost of reimbursement for webVisits® averaged $0.31 per member per month, and the return on investment was greater than five-to-one for the insurers. Patients and physicians were very satisfied with the program, and most (75%) agreed to continue using the service after the pilot program ended. Physicians indicated that reimbursement was critical in motivating them to use the program.

Based on the findings of this program, Blue Shield of California expanded the program to all of their Preferred Provider Organization (PPO) and Health Maintenance Organization (HMO) physicians. The medical director of the University of California–Davis Health System, a participant in the pilot program, indicated that in-person clinical productivity per day and per visit went up significantly. He postulated that this was likely due to the movement of non-urgent medical issues to the webVisit® format, which frees time for more acute office visits. Also in response to these findings, Blue Cross and Blue Shield of Massachusetts announced a similar pilot program using RelayHealth® in March, 2003.[4] The American Medical Association (AMA) and the American College of Physicians have issued position papers urging the Center for Medicare and Medicaid Services (CMS) to begin reimbursing physicians for these types of services for Medicare patients as well.[5]

In their position paper on the issue of reimbursement for e-visits, the American College of Physicians listed examples of reimbursable and non-reimbursable e-mail services.[5] Non-reimbursable e-mail services typically require no more than two minutes of physician time and could often be delegated to non-physician staff after instruction. Examples include reporting normal test results, e-mail with other clinicians in reference to patients, and renewing prescriptions (services that are typically not reimbursed today). Reimbursable services involve such things as a new diagnosis with treatment that does not involve a subsequent office visit, follow-up of chronic diseases that involve changes in medication, treating relapses of previously diagnosed conditions that require significant physician judgment, reporting lab tests that require changes in management, extended family counseling, review of computer-transmitted patient medical data, and answering questions about preventive health or general health questions. Without the electronic format, such services would typically involve a face-to-face visit, and thus are reimbursable today.

General recommendations for the appropriate use of electronic communication with patients are available from the AMA.[6] and other organizations. These include the following (not a comprehensive list):

- Develop a patient-clinician agreement for informed consent in using e-mail; specify appropriate use of e-mail versus phone or office consultation; ensure security mechanisms are in place; and have hold-harmless understandings for technical failure of the system.
- Install general security measures (e.g., password-protected screen savers, rules against sharing e-mail addresses with family members or outside third parties, etc.). Many recommend encrypting messages and using authentication or password protection methods for clinicians and patients.
- Use e-mail to communicate with established patients only.
- Include copies of all messages in the patient chart.
- Establish turn-around time expectations; provide coverage when the primary clinician is out of the office; provide guidelines on the length of messages and what constitutes appropriate content; use auto-reply features to assure that messages are received; use the patient’s identification numbers in the body of e-mail messages; have standard block text at the end of the e-mail regarding unintentional disclosure, and signature, phone and address of the sender, etc.

Several vendors offer products that meet such requirements. Examples include Medem’s iHealthRecord™, which is free to clinicians who do not charge their patients for the service, HealthyEmail®, and MyDocOnline™.[7]

Summary

Clinicians are rapidly gaining experience with online clinician-patient consultation, and more tools are becoming available to support these efforts. In addition, we now have evidence that using electronic communication is cost-effective to payers and appealing to patients and providers. At present, there appear to be few barriers to the adoption of these solutions for practices that use other online services. Security concerns can easily be overcome by using programs described in this commentary. Larger and longer studies that evaluate the benefits and cost savings in more detail may help convince other payers and providers of the utility of the Web-based programs. More studies are needed to understand the effect of clinician-patient electronic communication on the costs of caring for chronic illness. When these solutions also include support tools, such as electronic prescribing, which could improve patient safety and quality of care, they should be encouraged.

In their article entitled, “Electrons in Flight–Email between Doctors and Patients,”[8] Delbanco and Sands postulate that the future of e-communication in medicine will be integrated with a patient-controlled health record and will include secure synchronous and asynchronous communication, video conferencing and messaging, instant transcription into the written record, full-patient access to the record, translation into different languages, connectivity to multiple data sources, incorporation of multi-media educational materials. It will also allow data from home-based diagnostic technology to be sent to clinicians. "Electronic communication will move medicine inexorably toward such transparency, enabling doctors and patients to share knowledge, responsibility, and decision-making more equally. We need to explore rapidly how this change will affect the quality of care for patients and the quality of life for doctors."

The widespread dependence on Internet-based electronic communication to support a variety of commercial, educational, and entertainment needs and interests offers us an opportunity to develop innovative approaches to some long-standing problems—assuring the accessibility of clinicians to their patients and the effectiveness and timeliness of communication between them. It is exciting that we now have well-documented examples of how these new technologies can be used to enhance the quality of primary care practice in both large and small practice organizations. **NCMedJ**

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Innovations in the Practice of Primary Care:

Communicating with Patients through E-mail

Donald C. Spencer, MD, MBA

American medicine is used to technological change. We usually think of technologic advance in terms of the latest generation of magnetic resonance imaging (MRI) scanner or the newest composite material used for hip prostheses. Clinician-patient communication and the documentation of that communication have gone through technological change as well. In 1754 the managers of the Pennsylvania Hospital, including Benjamin Franklin, adopted new rules for its physicians and surgeons. Rule eight stated that "the practitioners shall keep a fair account (in a book provided for that purpose) of the several patients under their care, of the disorders they labor under, and shall enter in the said book the recipes or prescriptions they make each of them." The recording of medical information has gone through several technological changes over the past decades. I took over the practice of Dr. James Covington in Wadesboro, North Carolina in 1984, along with some meticulous records he had kept of the patients under his care. In the course of reviewing one patient's file, I noted that the doctor's handwritten notes in 1947 had been supplanted with notes Dr. Covington had personally typed on his typewriter. As I took over his practice, I was changing the technology of documentation once again by dictating my office notes, which were then transcribed by a paid technician. My current practice of entering parts of the patient's history directly into an electronic health record underscores the distance we have come from 1754. The technology of non-face-to-face patient communication is undergoing transition today as well. Alexander Graham Bell's invention of the telephone in 1876 is being increasingly supplanted by a patient preference for clinician-patient e-mail communication. Bell warned of the resistance to change by stating, "When one door closes another door opens; but we often look so long and so regretfully upon the closed door, that we do not see the ones which open for us."[1]

Given the controversies surrounding clinician-patient e-mail, I was asked by our medical school dean to chair the E-Health Committee in October 2002 at the University of North Carolina at Chapel Hill (UNC), where I serve as a clinical faculty member in family medicine. The primary charge of the committee during my leadership was to develop a pilot for clinician-patient e-mail that would explore the usefulness and the challenges of this new technology. The group consisted of four physicians, including the chief of the hospital staff and the chair of a clinical department, information technology experts, and a marketing professional. The committee performed a literature review of relevant communications on clinical e-mail and explored commercial options that might assist us in applying the technology effectively. The committee developed a pilot Web portal to test the concept of e-mail in two UNC clinics. We developed a survey of clinicians at UNC to explore their attitudes toward doctor-patient e-mail. Finally, we made recommendations to administration on how to proceed with system-wide implementation.

> *"'When one door closes another door opens; but we often look so long and so regretfully upon the closed door, that we do not see the ones which open for us.'"*[1]

In reviewing the work already done on clinical e-mail communication, acknowledgement of the "digital divide" is particularly important in a public hospital such as UNC. Not all patients have access to computer resources. The gap between digital "haves" and "have-nots" is real but narrowing. Twenty-four percent of Americans have no direct or indirect experience with the Internet. Americans more likely to be "wired" are younger,

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well-to-do, white, well-educated, and living in non-rural areas. Southerners are the least likely to use the Internet. Only 38% of Americans with disabilities go "on-line" as compared with 63% of all Americans.[2]

Kane published a classic reference in the *Journal of the American Medical Informatics Association* that our committee relied on heavily. The article presented guidelines to facilitate effective clinician-patient interaction, while using principles that would increase patient safety and decrease lawsuits.[3] We followed suggested communication guidelines, such as establishing turnaround time standards, warning against e-mail use for urgent matters, informing patients about e-mail privacy issues, and establishing categories of e-mail transactions (prescription refills, scheduling, etc.).

More recent work on patient e-mail has been published since our committee's work. Liederman and Morefield published their experience at University of California–Davis with a commercial Web messaging system (RelayHealth®). They confirmed the high patient satisfaction of such systems with 85.8% of patients either "very satisfied" or "somewhat satisfied." Seventy-five percent of clinicians were either "very likely" or "somewhat likely" to continue using the system after the study period.[4] Waldren and Kibbe, writing for the Center for Health Information Technology of the American Academy of Family Physicians, endorse the inclusion of provider-patient e-mail in the electronic health record.[5] In a two-part series, Car and Sheikh review the progress to-date of e-mail consultations and advocate for the coordinated action of healthcare professional organizations, patient groups, policy makers, and the information technology industry to facilitate widespread use.[6]

Our E-Health Committee reviewed commercial vendors that could help us with our development. We had presentations from Medem™ (www.medem.com), Tumbleweed® (www.tumbleweed.com), MedFusion (www.medfusion.net), and RelayHealth® (www.relayhealth.com, formerly Healinx™). Medfusion has collaborated with the American Academy of Family Physicians to provide physician members with Web portals for doctor-patient communication. Additional commercial options for doctor-patient e-mail are referenced by Scherger in Family Practice Management.[7,8]

The Committee developed Web portals for patients to communicate with clinicians in the UNC Family Practice Center (FPC) and the UNC Diabetes Care Clinic. The Web portal approach was used because of the advantages it offered. The structured format of a Web site allowed for easy categorization of the type of message with routing of the message to appropriate triage personnel. Information such as medical record number and pharmacy name could be entered as data fields on a Web form. Such information is frequently forgotten by patients in unstructured e-mail messages. The Web portal approach allowed for future technical security options, such as encryption, that are more difficult to attain with standard e-mail messaging. During our committee work, we had to deal with the upcoming Health Insurance Portability and Accountability Act (HIPAA) regulations that changed the scope of our project. Warnings and privacy disclaimers were "required reading" before a message could be sent by a patient using the Web portal approach we developed. Usage growth was continual in the Family Practice Center since the project was begun in October 2001. The Webmail address was promoted on the telephone answering welcome message for the clinic, as well as posters and patient brochures throughout the Family Practice Center. At the onset of the project, just over 100 e-mails were received by the FPC each month. As of the summer of 2004, the clinic received just under 600 messages per month. For comparison, the clinic received an average of 9,623 phone calls per month during the period October 2003 through September 2004 (not all of which are answered because of the high volumes of calls). During fiscal 2004, the FPC saw 46,538 visits, or an average of 3,878 patients per month. This works out to be about 0.15 e-mails per visit compared with 2.5 phone calls per office visit. In a simpler time and a smaller practice, I described the nature of telephone calls in my own practice in the 1980s.[9] The phone call-to-office-visit ratio was one-to-32 at that time. While my small rural practice in the 1980s cannot be directly compared to a complex academic family practice center, patient communications appear to have gotten more complex over time. We are hopeful that the ratio of e-mails and phone calls to office visits is a moving target, and, with time, we can increase the e-mails while decreasing the incoming phone calls to a point that we answer a higher percentage of them promptly.

The categories of e-mail messages we received are instructive. Forty-one percent of e-mails received from the Web portal messaging system in the FPC were in the "Ask Your Doctor" category. The "Request Appointment" category accounted for 29%. Prescription refills were requested 16% of the time. During the period of use of the system, we requested patients to call their pharmacies for refills so this may have cut down on the number of e-mail requests for refills that we were getting. The remainder of the other catgories ("Cancel Appointment," "Change Appointment," "Referral Request," "Address Change," "Billing Question," and "Name Change") account for the remaining 14%. The important observation from these data is that less than half of e-mails require the direct attention of the physician. Our committee concluded that a triage system was essential for a functional clinician-patient e-mail system.

During the development phase of the e-mail pilot we conducted a survey of our physicians concerning their opinions about clinician-patient e-mail and our plans. The survey was conducted online during February 2002. The topic was received enthusiastically and we received responses from 195 clinicians. Attending physicians comprised the majority of the sample, with responses from 163 (or 84%) of the total. There were 19 non-physician practitioners and 13 resident physicians who answered the survey. Our first question asked, "Given a plan for dealing with privacy, security, and triage concerns, which statement best fits your feelings about getting e-mails from patients?" Seventy-five percent of respondents replied either that they would use clinician-patient e-mail for all or some of their patients or they would continue to use standard e-mail on their own. The remaining 25% stated that they would not use clinician-patient e-mail. There was strong physician agreement with several of our questions. Physicians would never want to answer e-mail from patients who have not had a face-to-face visit (77%). They thought that all e-mails and responses should be part of the medical record (71%). E-mail communication was felt to improve patient satisfaction (57%). There was physician concern that patient related e-mail might increase physician workload rather than allow for improved efficiency (63%), and there was worry that patients would use e-mail for messages more appropriately communicated on the telephone or in-person (55%). Clinicians were equally split over the question "I think that documentation of e-mails in the medical record will reduce my legal liability."

Clinicians could freely comment on the survey. The range of responses underlined the potential for division in the medical staff over the topic of e-mail. Examples of positive comments were:

- "Eliminates telephone tag."
- "Scheduling appointments would flow more smoothly. Routine questions could be answered easily."
- "Patient families 'comparison shop' at times … I think communication by e-mail is one of the things some sophisticated families are looking for when then do their 'shopping'."
- "Allows physicians to answer questions when most convenient, and allows for thoughtful and informed response."

Negative comments were of equal interest to our committee:

- "One problem is that one of my patients is a little nutty and sends me daily five-page e-mails."
- "I know of several patients that would want a long-term e-mail conversation rather than an occasional question."
- "In clinical care by e-mail, you miss the communication from being face-to-face or 'voice-to-voice'."
- "I think that this is a VERY BAD IDEA."
- "My patients are mostly poor; few have e-mail."
- "Patients WILL use e-mail inappropriately. As an example, yesterday, I received a request from a parent to be a reference for her for a health-care job on my home e-mail. Secondly, I care for adolescents, and it is most unnerving when an IM [Instant Message] comes through from SWARM124 or such saying, 'Dr. So-and-so, is that you?'"

Our committee made recommendations to the administration that included extending our pilot program to all clinics with an "opt out" for non-inclined physicians. We emphasized the importance of the triage function, privacy and security, and administrative support. We are currently working with a commercial vendor to assure encryption of messages through an enhanced Web portal and incorporation of the e-mails easily into our electronic medical record. We suspect much current e-mail activity between doctors and patients goes on "under the radar screen" in a HIPAA non-compliant fashion. By continuing to work collaboratively with our patients and our physicians, we hope to evolve a system that will adopt the new technology of clinician-patient e-mail to enhance health. Someday we may even get reimbursed for it. **NCMedJ**

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Emerging Trends in Medical Education:

What Are They? And Why Are They Important?

David W. Musick, PhD

Introduction

Medical education is currently in a state of rapid evolution. The purpose of this paper is to consider some emerging trends in how our future physicians are trained during medical school. The initial four years after completion of the bachelor's degree, known as undergraduate medical education or UME, serve as the foundation of subsequent lifelong learning. Whether a given medical school has a strong primary care mission or primarily emphasizes the preparation of future academicians, the educational issues prominent today are basically the same: how can we best train the physicians who will likely care for us and our children? The importance of this educational mission and the need to ensure its continued prominence in our society cannot be over-emphasized.

There are many categories of educational trends that affect UME, but this paper will address only two. These trends may be classified into two broad categories as follows: *Educational Theory and Philosophy*; and *Medical Professionalism and Humanism*. I will speak briefly about each category.

Educational Theory and Philosophy

At first glance, one may be tempted to think that an emphasis on *educational theory and philosophy* is nothing different, so how can this be an emerging trend? After all, isn't education and related theories what a medical school is about?

Believe it or not, the answer is "yes and no." A seasoned medical educator once wrote a tongue-in-cheek editorial entitled "When Is a School Not a School? When It Is a Medical School."[1] Historically, much of what has passed for formal education in medical schools consisted of activities that appeared to have been given seemingly little advance thought. Part of the reason for this is the long-standing use of the apprenticeship model of education, where students simply followed physicians and learned by observation. Such learning, especially during the clinical years, is highly context-dependent; students learned about patient care based on the types of patients that happened to show up in the hospital or clinic during a given time frame. However, with major recent changes in the healthcare system itself (especially shorter lengths of stay for nearly all patients who are hospitalized), we are now challenged to incorporate as much "real world" training as possible into the medical curriculum. As a result, more and more training is moving out of teaching hospitals and into a variety of new settings. So part of this trend reflects the rapidly changing environment for training medical students and resident physicians.

We know from educational research that there are three things that correlate highly with student achievement, regardless of what field of study one is engaged in. Those three things are: clarity of purpose, organization, and understandability. In other words, if you, as a student, know what the *purpose* of a given course or clerkship is, in terms of educational objectives, if the course or clerkship is *organized* to maximize your chances of achieving the educational objectives, and if you have a clear *understanding* of what you are expected to know and do (and how to do it), then chances are you will learn what you are supposed to learn.

There is great variability in how medical schools go about planning and carrying out the educational experiences required of medical students. Most medical school faculty members have little, if any, formal training in educational methods. Partly because of this lack of training, educational activities are sometimes highly organized; but at other times, they aren't. There are many factors that have an impact on how well faculty organize and carry out the educational mission, most notably the increasing time pressures faced by many teaching physicians and the lack of a stable funding source for medical education that takes place outside of the teaching hospital itself. Nevertheless, as stated in a recent journal article on residency training (i.e., graduate medical education), the emerging trend today is to "put the E back in medical education."[2]

Specifically, a major emphasis that has surfaced in recent years is the "outcomes movement." This concept requires educators to pay increased attention to not only the *process* of education (i.e., how we teach), but also to the *outcomes* of the process (i.e., whether students actually learned what we claim to have taught them). An illustration might help here. There once was a small

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boy who told his friend, “I taught my dog Rover to whistle.” His friend leaned down in front of the dog and listened for a few moments, hearing nothing. He said to the dog’s owner, “I don’t hear him whistling.” His friend replied, “I said I taught him; I didn’t say he learned it.” Sadly, many in medical education seem to think almost exactly in those terms!

Emphasizing Competency

The new emphasis on outcomes is primarily a result of an educational paradigm called “the competency model” of education. National accreditation bodies for medical schools, as well as for residency and fellowship training programs, have adopted the competency model in earnest. Notable here, for example, is the new “Six General Competencies” model, a competency-based educational approach that has been adopted by both the Accreditation Council for Graduate Medical Education (ACGME) and by the American Board of Medical Specialties (ABMS). Medical students and faculty alike should become familiar with this terminology, because it will probably be with you for the rest of your professional lives. Residency programs are now expected to demonstrate clearly that graduating residents are competent in six categories and to certify that competence in a variety of ways. Physicians in practice will also be expected to maintain their specialty certification via a system of ongoing measurement of competency, or “maintenance of certification” (MOC). This process will also feature the “Six General Competencies” approach mentioned previously. And, predictably, this model has also begun to be emphasized within accreditation standards for medical schools. The competency model can be summarized generally by the following quote from the ACGME’s “Outcome Project” Web site:

> “[The] Outcome Project refers to educational outcomes which are ‘evidence showing the degree to which program purposes and objectives are or are not being attained, including achievement of appropriate skills and competencies by students’…Achievement of learning is the ultimate purpose of any well-structured educational activity.” [3]

Given the complex body of knowledge, skills, and attitudes that medical students are expected to achieve, the task of specifying, measuring, and documenting well-defined educational outcomes in each area has become very complex. Medical educators at all levels across the country are currently engaged in rigorous debates about this very task. Suffice it to say that the movement of medical education accreditation toward the competency model will result in many changes to the methods used to train future physicians and to the process of ensuring that physicians already in practice can maintain their specialty certifications.

Other issues are also emerging in regard to medical education philosophy. For example:

- *Technology in Education* will include how to incorporate computers and/or other information storage and retrieval devices into the teaching and learning process and into providing efficient patient care. This includes enhancing communication among members of the healthcare team, between health professionals and the patients they serve, and between physicians and those entities that pay for healthcare (e.g., insurance companies). Examples include the use of Palm® technology, electronic prescription services, and medical records; and taking full advantage of electronic resources available online that inform the provider about evidence-based medicine.
- *Quality of Care* will include how the traditional apprenticeship model of clinical education must be modified to include research findings about such things as human performance, quality assurance in medicine, and preventive care. Examples include an emphasis on patient safety, reporting and prevention of medical errors, duty hours for physicians in training, and community-oriented health intervention projects.
- *Alternative Assessment* will include how to measure learning based on a variety of methods that will give a complete picture of what the student knows, can demonstrate, and ultimately can do on a regular basis.[4] Gone are the days where we will rely solely on standardized multiple-choice exams (in the basic science years) and subjective ratings by faculty (in the clinical years) to tell us whether a medical student is ready to progress to the next stage of the learning process. Examples include documented personal observation of students in the clinical setting; testing students with standardized patients; learning procedural skills using computer-assisted human simulators; assessment of physicians by patients and/or other members of the healthcare team; and the use of educational portfolios to document a variety of educational accomplishments.

Some of these concepts and methods can seem intimidating to faculty, as they represent profoundly different approaches to teaching and evaluating student progress. Such methods require the active partnership and collaboration of one’s students, and this, in turn, requires viewing students in different ways than the more traditional approaches. It appears that the competency model will now be emphasized throughout medical training and well into the future clinical practices of our students.

Medical Professionalism and Humanism

The second major emerging trend that must be considered is *medical professionalism and humanism*. It must be acknowledged that this trend is certainly not completely new. After all, hasn’t the tradition of “medicine as a compassionate healing art” been with us from the very beginning of the profession? And haven’t physicians always been considered “professionals?” Yes, but there are some new developments worthy of attention.

One such development pertains to cultural diversity in medicine, including the issue of “spirituality in medicine.” This emphasis is a reflection of the increased diversity of the patient population in the United States. For example, at least two thirds of the medical schools in this country now offer formal courses of study that examine the role of patient spirituality in the healing process. Recent scholarly literature suggests that certain health outcomes may be heavily influenced by the patient's cultural background, spiritual practices, and/or native traditions. This is an emerging and important area of research inquiry at the national level.

Some people place this type of thing squarely in the category of complementary or alternative medicine. But it's more than that; much more. It is foundational to the practice of what is now called "holistic, patient-centered care." In order to practice such care, it is necessary to be familiar with the types of patients served and their cultural backgrounds. Included is the need to expand our horizons a bit to consider not only the health of the individual patient, but the entire community from which the patient comes. We must be willing to accept a greater level of community involvement as part of the educational process, including a willingness to contribute to regional and national discussions about the healthcare system itself.

Related to this is dialogue taking place nationally and within every medical discipline about what it means to be a "medical professional." The concept of professionalism, which is included as one of the "Six General Competencies" mentioned earlier, has been defined in a variety of ways. Perhaps most noteworthy is the definition offered by the American Board of Internal Medicine and the American College of Physicians in a 2002 document entitled "Medical Professionalism in the New Millennium: A Physician Charter."[5] This document contains three fundamental principles that help define professionalism: the primacy of patient welfare; patient autonomy; and social justice. These principles are to be worked out in everyday practice through adherence to a set of ten professional responsibilities. Both current and future physicians should obtain this document and think seriously about the implications it will have on their future careers as physicians. (see Table 1).

Another way to think about the professionalism trend has to do with the churning debate about healthcare in our country. Is healthcare a right or a privilege? Clearly, we haven't decided yet. Issues such as managed care, increasing numbers of patients without health insurance, and the malpractice insurance crisis are contributing to a re-examination of medicine as a career choice. Many practicing physicians are changing careers, choosing to opt out of the system entirely rather than continue facing the daily pressures of dealing with frustrated patients, cost-cutting measures that threaten basic care, complex billing systems, and payers who don't want to pay claims. Organizations have sprung up across the country to provide retreats and other types of interventions for physicians who are angry, exhausted, emotionally burnt out, and exceedingly frustrated with a system that they have little control over. One popular healthcare consultant has observed emphatically that "the soul of medicine is on trial."[6]

As part of this emerging trend that compels us to think about medical professionalism and why people should want to be physicians in the first place, it is critically important for us to focus on the related issue of *why* the process of educating new physicians is so important. To do that, I share a brief story. In December of 2002, a young man that I knew well visited our home. He was a 21-year-old college student. He had not felt well recently; he seemed unusually tired. He complained of several symptoms related to a significant pain in his right upper arm. In fact, this pain had been present, off and on, for over three years. He had been to see doctors in several different locations over the course of the previous three years and had received several different diagnoses—everything from "repetitive motion injury" to "carpal tunnel syndrome" to "muscle strain of unknown origin." He was given pain medication a time or two, but some of the physicians seemed suspicious about his asking for pain medicine, in spite of his experiencing such severe pain that he couldn't concentrate very well on his studies and often missed class due to feeling badly. He saw a total of 13 different physicians during that three-year period for this problem. He had numerous exams, tests, physical therapy sessions, blood work, needle sticks, and electrodiagnostic studies. And he spoke frequently about how harried and tired the physicians seemed to be.

Table 1.
Medical Professionalism in the New Millennium*+

Fundamental Principles	Set of Professional Responsibilities
Primacy of Patient Welfare	Professional Competence
	Honesty with Patients
	Patient Confidentiality
Patient Autonomy	Maintaining Appropriate Relations with Patients
	Improving Quality of Care
	Improving Access to Care
	Just Distribution of Finite Resources
Social Justice	Scientific Knowledge
	Maintaining Trust by Managing Conflicts of Interest
	Professional Responsibilities

**From Physician Charter on Medical Professionalism; Medical Professionalism Project (2002).*
+Jointly Adopted by: the American Board of Internal Medicine Foundation, American College of Physicians Foundation, and European Federation of Internal Medicine.

This young man was very discouraged about his interactions with the healthcare system. He felt that his problem had not been taken seriously and that some of his physicians had been dismissive of him. He was also frustrated because his problem seemed to be getting worse, but he wasn't quite sure what to do about it. At the time of our conversation, his arm appeared grossly swollen. A physician colleague was contacted the next day, and arrangements were made for the young man to be seen immediately; in fact, he had a biopsy under anesthesia on

Christmas Eve of 2002.

As it turned out, the young man was diagnosed with a soft tissue Ewing's Sarcoma, a fairly aggressive type of cancer. He spent the entire 2003 year in and out of the hospital. He was hospitalized 11 times that year. He had nine rounds of inpatient chemotherapy, along with surgical removal of his tumor. During the surgery, he lost the median nerve in his upper arm, his dominant arm, resulting in some permanent loss of function in his right hand. He also endured five weeks of outpatient radiation therapy. He had a very scary neutropenic episode. This was a tough year for this young man and his family. The rest of his story is better. He received excellent care after the correct diagnosis had finally been made. His surgery was successful, he has undergone follow-up exams every three months, and, as of today, he is cancer-free and feels well. He is also back in school on a full-time basis. What does his story say about medical professionalism? Does the structure of our modern healthcare system, which often frustrates physicians and patients alike, encourage or hinder the practice of medicine in its best sense?

In the fall of 2003, at the annual meeting of the Association of American Medical Colleges in Washington, DC there was a panel presentation concerning the future of medical education in this country. One of the speakers was the mother of two children who suffer from cystic fibrosis. This mother spoke eloquently about her dilemma as the parent of a sick child. She spoke of the uncertainties that her family has to face and live with every day. These uncertainties are about: her children's treatments and their future prognosis, how to deal with information overload about their disease, what that information might mean to them, how to negotiate their way through the maze that is our current healthcare system, and how to make medical decisions for her children (e.g., confronting frequent questions, such as, "Is this a lung infection or just a simple cold? Should I go to the emergency room tonight or wait and call the doctor in the morning?").

"the soul of medicine is on trial."

Interestingly, this mother also saw many similarities between the uncertainties that her family faced and the uncertainties that define medical practice itself. She told her audience that it is not only an uncertain time to be a patient, it is also an uncertain time to be a physician, given complex new scientific discoveries, clinical ethical dilemmas, and ever-increasing levels of knowledge needed by tomorrow's physicians. She suggested that her physicians faced many uncertainties of their own during their everyday practices with such questions as, "Will this patient trust me? Is this the right treatment approach? Will I have enough time to spend with this family? Will the insurance plan cover the tests this child needs?"

This brave woman went on to talk about the importance of what many now refer to as "collaborative medicine"—how patients and their physicians must learn to be partners in the medical care given and received. She was asked what she wanted today's medical students to know from her perspective as a mother of two children with chronic illness. Here is part of what she said:

> "I want every medical student to know that all of the science they are learning will bring physical healing, but I equally want them to know the power of words. I want them to know the impact a doctor has when they choose words that support human partnerships. Like being able to say to a patient, 'I want to know what is happening.' 'I understand how you are feeling.' 'I believe I can help.' I hope we can beat this.' What matters to patients and families is not just what the doctor says, but how he or she says it. The echoes of our doctors' words played on and on long after we learned the technical meaning of cystic fibrosis."

And then she closed her remarks by making a profoundly important statement:

> "I want the doctors of tomorrow to know that when all the formal teaching is over, and I walk into your office, my need is for medical care for my child; but my desperate hope is that you have the same stake in my child's health as I do."[7]

Powerful words! These remarks from the perspective of a consumer of modern healthcare are important, not only to physicians in training, but to those who teach them. They illustrate in a very personal way the need to pay close attention to the training process and to acknowledge how the non-technical "art of medicine" will always be vitally important.

This issue of professionalism is intensely personal for each of us. Do you remember the young man mentioned earlier in this article? He is my son. We live as a family with the uncertainties associated with his illness. It is never far from our thoughts, and it impacts our lives every day. And our experiences as a family with the healthcare system, both during his illness and since then, have had a profound impact on how I think about and contribute to the process of educating physicians.

Conversations about professionalism and humanistic medical practice, about being sensitive to cultural issues, and about providing holistic care are an important part of the physician training process. They should remind us of what medicine is truly all about: the patients. When tomorrow's physicians progress to the point of their training where they put on the white coat for the first time, and, subsequently, wear it to the wards and the clinics every day, they must always remember how important mere words can be to the patients receiving their care. This is the essence of professionalism, and our training process must not overlook it.

Conclusion

The uncertainties that tomorrow's physicians will face are, in fact, a reflection of the uncertainties we all face—as people. Modern medicine is indeed a partnership between the physician and the patient. Equally, in lieu of the emerging trends just discussed, medical education *must* become more of a partnership between students and faculty, between medical schools and the community physicians who sacrifice their own time in order to help teach our students, and between medical schools and the communities they should be dedicated to serving.

This article has briefly summarized two emerging trends in the process of educating tomorrow's physicians: an emphasis on educational theory and philosophy and a focus on professionalism and humanistic medical practice. Medical education is evolving rapidly with new methods; increased emphasis on lifelong learning; and new ways of assessing the knowledge, skills, and attitudes of our students. Medical education takes place in an elaborate cultural milieu, one that is uniquely hierarchical and tends to embrace change very slowly. Nevertheless, we must embrace these trends if we are to be successful in efforts to educate competent, humanistic physicians for the next generation. **NCMedJ**

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Remembering Eben Alexander, Jr., MD

David L. Kelly, Jr., MD

Dr. Eben Alexander, Jr., died at his home in Winston-Salem, North Carolina, Thursday, November 4, 2004. Dr. Alexander was born in Knoxville, Tennessee on September 14, 1913, to Elizabeth McMath Alexander and Eben Alexander, MD, a prominent surgeon in Knoxville. He graduated from the McCallie School and then attended and graduated from the University of North Carolina at Chapel Hill where he was Phi Beta Kappa. He graduaged cum laude with a doctor of medicine (MD) from Harvard Medical School in 1939 and was elected to Alpha Omega Alpha, the honorary medical society. He was later made permanent president of his medical school class of 1939, which included many prominent physicians and surgeons.

He began his residency training in neurosurgery at the Peter Bent Brigham and Children's Hospital in Boston. His training, however, was interrupted when he joined the Air Force in 1942. He received training at the Walter Reed General Hospital prior to being transferred to the Pacific theater where he served in New Guinea and the Philippines. He was awarded the Bronze Star and was discharged with the rank of major in 1946. After the war, Eben returned to Boston and then to Toronto and New Haven, where he completed his formal neurosurgical training. In 1949, he joined the full-time faculty at the then Bowman Gray School of Medicine of Wake Forest College in 1949, being appointed assistant professor of surgery in charge of neurosurgery. In 1954, he was appointed professor of surgery (neurosurgery). From 1949 to 1978, he was professor and head of the department of neurosurgery. He built a superb clinical program in neurosurgery and participated in the training of 39 residents, as well as enriching the learning experience of numerous medical students, interns, and residents. A review of his writings (some 200 publications) reflects an unbelievably broad interest and grasp of professional and societal concerns.

He was chief of professional services at the Medical Center for 20 years, participating in a substantial way to both the hospital and the medical school's growth and development. He arguably was the most influential member of the faculty in the history of the Bowman Gray School of Medicine. Dr. Alexander was president of virtually every important neurosurgical society including the American Association of Neurological Surgeons (the Harvey Cushing Society), the Society of Neurological Surgeons, and the American Academy of Neurological Surgeons. He served many years on the editorial board of the *Journal of Neurosurgery* and was an assistant editor, and later editor, of Surgical Neurology. He also served on the *North Carolina Medical Journal*'s editorial board and was a major contributor to their efforts.

He served six years as a member, and later chairman, of the North Carolina Board of Medical Examiners and was founder and chairman of the committee on ethics for the Medical Center.

His honors and awards are much too numerous to list; however, they include the North Carolina Physician of the Year in 1969; the Medallion of Merit at Wake Forest University in 1989, which is the highest award that can be awarded to a member of the faculty; the Distinguished Service Award from the American Medical Association; and the Distinguished Service Award from the Society of Neurological Surgeons.

In 1983, he was appointed professor emeritus. At that time he stopped active clinical practice, but continued writing and editing and also performed as an unofficial ombudsman for many friends and patients in need of medical care.

His activities in the community were numerous. He was a loyal and faithful member of the Centenary United Methodist Church and a weekly attendee of the Rotary Club of Winston-Salem where he served as president in 1959-1960.

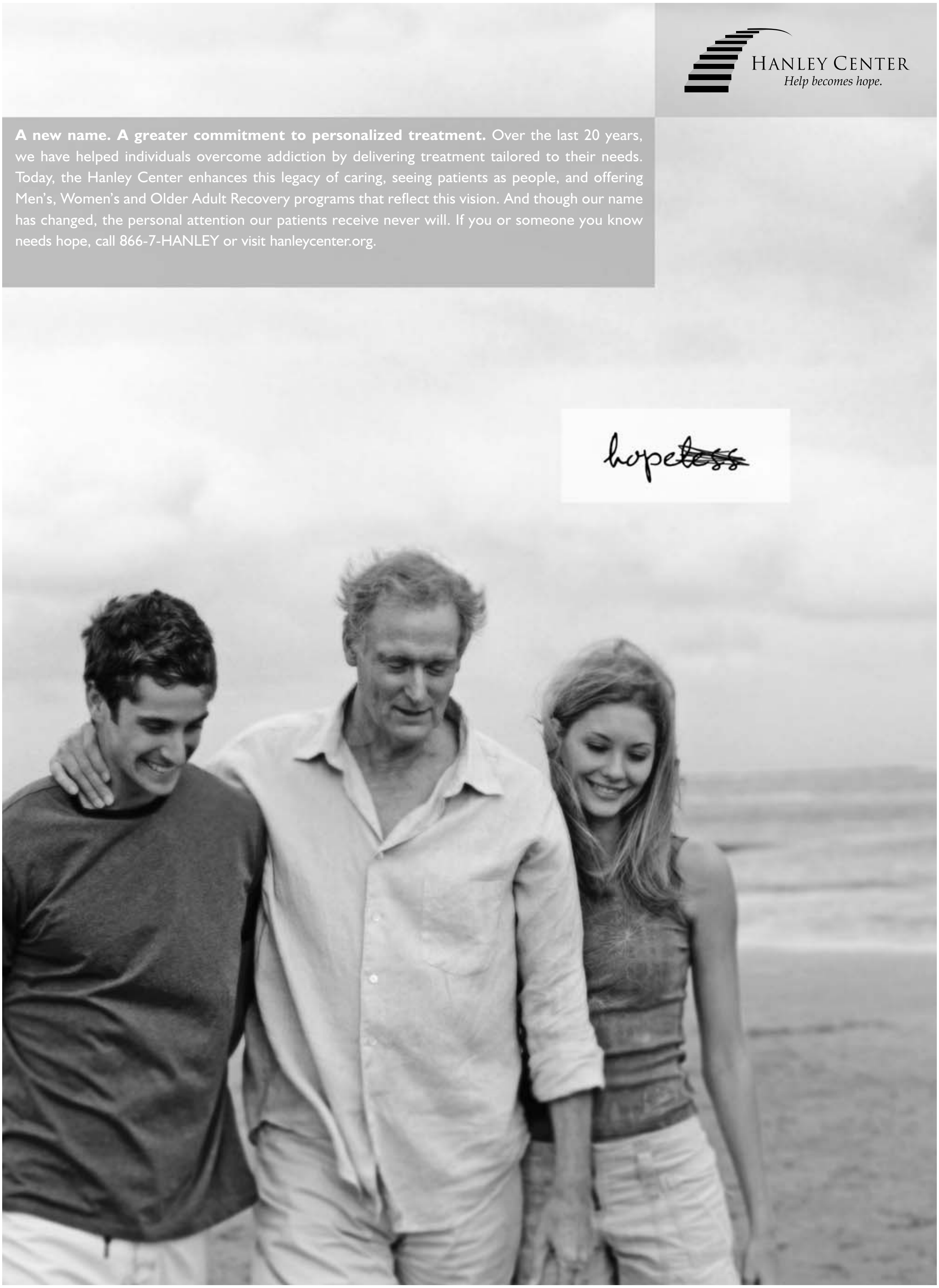
He possessed an excellent innovative spirit and energy. He was among the first to advocate seat belts. He was an advocate for people with disabilities and was instrumental in the movement to improve sidewalk and ramp access. He established a successful support group for paraplegics, as well as special clinics for them and children with spina bifida.

Dr. Alexander will always be remembered for his enthusiasm and proficiencies, his perseverance and attention to detail, his spirit of compassion, honesty and excellence in all that he did.

We at the Wake Forest University Baptist Medical Center have benefited greatly from his skills, his good works, and have been blessed to have witnessed a career of great breadth and success and a life of abundance.

Dr. Alexander is survived by his wife, Mrs. Betty Alexander, four children, and four grandchildren. **NCMedJ**

David L. Kelly, Jr., MD, is Professor in the Department of Neurosurgery at Wake Forest University School of Medicine. He can be reached at the Department of Neurology, Medical Center Boulevard, Winston-Salem, NC 27157-1029. Telephone: 336-716-4049.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Coming in the July/August 2005 issue of the

North Carolina Medical Journal

a look at

Dietary Quality in Long-Term Care

The North Carolina Institute of Medicine

Since January 2002,
Publisher of The *North Carolina Medical Journal*

In 1983 the North Carolina General Assembly chartered the North Carolina Institute of Medicine as an independent, nonprofit organization to serve as a non-political source of analysis and advice on issues of relevance to the health of North Carolina's population. The Institute is a convenor of persons and organizations with health-relevant expertise, a provider of carefully conducted studies of complex and often controversial health and healthcare issues, and a source of advice regarding available options for problem solution. The principal mode of addressing such issues is through the convening of task forces consisting of some of the state's leading professionals, policy makers and interest group representatives to undertake detailed analyses of the various dimensions of such issues and to identify a range of possible options for addressing them.

Members of the North Carolina Institute of Medicine are appointed for five-year terms by the Governor, and each task force convened by the Institute typically includes at least one-third of its membership from among the appointed members. Topics to be addressed through task force efforts are chosen following requests from the Governor, the General Assembly or agencies of state government. In some cases, topics are selected on the basis of requests from a number of stakeholder organizations across the state where this type of analytical process is considered to have potential value.

The North Carolina Institute of Medicine assumed the role of publisher of the *North Carolina Medical Journal* in January 2002 through an agreement with the North Carolina Medical Society, which founded the Journal in 1845. The Institute views the *North Carolina Medical Journal* as an extension of its mission. The Journal provides a forum for stakeholders, healthcare professionals, and policy makers and shapers to study and discuss the most salient health policy issues facing our state. Like many states, North Carolina is grappling with issues such as an increasing number of uninsured, the unmet health needs of the growing Latino population, a critical shortage of nursing personnel, the health risks of tobacco and obesity, rising prescription drugs costs, mental health system reform, the increasing societal burden of chronic illness care, the threat of bioterrorism and the necessity of assuring adequate public health preparedness—all in the midst of an economic downturn. Each of these issues presents unique challenges to healthcare providers and state policy makers. Yet, a fully implemented task force to consider each of these sets of issues is not feasible. The Journal makes it possible to present an organized and balanced overview of some of these issues, six times per year, and allows interested persons the opportunity to engage in the ongoing discussion of these issues throughout the year. The Institute hopes that our readers of the *Journal* will, in this way, become involved in the continuing debate about the most promising avenues for assuring the highest standards of health and healthcare for all North Carolinians.

health policy

North Carolina Institute of Medicine

Running the Numbers

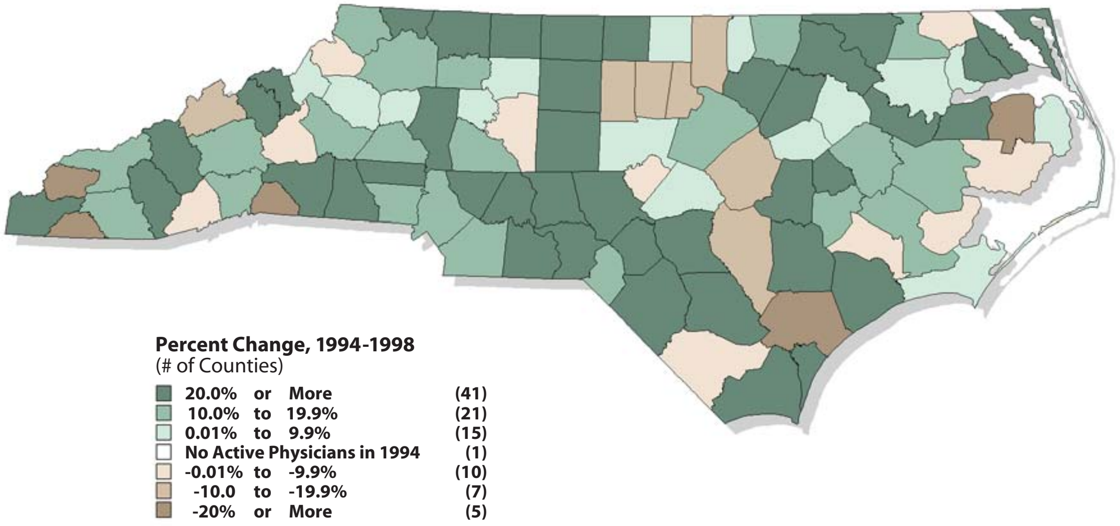
A Periodic Feature to Inform North Carolina Healthcare Professionals about Current Topics in Health Statistics

Contributed by Thomas C. Ricketts III, PhD, MPH, and Katie Gaul, MA
Cecil G. Sheps Center for Health Services Research

Primary Care Physician Supply in North Carolina

The first map shows changes in the ratio of physicians-to-population for the period 1994-1998, and there is a general trend toward improved ratios and better distribution of primary care physicians across most counties in the state. This trend slows in the next period, 1998-2003. There are smaller increases in the ratio of doctors-to-population, and we are beginning to see more areas where there are physician losses. The final map shows that some of these changes in ratio are due to population shifts. In some counties the population has grown faster than the doctor supply, and in others, the doctor supply has decreased along with the population. The latter category includes places where the economy has slowed and places that are at real risk for losing important human and professional resources. Counties where there is rapid population growth present other challenges for physician supply as the professionals have to meet the needs of more people.

**Percent Change in Primary Care Physicians per 10,000 Population
North Carolina, 1994-1998**



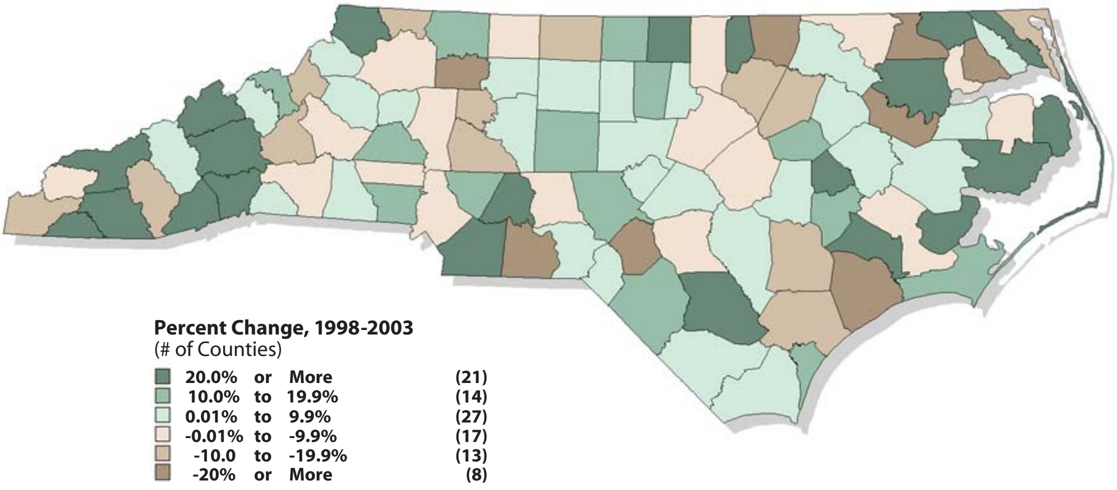
Source: North Carolina Health Professions Data System, Cecil G. Sheps Center for Health Services Research, University of North Carolina at Chapel Hill, with data derived from the North Carolina Medical Board, 1994-1998.

* There were no active physicians in 1994; there were two active physicians in 2003. Counts include active, instate, nonfederal, non-resident-in-training physicians who indicated a primary specialty of family practice, internal medicine, general practice, OB/GYN or pediatrics.

continued on page 254

continued from page 253

Percent Change in Primary Care Physicians per 10,000 Population North Carolina, 1998-2003



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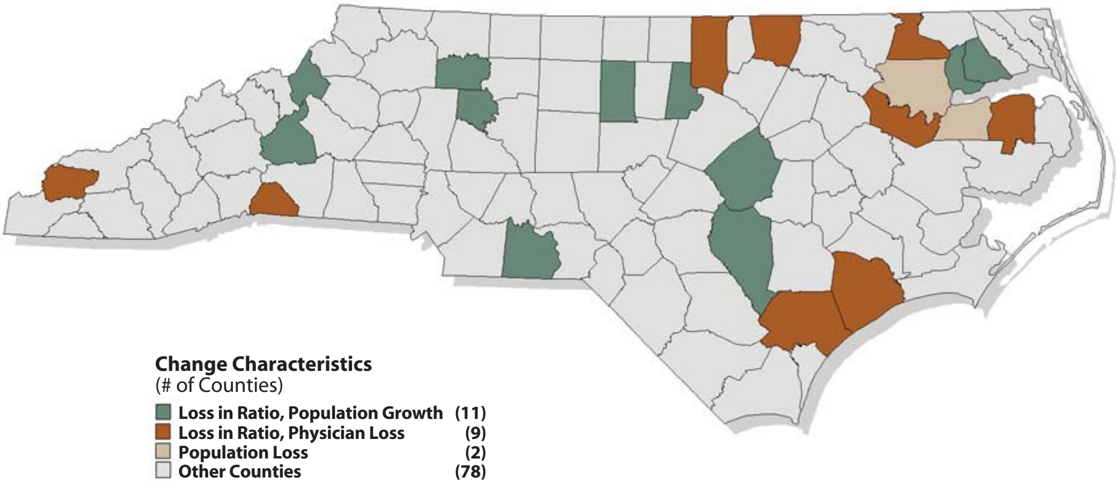
Counts include active, instate, nonfederal, non-resident-in-training physicians who indicated a primary specialty of family practice, internal medicine, general practice, OB/GYN or pediatrics.

Components of Primary Care Physicians Ration Change North Carolina, 1994-2003



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Counts include active, instate, nonfederal, non-resident-in-training physicians who indicated a primary specialty of family practice, internal medicine, general practice, OB/GYN or pediatrics.

Readers' Forum

The North Carolina Healthcare Safety Net

To the Editor

The North Carolina Healthcare Safety Net Edition (Volume 66, Number 2) is worthy of everyone's attention, for it shows how tenuous the safety net is and how easily it can be torn further.

On reading and rereading this volume, I have not found a reference to a valuable, but overlooked resource for low-cost and excellent patient care, the retired physicians who reside in almost all of our communities.

I have spent the past 14 years as a member of the Senior Physician Services Group Committee of the American Medical Association (AMA) and have learned that many of our retired colleagues all across the country would gladly help meet the need by volunteering their services. As physicians retire earlier to escape the rigors and changes associated with medical practice today, more are available to help in the volunteer arena. We have learned, too, that after a few months to years of retirement, these healthy, experienced, and, sometimes bored, retirees are more than ready to once again don their white coats part-time and care for patients. Often, the only reason they do not offer their talents is that they are not asked.

Hilton Head Island has a splendid free clinic, which is staffed largely by retired physicians. Visit them while you are there and see what can be done. They have a complete plan for an all volunteer clinic and seem pleased to share their expertise. Several of our North Carolina communities have utilized the retired physicians as well.

The two major impediments to volunteer care by retirees have been liability and licensure. However, if one stays in the same state and has not relinquished his or her license to practice, there is not a problem as long as continuing medical education (CME) credits are maintained. As to liability, there is a recently funded legislative mandate that volunteer physicians are to be treated as federal employees in the matter of liability and, thus, are covered. The North Carolina Medical Society would likely be the best source for exploring this avenue, as there are some other provisions to be considered. Another source of information is the Senior Physicians Group at AMA.

In addition, North Carolina Medical Mutual provides a very low-cost policy, which covers the purely volunteer retiree, subject to underwriting. This has the advantage of full-time coverage, not just while working in a clinic. Kudos to Med Mutual for offering this excellent policy, for not all mutual or commercial companies offer this kind of community service coverage.

The purpose of this letter is to encourage readers to volunteer and to encourage those who need physician volunteers to ask the retirees in their area to serve. There is a wealth of talent and experience withering on the vine, and some of it is just waiting for an opportunity to be a part of the North Carolina healthcare safety net. It deserves more attention than it has been given.

James H. Burrus, MD, FACOG
Shelby, NC

To the Editor

Access to and delivery of quality healthcare to ALL of our people should be the goal of any healthcare system. At present, ready access is limited to the insured (corporate and self-insured; Medicare and Medicaid; veterans; and government employees, including politicians) and much less to the uninsured (more than 45 million, including approximately nine million infants and children) and many underinsured. You briefly allude to this in your introduction to the North Carolina healthcare safety net and offer a solution: "…until healthcare insurance is universal, the uninsured will remain a health policy issue of concern."

There are 1,200+ for-profit health insurers in the United States with consequent duplication of administration (CEOs, directors, employees, and stockholders), forms, and procedures amounting to about one-third (about $500 billion per year) of the cost of our healthcare (about $1.6 trillion in 2003 and rising 7-8% per year).

A crisis begs for action. Access and much of those insurance costs could be addressed with universal, single-payer, tax-funded (like Medicare and Medicaid and the rest of the developed world) national insurance. The overwhelming majority of our people want it, but are not heard or represented. So far, special interest politics have prevented this with for-profit health insurers each, or collectively, vigorously opposing, if not lobbying against, any change (remember the Harry and Louise ads?). If we could ever get over this obstacle, many of the other problems with the delivery of healthcare could be more readily solved.

Another problem that immediately comes to mind is the myth of perfection in medicine and the unrealistic expectation of those we serve. Ours is the most litigious society in the world (300+ lawyers per 100,000 persons compared with 50 in the United Kingdom and five in Japan), and this has led to rising defensive medicine with many unnecessary and very expensive tests and procedures. Carefully organized mediation boards to evaluate the legitimacy of claims and awards might help. Are we driving potential students from careers in medicine with these problems?

I heartily agree with and endorse your comment regarding the need for universal health insurance. Until that is accomplished, we will continue to flounder in a sea of discontent and disservice to our people and our profession.

Robert McLelland, MD, FACR
Durham, NC

To the Editor

Thank you so much for your well timed and thoughtful discussion of the dissipation of the safety net for healthcare in North Carolina.

As President of the North Carolina College of Emergency Physicians, I can safely say that most emergency physicians will be surprised that there was not more emphasis on emergency departments (ED), other than an isolated comment that almost 700,000 uninsured received care in an ED in North Carolina last year. This volume might be greater than all of the other components of the safety net that you describe combined.

The ED is, in fact, the safety net to the safety net, as you describe it, which warrants additional discussion of its own. Emergency departments in the state are routinely used for non-emergent clinic problems by the uninsured who have no local clinic or are turned away from their clinic because of capacity issues. The ED is by far the most expensive place to treat these patients because the overhead of running an ED is so much higher than that of a clinic. It is naive to believe that the state and local governments do not ultimately pay for the increased cost of trying to provide this care in the most expensive environment available.

It is a profound disservice for the uninsured to try to treat many of these patients in an ED because proactive continuity of care and disease management is so badly needed to successfully manage many of their their ailments. This cannot be provided in an ED.

Most ED's in North Carolina are so backed up with non-emergent uninsured clinic patients, that it has a profound effect on the efficiency and safety, never mind the convenience, with which patients with true emergencies can be managed in our EDs. On most days, any given ED has patients with significantly urgent or emergent medical problems who wait unacceptably long periods for non-emergent patients to be screened and helped however possible.

Because of EMTALA,* emergency departments cannot turn away these patients based on the ability to pay. This well intentioned federal statute ensures that all unsured will have access to EDs for healthcare, but provides no funding to hospitals to provide this mandated care. The uninsured probably represent at least 25% of patients seen in EDs across the state, and much more in some areas. As you point out, these same hospitals and physicians remain vulnerable to the skyrocketing malpractice costs associated with caring for these patients, despite providing care that is more often than not unreimbursed.

I thought it was curious that the North Carolina College of Emergency Physicians was not asked to contribute to your otherwise outstanding task force, since our constituents provide the majority of the "safety net" care of the uninsured that you desribe. We would be happy to particpate in your discussions in the future, if you so see fit. Thank you.

Edward N. LaMay, MD
President, North Carolina College of Emergency Physicians
Durham, NC

* See page 230.

To the Editor

I read the Issue Brief and Commentaries in the March-April 2005 issue of the *North Carolina Medical Journal*. These reports focused on providing healthcare to the uninsured and the North Carolina healthcare safety net.

I found the Issue Brief and Commentaries interesting. However, I was dismayed to learn that the Task Force, and Task Force Steering Committee, was without representation from North Carolina's emergency medicine specialists. More importantly, I was distressed that the critical and essential role that emergency medicine specialists play in the North Carolina healthcare safety net was not well-described, and that Task Force recommendations made no attempt to address the unique problems that care of the uninsured present to emergency medicine providers. My dismay and distress are all the more acute since using the numbers that the Task Force provided in its reports, emergency medicine specialists cared for more uninsured patients in 2003 than all other components of the healthcare safety net combined!

It is critical that North Carolina Institute of Medicine, North Carolina state legislators, and all North Carolina citizens be aware of the role emergency medicine specialists play in North Carolina's healthcare safety net. Emergency medicine specialists are the very fabric of the ultimate safety net. Providing this safety net 24 hours-a-day, seven days-a-week is part of the mission of emergency medicine. However, fulfilling this mission poses a unique set of problems that affects not only the uninsured, but every patient who needs or may need emergency care. It is absolutely essential that any discussion of the North Carolina healthcare safety net include emergency medicine specialists.

I am optimistic that as debate and discussion of the Task Force's reports and Commentaries ensue, it will be apparent that including representation from North Carolina's emergency medicine profession is an integral part of achieving better healthcare, not only for North Carolina's uninsured citizens, but for all North Carolinians.

C. Michael Sheppa, MD, FACEP
President Raleigh Emergency Medicine, Inc.
Raleigh, NC

Response from the Task Force Director

Drs. Lemay's and Sheppa's letters, published in this issue of the Journal, raise questions about the lack of representation of emergency physicians on the Task Force on the North Carolina Healthcare Safety Net, and in the commentaries on the special issue on the healthcare safety net published in the March-April issue. We appreciate the comments of Drs. LeMay and Sheppa, but want to assure them that the Task Force was acutely aware of the problems faced by the state's hospital emergency rooms in addressing the healthcare needs of the rising numbers of uninsured. The Task Force included several chief executives of urban and rural hospitals throughout the state, who raised these issues throughout the Task Force deliberations. While we feel that enormity of the contribution made by hospital emergency departments to the care of the uninsured in our state were appropriately dealt with in our discussions and in our final report, we agree with Drs. LeMay and Sheppa that it would have been better to have included representation from the physicians who actually provide this care. We have included representation of emergency medicine physicians in our new Task Force that is studying ways to expand health insurance coverage to the uninsured.

Pam C. Silberman, JD, DrPH
President Elect
North Carolina Institute of Medicine
Durham, NC

Alzheimer's Disease and Family Caregivers

To the Editor

The January/February 2005 issue of your Journal dealing with Alzheimer's disease was a truly valuable work relating to this condition. The broad range of Alzheimer's concerns from basic medical issues to socioeconomic ramifications was addressed admirably. This range of articles underscores the cruel irony that the burden of this disease is born by family, caregivers, and society at large.

Efforts to promote early recognition, diagnosis, and reasonable treatment interventions can only serve our state well into the future. Thank you for bringing this issue to publication.

Michael J. Kushner, MD
Wilson Orthopaedic Surgery and Neurology Center, PA
Wilson, NC

To the Editor

Please express appreciation to Myron Green for sharing his experience caring for his wife, Sadie, who has advanced dementia, in the January/February 2005 issue of the *North Carolina Medical Journal*. His capacity is remarkable, and it was a great privilege to read his description of coming to accept "… the way she is …" and then to give her all that she needs, day after day, with steady skill and amazing grace.

Thanks also to Dr. Donald Madison, who gave us the eyes and ears to see and listen to what it is like to do this. His essay told us what we must do without lectures, facts, figures, or predictions. It put a face on Alzheimer's disease and on the remainder of the issue, which then provided a larger context for this call to action.

We must act personally, regionally, and nationally to support Myron and Sadie, husbands and wives, neighbors, parents, and grandparents. Once we accept " … the way [it] is … ," maybe we will learn and teach and act together to do what we must do.

Lynn M. Cleary, MD
Associate Dean for Curriculum
Upstate Medical University, State University of New York
Syracuse, NY

Call for Papers

John W. Williams, Jr., MD, MHS
Scientific Editor, *North Carolina Medical Journal*

North Carolina is blessed with some of the finest medical research institutions in the world. The work of the medical scientists that labor in our research facilities becomes complete (in many ways) and public when it is published in peer-reviewed journals.

While medical researchers in North Carolina have many journals to which they can submit their manuscripts, we want them to consider keeping their work here at home. To be more specific, we invite the authors of our state to submit their papers to the *North Carolina Medical Journal*.

The Journal seeks papers that convey the results of original research. We are especially interested in publishing research papers that have relevance to the health of the people of our state.

An editor reviews all papers received and those of sufficient quality are peer-reviewed. As with any journal of merit, only papers of high quality will be published. Papers printed in the Journal are indexed in the National Library of Medicine's MEDLINE public database.

The *North Carolina Medical Journal* is published six times a year. It is distributed free of charge to the members of the North Carolina Medical Society, the North Carolina Hospital Association, the North Carolina College of Internal Medicine, the North Carolina Academy of Physician Assistants, the North Carolina Board of Pharmacy, the North Carolina Association of Pharmacists, the North Carolina Division of Public Health, the North Carolina Association of Health Plans, and the Medical Review of North Carolina. The Journal is available by subscription to others.

For guidance on manuscript preparation, authors should consult the "Author Guidelines," which can be found at www.ncmedicaljournal.com.

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North Carolina MEDICAL JOURNAL

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Quality of **Long-Term Care:** **Nutrition** as a Critical Dimension

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July/August 2005, 66:4


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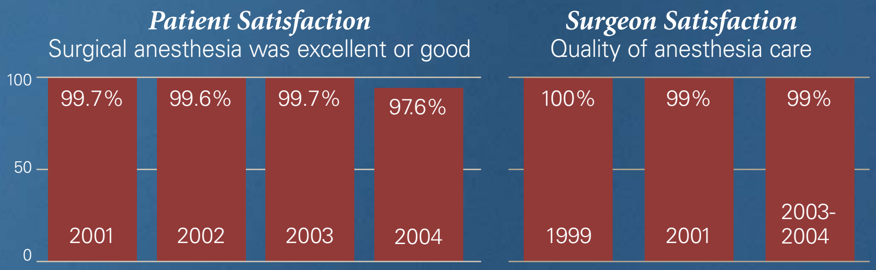

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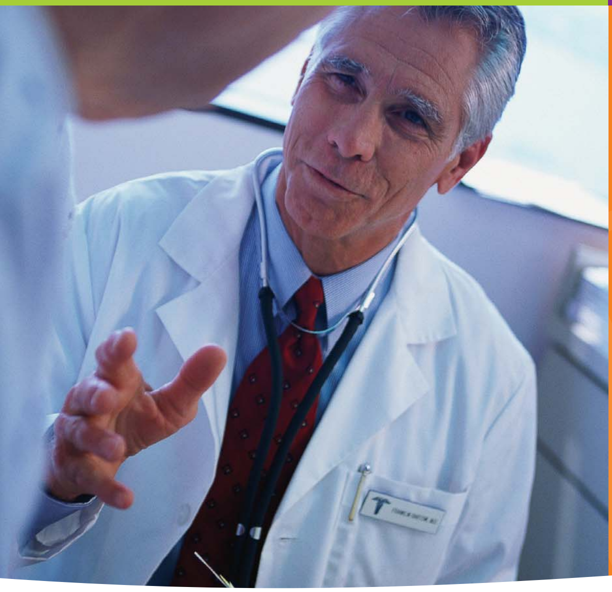

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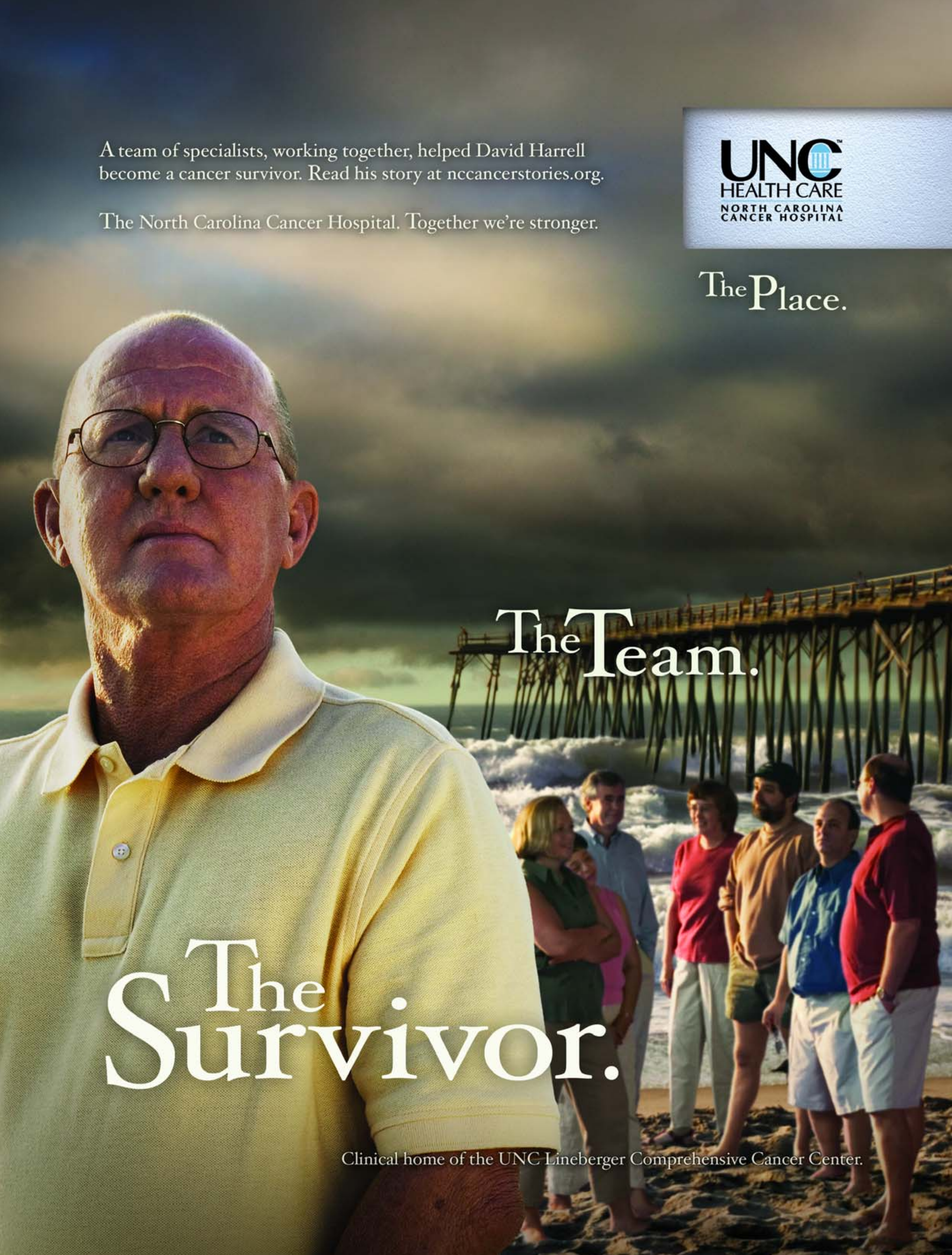
A team of specialists, working together, helped David Harrell become a cancer survivor. Read his story at nccancerstories.org.

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July/August 2005, Volume 66, Number 4 **Published by the North Carolina Institute of Medicine and The Duke Endowment**

ARTICLES

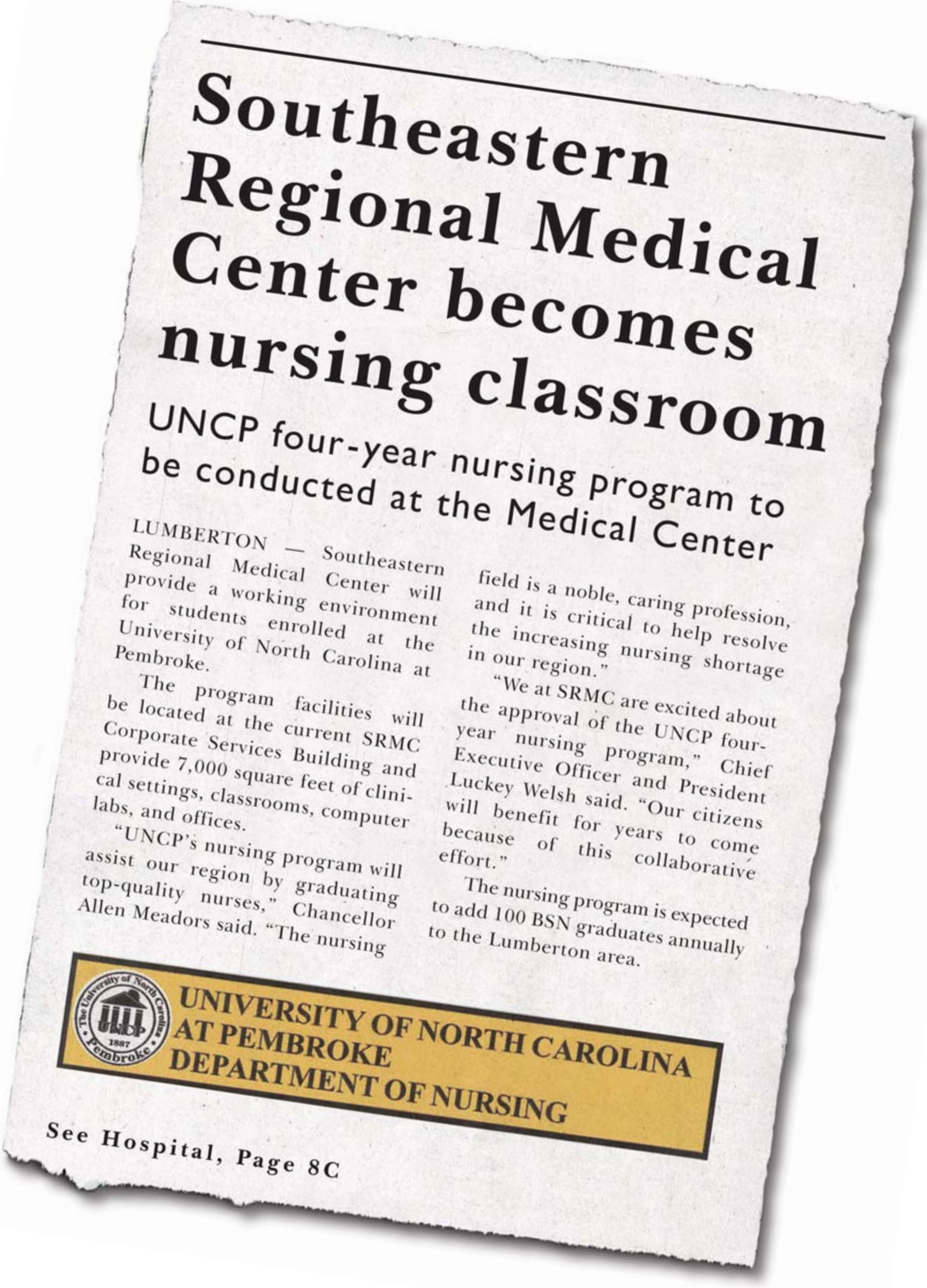
POLICY FORUM

Quality of Long-Term Care: Nutrition as a Critical Dimension

COMMENTARIES

DEPARTMENTS

> *"For the frail elderly, mealtime can be the highlight of each day and a key component of health and quality of daily living."*



Southeastern Regional Medical Center becomes nursing classroom

UNCP four-year nursing program to be conducted at the Medical Center

LUMBERTON — Southeastern Regional Medical Center will provide a working environment for students enrolled at the University of North Carolina at Pembroke.

The program facilities will be located at the current SRMC Corporate Services Building and provide 7,000 square feet of clinical settings, classrooms, computer labs, and offices.

"UNCP's nursing program will assist our region by graduating top-quality nurses," Chancellor Allen Meadors said. "The nursing field is a noble, caring profession, and it is critical to help resolve the increasing nursing shortage in our region."

"We at SRMC are excited about the approval of the UNCP four-year nursing program," Chief Executive Officer and President Luckey Welsh said. "Our citizens will benefit for years to come because of this collaborative effort."

The nursing program is expected to add 100 BSN graduates annually to the Lumberton area.

UNIVERSITY OF NORTH CAROLINA AT PEMBROKE DEPARTMENT OF NURSING

See Hospital, Page 8C

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Perceived Racial/Ethnic Bias in Healthcare in Durham County, North Carolina:

A Comparison of Community and National Samples

Joëlle Y. Friedman, MPA, Kevin J. Anstrom, PhD, Kevin P. Weinfurt, PhD, Mary McIntosh, PhD, Hayden B. Bosworth, PhD, Eugene Z. Oddone, MD, MHS, Cedric M. Bright, MD, and Kevin A. Schulman, MD

Abstract

Background: *We sought to compare findings of a national survey of perceptions of racial/ethnic discrimination in healthcare to those of a community survey, with emphasis on the perceptions of Latinos.*

Methods: *Responses from a national survey were compared to a telephone survey of residents of Durham County, North Carolina.*

Results: *Black respondents in the Durham sample were more likely than those in the national sample to feel that a healthcare provider had treated them with disrespect because of health insurance status (28% vs 14%; $P < 0.001$). Approximately one third of Durham Latinos and 14% of Latinos in the national sample felt they had been treated with disrespect because of their English-language ability ($P < 0.01$). Compared to a national sample of white participants, white respondents in Durham were more likely to believe that black persons are worse off in terms of receiving routine medical care (40% vs 27%; $P < 0.01$) and having health insurance (58% vs 43%; $P < 0.01$). As compared to their national counterparts, there was a similar trend for how white respondents in Durham perceived how Latinos fared ($P < 0.001$ for all comparisons).*

Conclusions: *Overall, the perception of bias in healthcare was greater among Durham residents, especially among newly immigrated Latinos, than among their national counterparts.*

Introduction

Over the past two decades, there has been growing interest in racial and ethnic disparities in the use of preventive health services and medical procedures for many conditions.[1,2] Differential use of appropriate medical therapies is a crucial flaw in the United States healthcare system, impeding our ability to achieve the goals of *Healthy People 2010*.[3] These goals include the elimination of disparities in care for cancer screening and management, cardiovascular diseases, diabetes mellitus, human immunodeficiency virus infection (HIV) and acquired immunodeficiency syndrome (AIDS), and child and maternal health.[3]

Attempts to develop interventions that rectify disparities in healthcare have had varying degrees of success. Interventions have included cultural competency programs,[4,8] screening and outreach services for minority populations,[9,12] and programs to enhance patient-provider communication.[13,14] Most reports of these programs do not describe a needs assessment component of the projects, although needs assessment is usually the first step in the development of an effective intervention, because it provides a comprehensive description of the problem and its origins.[15]

We set out to describe the local community of Durham County, North Carolina, regarding public perceptions of racial and ethnic discrimination in healthcare, with the goal of developing interventions designed to improve healthcare for minority patients. We were especially interested in exploring the healthcare experiences of newly immigrated Latino residents, a sizable and underexamined segment of the community. Durham County is a diverse community, having almost equal percentages of black and white residents[16] and a rapidly growing Latino population.

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From 1990 to 2000, the Latino population in the Raleigh-Durham metropolitan area increased from 9,923 to 72,580, a 631% increase.[17]

The starting point of this study was the report of the Henry J. Kaiser Family Foundation (KFF) entitled *Race, Ethnicity & Medical Care: A Survey of Public Perceptions and Experiences.*[18] The report offered the first national description of the public's knowledge of and attitudes about racial and ethnic differences in health and healthcare. Among 3,884 adult respondents living in the continental United States, approximately three quarters of respondents viewed racism as a problem in healthcare.[18] However, it was not clear how we were to extrapolate the KFF findings to the local community. Any such extrapolation would be important in efforts to inform interventions that focus on local rather than national concerns and to encourage buy-in and endorsements by local governments and community organizations. Therefore, we sought to determine how applicable the findings of the national survey were to the local community, with special emphasis on exploring how members of the Latino community perceive their experiences with the healthcare system.

Methods

We compared responses to the KFF national survey and responses to a community-based survey. The KFF survey has been described elsewhere;[19] the community survey is described below. This study was approved by the institutional review board of Duke University Medical Center.

Sample Design

Eligible subjects were adults living in Durham County, North Carolina, in households with telephones. The sampling design targeted interviews with disproportionately large subsamples of black and Latino adults. The sample was designed to generalize to the Durham County adult population in telephone households and to allow separate analyses of responses by black, Latino, and white respondents.[20,21]

Two separate samples (Survey Sampling, Inc., Fairfield, Connecticut) were used to complete all interviews. The first was a disproportionately stratified sample drawn for telephone exchanges serving Durham County. The sample was drawn using standard, list-assisted, random-digit survey methodology. Active blocks of telephone numbers (area code + exchange + two-digit block number) that contained three or more residential directory listings were selected with probabilities in proportion to the number of listed phone numbers. After selection, two more digits were added randomly to complete the number. The resulting numbers were compared against business directories, and matching numbers were purged. Exchanges with higher than average density of black households were oversampled to increase the overall sample incidence of black respondents.

For the second sample, to achieve an oversampling of Latino respondents, participants were recruited by random-digit dialing from a list of households with Latino surnames. We selected this approach because Durham has few nonclustered Latino households.

Survey Development and Administration

The KFF survey was the foundation for our assessment.[18] We adapted additional survey items from the California Health Interview Survey (CHIS),[22] the El Centro Hispano/Proyecto LIFE survey,[23] and a review of the literature.[24,25] Specifically, we used the Health Belief Model to identify potential barriers to care. The Health Belief Model was developed to explain why people fail to engage in disease prevention or screening tests before the onset of symptoms.[26] The model proposes that the likelihood of one carrying out a particular health behavior (e.g., seeking healthcare) is a function of personal beliefs about perceived susceptibility, severity, benefits, and barriers.[27]

We augmented the candidate survey items with items derived from a provider survey. The brief, informal provider survey was administered by e-mail to PrimaHealth IPA Network providers (a provider network local to Durham County). The provider survey was used to identify perceptions of barriers regarding the provision of medical care for persons of different cultures. We also provided a draft of the survey to a convenience sample of community leaders (i.e., public health officials, public officials, community group leaders) for comment to ensure that we considered relevant factors that cause or contribute to local barriers to healthcare. Finally, we conducted a small pilot test by conducting cognitive interviews with black and Latino community members to assess content validity and to verify that many barriers to care were considered as pre-coded responses in the survey. For Latino participants, the final survey was translated into Spanish and back-translated for validation purposes.

Given the length of the survey, we split the survey instrument into three components—the core survey, additional items for split-half sample 1, and additional items for split-half sample 2. All subjects completed the core survey items and one of the split-half sets of questions.

Similar to the KFF survey, the survey was administered by telephone from October through December 2002 in either English or Spanish, according to the preference of the respondent, by Princeton Survey Research Associates (Washington, DC). At least 15 attempts were made to contact a respondent at every sampled telephone number. Calls were staggered over times of day and days of the week to maximize the chance of contacting potential respondents. Each household received at least one daytime call. In each contacted household, interviewers asked to speak with the youngest adult male currently at home. If no adult male was available, interviewers asked to speak with the oldest adult female at home. This systematic respondent selection technique is regularly used by the survey firm to produce samples that closely mirror the population in terms of age and gender. The proportion of working numbers where a request for interview was made was 77% (2,615/3,384). The proportion of contacted numbers where consent for interview was at least initially obtained was 54% (1,415/2,615). Eighty-three percent (1,175/1,415) of the contacted numbers were eligible for the study. (A household was considered ineligible if there was no adult in the household or if there was a language barrier). The proportion of initially cooperating and eligible interviews that were completed was 96% (1,131/1,175).

We developed survey weights to adjust for planned effects of the sample design and to compensate for patterns of nonresponse that might bias the results. Additional details on the weighted analysis are available from the authors upon request.

Measures

Since our survey was based on the KFF survey, our domains mirror themes described in the KFF report.[18] The final survey domains were as follows: demographic characteristics, knowledge of differences in health and healthcare access, personal experiences with being treated unfairly, and perceptions of the influence of race/ethnicity and racism. The coding scheme described below refers to response categories for both the national and Durham surveys, unless otherwise noted.

For all measures described below, except for demographic characteristics, we included "don't know" and "refused" in the "other" category, because we were interested in examining the probability of a participant responding in a certain manner compared to all other responses.

Demographic Characteristics

Demographic information included self-identified race/ethnicity, age, sex, country of origin, marital status, education level, income, home ownership, and health insurance status. Respondents were asked to indicate if they were Latino or of Latino descent and then to indicate their race (Asian, black, white, other). For purposes of this analysis, we excluded respondents who identified themselves as Asian or other. All respondents who reported that they were Latino or of Latino descent were coded as Latino, and the remaining sample was coded as black or white. Due to the relative homogeneity of country of origin among Latino respondents (69.4% reported Mexico as the country of origin), we recoded country of origin as a dichotomous variable (1 = United States, 0 = other). We also recoded marital status (1 = married, 0 = other), education level (1 = at least some college, 0 = other), and home ownership (1 = own home, 0 = other) as dichotomous variables. We created four sets of indicator variables for regression analysis. Two indicator variables were created to represent race, with white as the reference category. Three indicator variables (30 to 39, 40 to 49, ≥ 50) were created for age, with 18 to 29 serving as the reference group. We created three indicator variables for health insurance (i.e., Medicare, other, and no insurance), with private insurance as the reference group. Finally, financial status in the Durham survey was assessed using a single item with five response options, as follows: "you are having difficulty paying the bills, no matter what;" "enough money to pay for bills, but you have to cut back;" "enough money to pay bills, but little to spare for extras;" "bills are paid and still have enough for extras;" and "don't know" or refused to answer. Due to small cell sizes, we combined the first two categories of financial status, resulting in low income as the reference category.

By comparison, the KFF survey asked respondents to report income in terms of income distribution (e.g., \$25,000 to < \$30,000), and three indicator variables were used to represent low income (< \$25,000; referent category), middle income (\$25,000 to < \$40,000), high income (≥ \$40,000). Due to small cell sizes, we combined "don't know" and "refused to answer."

Knowledge of Differences in Health and Healthcare Access

We used two questions to assess knowledge of racial/ethnic differences in health and healthcare access. The first question asked respondents how they thought black persons fared, compared to the average white person, in receiving routine medical care when they needed it, having health insurance, and getting needed healthcare. The second question was identical, except that it asked respondents how they thought Latinos fared, compared to the average white person. Response options for both questions were "better off," "worse off," "just as well off," and "don't know/refused to answer." We dichotomized these variables as "worse off" and other.

Perceptions of the Influence of Race and Racism

We defined racism as being treated worse than others because of race or ethnicity. To give the perceived influence of race/ethnicity in healthcare a frame of reference, participants in both samples were asked about perceptions of the influence of race/ethnicity in major social institutions. Respondents were asked whether they thought racism was a major problem, a minor problem, or not a problem at all in education, the workplace, housing, and healthcare. We recoded the response options so that 1 indicates a major problem and 0 indicates other (including don't know/refused to answer).

Respondents were then asked if they thought black and Latino persons received the same quality of care, higher quality of care, or lower quality of care compared to most whites. We dichotomized the response options so that 1 indicates lower quality of care and 0 indicates other (including don't know/refused to answer).

Personal Experiences with Being Treated Unfairly

Respondents were asked to recall their experiences with healthcare in the past few years and whether they ever felt that healthcare providers or other staff members judged them unfairly or treated them with disrespect because of whether they had health insurance, how well they spoke English, or their racial/ethnic background. Responses included "yes," "no," and "don't know/refused to answer." We recoded the responses as 1 for yes and 0 for other.

Statistical Analysis

We used survey weights for all analyses to correct for the complex survey design and nonresponse bias. (A detailed report regarding the weighted analysis is available from the authors upon request.) Our first set of analyses compared responses between the two samples by race/ethnicity for 15 key questions. We used simple statistics to describe both samples, and we used normal approximations to compare the groups to calculate P values. Our large sample size afforded statistical power to detect very small differences. Thus, we considered a difference between the community and national samples practically significant only if there was an absolute difference of ≥ 10% and a P value ≤ 0.05.

For the second set of analyses, we attempted to determine how perceptions of racism in education, the workplace, housing, and healthcare (hereafter termed institutions) differed across race/ethnicity after adjusting for demographic characteristics. Using survey-weighted multiple logistic regression analysis, we developed eight models. The first four models analyzed perceptions of racism across institutions for Durham respondents, and the remaining four models analyzed perceptions for national respondents. We included the following demographic characteristics in the models: age, sex, income, education level, and marital and health insurance status—all factors related to access to care. (We did not include country of origin in the models because it was strongly correlated with Latino ethnicity.) We converted parameter estimates for each variable to approximate relative-risk ratios using the method described by Zhang & Yu.[28]

We performed all analyses using Stata version 8.0 (Stata Corporation, College Station, Tex).

Results

Table 1 shows the demographic characteristics of the Durham and national samples. The samples were similar across race/ethnicity with respect to marital status, and white and black respondents in Durham were similar to their national counterparts in terms of sex, country of origin, home ownership, and health insurance status. However, whereas 54% of white respondents and 41% of black respondents in the national sample had at least some college education, these figures were 72% for white respondents and 50% for black respondents in the Durham sample ($P < 0.001$; $P = 0.02$).

Durham Latinos differed from Latinos in the national sample in terms of age, sex, country of origin, education level, home ownership, and health insurance status. Durham Latinos were younger and were significantly less likely to report the United States as their country of origin, to have health insurance, to have at least some college education, and to own a home ($P < 0.001$ for all comparisons). A greater percentage of Latino respondents in the Durham sample were men, as compared to the national sample (64% vs 50%; $P = 0.01$).

Knowledge of Racial/Ethnic Differences in Health and Healthcare Access

As shown in Table 2, when asked if the average black person is worse off than the average white person across a variety of factors, responses of white respondents differed greatly in the Durham and national samples. For example, 40% of white respondents in Durham thought that blacks are worse off in terms of receiving routine medical care, compared to 27% in the national sample ($P < 0.01$). Fifty-eight percent of Durham whites believed that blacks are worse off than whites in terms of having health insurance, compared to 43% in the national sample ($P < 0.01$). In most cases, black participants' responses differed by less than 4% between the two samples.

There was an even greater difference between the white samples on questions of whether Latinos are worse off than the average white person, with white respondents in Durham more likely to perceive that Latinos are worse off ($P < 0.001$ for all comparisons). Despite being quite different demographically, there were only small response differences on these items between the two Latino samples. The only major difference among the Latino samples was that 70% of Durham Latinos reported that Latinos were worse off than whites with respect to having health insurance, as compared to 54% of national Latinos ($P < 0.01$).

Perceptions of the Influence of Race and Racism

There were small differences between the national and community samples with respect to whether blacks receive lower quality of care than whites. However, more whites in the Durham sample than in the national sample perceived that Latinos receive lower quality of care ($P < 0.001$).

Overall, black respondents in Durham were less likely than

Table 1.
Subject Characteristics

Variable	White		Black		Latino	
	Durham (n=392)	National (n=1,479)	Durham (n=338)	National (n=1,189)	Durham (n=332)	National (n=983)
Age, mean (SE)[a]	46 (1.03)	46 (0.75)	43 (1.02)	43 (0.77)	34 (0.83)[c]	39 (0.87)
% Male sex	47	47	38	45	64[b]	50
% United States-born	94	97	97	95	5[b]	51
% Married	51	55	32	31	50	48
% At least some college	72[c]	54	50	41	15[b]	29
% Own home	69	68	40	46	15[b]	43
% Having health insurance	91	88	77	82	32[b]	69

All values are weighted.

[a] Eight responses from the Durham sample and 51 responses from the national sample were missing because the respondents refused to answer.

[b] Indicates a significant difference at $P \leq 0.05$ and a response difference of ≥ 10 percentage points in the comparison with race/ethnicity-matched respondents in the national sample.

[c] Indicates a significant difference at $P \leq 0.05$ and a response difference of > two years in the comparison with race/ethnicity-matched respondents in the national sample.

SE indicates standard error.

Table 2.
Comparison of Responses to Selected Questions[a]

Variable	White		Black		Latino	
	Durham %	National %	Durham %	National %	Durham %	National %
Do you think the average African American is worse off as compared to the average white person in terms of…?						
Getting routine medical care when they need it	40[b]	27	53	51	14	32
Having health insurance	58[b]	43	56	59	28	36
Getting needed healthcare	45	36	57	53	10	37
Do you think the average Latino is worse off as compared to the average white person in terms of…?						
Getting routine medical care when they need it	51[b]	33	54	52	50	47
Having health insurance	72[b]	48	60	60	70[b]	54
Getting needed healthcare	55[b]	35	53	51	51	47
Have you ever felt that a healthcare provider judged you unfairly or treated you with disrespect because of…?						
Whether or not you have health insurance	12	10	28[b]	14	20	21
How well you speak English	4	1	11	5	34[b]	14
Your race or ethnic background	2	1	20	12	22	15
Do you think most African Americans receive lower quality of healthcare than most whites?	23	23	56	64	22	43
Do you think most Latinos receive lower quality of healthcare than most whites?	53[b]	27	61	61	62	56
Do you think racism is a major problem in the following institutions?						
Education	22	27	40b	50	40	40
Workplace	13	21	40b	59	37	41
Healthcare	14	16	27	35	40[b]	30
Housing	20[b]	30	41[b]	59	35	41

[a] Values are expressed as weighted proportions that agree with the statement, unless otherwise indicated.

[b] Indicates a significant difference at $P \leq .05$ and a response difference of ≥ 10 percentage points in the comparison with race/ethnicity-matched respondents in the national sample.

their national counterparts to perceive racism as a major problem in education ($P < 0.01$), the workplace ($P < 0.001$), and housing ($P < 0.001$) (see Table 2). While there were small differences between the Latino samples with respect to education, the workplace, and housing, 40% of Durham Latinos thought that racism was a major problem in healthcare, compared to 30% of national Latino respondents ($P = 0.02$).

Personal Experiences with Being Treated Unfairly

Black respondents in the Durham sample were more likely than those in the national sample to feel that a healthcare provider had treated them with disrespect because of health insurance status (28% vs 14%; $P < 0.001$). Thirty-four percent of Durham Latinos and 14% of Latinos in the national sample felt they had been treated with disrespect because of their English-language ability ($P < 0.01$).

Multivariable Analysis

We performed multivariable analyses to determine whether racial/ethnic differences regarding perceptions of racism in the four social institutions held after adjusting for age, sex, income, education level, and marital and health insurance status. The magnitude of the adjusted differences in perceptions of racism was comparable to that found in the unadjusted analyses (see Tables 3 and 4).

Table 3.
Multivariable Analysis—Durham Sample: Racism as Major Problem in Social Institutions

Characteristic	Education RR (95% CI)	Workplace RR (95% CI)	Housing RR (95% CI)	Healthcare RR (95% CI)
Race/ethnicity				
White	1.00	1.00	1.00	1.00
Black	1.93 (1.51-2.37)	3.30 (2.51-4.14)	2.23 (1.75-2.73)	1.90 (1.36-2.56)
Latino	2.27 (1.65-2.88)	3.30 (2.25-4.44)	2.05 (1.43-2.73)	3.02 (2.07-4.05)
Age group				
18 to 29 years	1.00	1.00	1.00	1.00
30 to 39 years	1.21 (0.86-1.60)	1.02 (0.70-1.41)	1.09 (0.77-1.47)	1.27 (0.83-1.84)
40 to 49 years	1.03 (0.71-1.43)	0.79 (0.51-1.15)	0.96 (0.65-1.33)	1.18 (0.75-1.77)
50 to 98 years	0.97 (0.68-1.32)	0.75 (0.49-1.09)	0.81 (0.55-1.14)	1.01 (0.63-1.53)
Education level				
No college	1.00	1.00	1.00	1.00
At least some college	1.45 (1.12-1.81)	1.42 (1.05-1.85)	1.44 (1.09-1.82)	1.36 (1.00-1.79)
Sex				
Female	1.00	1.00	1.00	1.00
Male	0.82 (0.63-1.04)	0.94 (0.70-1.24)	0.91 (0.70-1.15)	0.83 (0.60-1.12)
Household income				
Low income	1.00	1.00	1.00	1.00
Middle income	0.77 (0.53-1.05)	0.80 (0.55-1.12)	0.69 (0.47-0.96)	0.80 (0.55-1.13)
High income	1.06 (0.77-1.39)	0.82 (0.56-1.13)	0.82 (0.57-1.12)	0.85 (0.58-1.21)
Don't know/refused	0.97 (0.43-1.74)	0.22 (0.06-0.71)	0.27 (0.09-0.69)	0.29 (0.09-0.82)
Health insurance status				
Private insurance	1.00	1.00	1.00	1.00
Medicare	1.06 (0.53-1.77)	1.19 (0.56-2.06)	1.43 (0.84-2.14)	1.33 (0.62-2.41)
Other insurance	0.88 (0.44-1.50)	0.98 (0.46-1.78)	0.47 (0.19-1.01)	1.05 (0.43-2.13)
No insurance	1.04 (0.74-1.40)	0.90 (0.61-1.28)	0.97 (0.68-1.33)	1.17 (0.80-1.66)
Marital status				
Not married	1.00	1.00	1.00	1.00
Married	0.94 (0.73-1.19)	1.01 (0.75-1.32)	1.06 (0.81-1.34)	1.03 (0.76-1.37)

RR indicates relative risk; and CI indicates confidence interval.

Discussion

Our goal was to compare the findings of a national survey of perceptions of racial/ethnic discrimination in healthcare to those of a community survey, with a special emphasis on the healthcare experiences and perceptions of newly immigrated Latinos.

Although the demographic characteristics of the samples were quite different, perceptions of racial/ethnic bias among Latinos in the national and Durham samples were similar. However, we found substantial differences in attitudes about health insurance and English-language ability on one's ability to receive medical care. Durham Latinos were significantly more likely than Latinos in the national sample to report that Latinos were worse off than whites in terms of having health insurance, and Durham Latinos were more likely to feel they had been treated with disrespect by healthcare providers because of their English-language ability. Also, Durham Latinos were more likely to believe that racism was a major problem in healthcare.

One possible explanation for our findings is that a greater percentage of Latinos in Durham, compared to Latinos in the national sample, were born outside the United States (95% vs 49%). Research has shown that more acculturated Latinos have higher rates of insurance coverage and access to care.[29,34] The Durham Latino population may be less assimilated than Latinos in the national sample and may not be as fluent with the English language. Latinos who have lived in the United States for longer periods might speak English better than recent immigrants and may be more likely to have acquired health insurance. A decrease in language barriers and greater access to health insurance may alleviate some of the negative perceptions

Table 4.
Multivariable Analysis—National Sample: Racism as Major Problem in Social Institutions

Characteristic	Education RR (95% CI)	Workplace RR (95% CI)	Housing RR (95% CI)	Healthcare RR (95% CI)
Race/ethnicity				
White	1.00	1.00	1.00	1.00
Black	1.80 (1.54-2.07)	2.74 (2.39-3.08)	1.93 (1.69-2.15)	2.14 (1.71-2.60)
Latino	1.47 (1.18-1.79)	1.82 (1.44-2.23)	1.39 (1.13-1.67)	1.78 (1.34-2.30)
Age group				
18 to 29 years	1.00	1.00	1.00	1.00
30 to 39 years	0.92 (0.68-1.18)	1.21 (0.89-1.57)	1.18 (0.91-1.47)	1.52 (1.03-2.14)
40 to 49 years	0.91 (0.66-1.18)	1.01 (0.74-1.36)	1.01 (0.76-1.29)	1.39 (0.93-1.98)
50 to 98 years	0.77 (0.58-1.01)	0.63 (0.45-0.88)	0.83 (0.62-1.08)	1.25 (0.86-1.77)
Education level				
No college	1.00	1.00	1.00	1.00
At least some college	1.34 (1.07-1.63)	1.02 (0.79-1.29)	1.41 (1.16-1.68)	1.05 (0.78-1.39)
Sex				
Female	1.00	1.00	1.00	1.00
Male	0.82 (0.66-1.01)	0.72 (0.56-0.90)	0.78 (0.63-0.95)	0.79 (0.60-1.03)
Household income				
Low income	1.00	1.00	1.00	1.00
Middle income	1.17 (0.89-1.48)	1.13 (0.85-1.45)	1.17 (0.90-1.45)	1.08 (0.76-1.49)
High income	1.15 (0.86-1.48)	1.09 (0.81-1.40)	1.18 (0.89-1.49)	0.98 (0.65-1.41)
Don't know/refused	0.73 (0.41-1.19)	0.75 (0.39-1.27)	0.73 (0.42-1.15)	1.19 (0.62-2.02)
Health insurance status				
Private insurance	1.00	1.00	1.00	1.00
Medicare	0.80 (0.54-1.16)	1.05 (0.72-1.44)	1.07 (0.77-1.38)	1.01 (0.62-1.56)
Other insurance	1.41 (0.96-1.75)	1.47 (0.99-1.92)	1.37 (1.00-1.67)	1.71 (1.07-2.42)
No insurance	1.27 (0.96-1.53)	1.09 (0.80-1.43)	1.17 (0.90-1.41)	1.19 (0.81-1.67)
Marital status				
Not married	1.00	1.00	1.00	1.00
Married	0.79 (0.62-0.97)	0.96 (0.76-1.20)	0.75 (0.60-0.93)	1.03 (0.78-1.34)

RR indicates relative risk; and CI indicates confidence interval.

that Latinos have of the healthcare system. Furthermore, the influx of Latino immigrants into Durham County is a recent phenomenon, and the local healthcare system may still be building up the infrastructure needed for this population. Nevertheless, Durham Latinos face considerable challenges in the healthcare system, and interventions to address their concerns should be developed.

Although black respondents in the Durham sample were less likely than those in the national sample to view racism as a major problem in education, the workplace, and housing, there was no difference between the national and community samples with respect to perceived racism in healthcare. One striking difference between national and community samples of black respondents concerns personal experiences with being treated unfairly. Compared to the national sample, twice as many blacks in the Durham sample felt that a healthcare provider had treated them with disrespect because of their health insurance status. This may be attributable to the sources of insurance in the two samples: Although equal proportions of black respondents in both samples reported having health insurance, 16% of Durham blacks reported Medicaid as their primary source of insurance, compared to 8% of blacks in the national sample. We conducted a post hoc analysis to address this finding and found that Durham blacks with Medicaid had similar complaints about disrespect as those who reported being uninsured. Respondents with Medicaid may face greater challenges in accessing healthcare than do respondents with other types of insurance.

Compared to the national sample, white respondents in Durham reported a greater understanding of the lower quality of care and poorer health outcomes experienced by blacks and Latinos. These results may confirm the presence of barriers or may reflect a greater awareness among whites living in the multiracial community of Durham County. Black residents of Durham County make up 39.5% of the population, compared to 12.3% nationwide.[16] As a result, Durham whites may be more attuned to racial/ethnic differences and perceptions than their national counterparts.

A strength of this study was our ability to partner with community groups. Specifically, we collaborated with a grassroots organization that provides services to Latino residents, a community organization dedicated to promoting effective approaches to removing barriers to healthcare, and researchers from a local historically black university. The involvement of these groups ensured that our assessment addressed problems of interest to the local community.

Our study has several limitations. First, our survey method excluded people who did not have telephones, so persons of very low socioeconomic status may not have been able to participate. Also, the phone numbers used in the survey did not include mobile phone numbers, perhaps further contributing to sample bias. The low response rate for both the Durham and national surveys increases the likelihood that those who responded differ from those who did not. While our survey weights attempt to correct for nonresponse bias, this correction was limited to key demographic variables. However, for both limitations, it is difficult to estimate the magnitude of the potential bias. Moreover, the KFF survey was conducted in 1999, whereas the Durham study was conducted in 2002. Given the age of the KFF data, there is the possibility of a temporal bias.

In summary, we found significant variation in the experiences and perceptions of racism in healthcare between national and community cohorts. These differences are especially important at the community level for setting public policy priorities and informing decision makers about issues of interest to the community. For example, according to Census 2000 data, 35% of black Durham County residents report having at least a college degree, compared to 17% statewide; and 23% of black Durham residents have annual incomes less than $20,000, compared to 30% statewide.[16,35] These data illustrate that there can be regional variation among state constituents and underscores the importance of conducting local needs assessments.

Furthermore, our findings regarding the perceptions of Durham Latinos could generalize to the experiences of other rapidly growing, newly immigrated Latino communities. Health concerns in these communities are understudied, and our findings provide preliminary data for researchers and community workers seeking to better understand this population. Finally, our findings show that racial/ethnic minorities perceive racism to be a major problem across four major social institutions after adjusting for several factors. Interventions that address the barriers to care identified in both the community and national surveys could be effective in reducing health disparities and improving the health of minority patients. **NCMedJ**

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POLICY FORUM

Quality of Long-Term Care: Nutrition as a Critical Dimension

> *"Finding the balance between medical/nutritional need and resident preference is an on-going effort of nursing home staff that requires individualized attention, creative thinking, and shared decision-making between staff and residents and their family members."*

COMMENTARIES

INTRODUCTION

Policy Forum:
Quality of Long-Term Care: Nutrition as a Critical Dimension

Over the next decade or two, the American healthcare industry will experience a dramatic shift in focus as the nation's older adult population grows rapidly—especially the population beyond age 85. There will be unprecedented pressure on the long-term care field as more of our population living to these advanced ages is no longer able to live independently for reasons of physical or cognitive decline. This demographic transition, and the service demand likely to come with it, has created a growing concern that skilled nursing facilities may not be prepared for these mounting expectations.

In addition to our expectations for skilled nursing facilities to provide medical and nursing care of the highest technical level, these facilities are expected to make every effort to provide a residential environment that is safe, nurturing, stimulating, and, wherever possible, like "home." Unfortunately, no nursing home, regardless of the quality of care provided or the staff efforts to make the facility pleasing and comfortable, is ever "just like home."

An aspect of nursing home care most frequently mentioned by residents and families is the quality of the food and dining services. In this issue of the *North Carolina Medical Journal*, we have invited some of North Carolina's most knowledgeable individuals in long-term care to examine the challenges and opportunities for addressing food/fluid intake/dining issues in skilled nursing facilities. Polly Godwin Welsh, RN-C, Director of Regulatory Systems for the North Carolina Health Care Facilities Association (NCHCA), has written an Issue Brief outlining the many facets of this important dimension of long-term care quality. A number of Commentaries (by physicians, nurses, dietitians, regulators, and advocacy personnel) describe the complexities and difficulties of meeting the expectations and nutritional needs of nursing home residents follow the Issue Brief. The Commentaries were organized by members of the Quality Standards Work Group, a legislatively mandated, interdisciplinary group that has been working on a wide range of issues related to quality of care in North Carolina's nursing home industry for three years.

No one in our state, regardless of their economic situation, should think these issues have little relevance to their own future. Few of us will escape the necessity of dealing with the availability or quality of long-term care. As we face these matters in our own lives and in the lives of our loved ones, they seem of utmost importance. Yet, the discussion of quality of care definition and measurement in long-term care has received relatively little emphasis in health policy deliberations.

North Carolina is fortunate that NCHCFA, our state's nursing home trade association, has embarked on a monumental effort to make the nursing homes of North Carolina the "best in the nation." As part of this effort, NCHCFA is making food consumption and dining (and attention to fluid intake and hydration) key components of their expanded effort to change the total experience of long-term care residence.

We hope that by describing these issues, Journal readers will appreciate the challenges facing this healthcare sector. We also hope that this issue will prompt policy makers and other stakeholders to begin working together to prepare for a future long-term care delivery system that will have the capacity to provide high-quality care for the many who will need this level of service.

As always, we invite our readers to comment on these articles in future issues of the Journal.

Gordon H. DeFriese, PhD
Editor-in-Chief

Kristie Weisner Thompson, MA
Managing Editor

ISSUE BRIEF

Nutrition and the Dining Experience in Long-Term Care:

Critical Indicators of Nursing Home Quality of Care

Polly Godwin Welsh, RN-C

Long-term care facilities of all types, those providing skilled nursing care in particular, are at a crossroads. With the predicted growth of the older adult population, and the population of older adults who will require dementia-specific care, long-term care facilities face a probable and rapid increase in the need and demand for skilled nursing services. In fact, the number of adults over the age of 65 in nursing facilities* is predicted to double by 2020.[1] Currently, there are 16,032 nursing facilities in the United States with more than 1.4 million residents.[2] In North Carolina, there are 424 nursing facilities with capacity for 42,897 residents.[3] In the face of the changing demographics in our society, nursing facilities are re-engineering to embrace the future and successfully meet these challenges. Part of the re-engineering will involve modifications of the physical plant, new construction and innovations in technology and services to match the evolving needs of residents.

This issue of the *North Carolina Medical Journal* focuses on one of the most salient aspects of long-term care quality—food and the dining experience (as well as hydration and fluid intake). Nutrition is one of the major determinants of successful aging and, for most, eating is one of life's most pleasant daily experiences. In the long-term care setting, the medical-nutritional needs of nursing facility residents are often competing with the provision of "consumer-defined" quality of care. To begin with, nursing facility residents often have complex healthcare conditions that limit their function, depress their senses of taste and smell, require multiple medications, and necessitate therapeutic or mechanically altered diets. These treatments can limit independence, choice, and pleasure and, thus, have a negative effect on quality of life. In the interest of preserving both the health and happiness of their residents, long-term care facilities are trying to find a balance between the residents' required medical treatments and personal preferences. North Carolina's nursing facilities are finding ways to achieve this balance as they also juggle the logistic challenges of feeding large numbers people in a highly regulated industry. Many of these specific efforts are described in the commentary by Nadine Pfeiffer, BSN, RN, and her colleagues in this issue of the Journal.[4]

> *"Though nutrition, hydration, and the dining experience in general is but one indicator of overall quality of care, it is clearly among the most critical indicators of quality from a consumer's point of view."*

Those of us who have been asked to contribute to this discussion bring a variety of perspectives (viz., industry, regulatory, advocacy, clinical, administrative) and extensive periods of professional experience in dealing with the challenges of providing high-quality nutrition and fluid options to those served by North Carolina's nursing facilities. Though nutrition, hydration, and the dining experience in general is but one indicator of overall quality of care, it is clearly among the most critical indicators

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* Skilled nursing facilities are "institution[s] (or a distinct part of an institution) which are primarily engaged in providing skilled nursing care and related services for residents who require medical or nursing care, or rehabilitation services for the rehabilitation of injured, disabled, or sick persons, and is not primarily for the care and treatment of mental diseases." § 1819(a) and 1919(a) of the Social Security Act.

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of quality from a consumer's point of view. We view the challenge of addressing these issues as one of our most important tasks.

The Social and Cultural Importance of Food and Dining to Long-Term Care Quality

Few would question the importance food plays in everyday life. From physiologic, social, and personal financial perspectives, food plays an enormous role in the human experience. Americans spend about 13% of their annual income on food, the third highest household expense, behind housing (33%) and transportation (19%).[5] The food industry markets to the young and old. Restaurants and grocery stores are multi-billion dollar industries, offering nearly unlimited choices to those who can afford them. Most Americans can eat anything they want, whenever they want, and often chose to eat too much. We have television channels, shows, and magazines dedicated to food preparation. Holidays are typically centered on food and dining. We don't think of Thanksgiving, Halloween, or a birthday without thinking of turkey, candy, and cake, respectively. Food is the center of celebration, pleasure, and entertainment throughout life in the United States, even in nursing facilities. For nursing home residents, mealtime may be the highlight of each day and is a key component of health and quality of daily living.

On any given day, approximately 40,000 North Carolinians reside in skilled nursing facilities due to catastrophic health events, disability, frailty, and/or declining health.[3] Each resident has a unique, but usually culturally-defined life history of nutrition, consumption, and food experience. As part of their effort to provide patient-centered care, nursing facilities strive to meet reach resident's nutritional needs, dietary preferences, and expected dining experiences at a time when many other personal choices and freedoms are being lost. These losses make preserving resident choice an even more critical component of quality care. The commentary by Beverly A. Speroff, RD, LDN, and her colleagues in this issue of the Journal provides a useful overview of the dining experience in nursing facilities and describes ways nursing facilities balance residents' nutritional needs and preferences.[6]

Medical Care and Quality of Life: Competing Issues

Long-term care facilities face two, sometimes seemingly competitive, goals with regard to nutrition: (1) maintaining optimal levels of health through dietary means, and (2) assuring the highest possible quality of life. In order to accomplish the first goal, nursing home staff must do a thorough and nutrition-focused assessment and develop an individualized plan for meeting the resident's medically-defined nutritional needs. To meet the second of these goals, it is essential that nursing home staff frequently assess and document each resident's dietary preferences so explicit arrangements can be made to assure that residents have as much choice and independence as possible. Facility staff try to reach both goals without compromising the health or happiness of the resident. Accomplishing this requires consultation with the resident (when possible), family members, and the resident's physician.

The notion of involving nursing home residents themselves in decisions about diet and fluid intake is consistent with the idea that, for many nursing home residents, living in such a facility is "home." With average length of stay in such facilities being approximately 2.5 years (901 days) for current residents and just over one year (388 days) for discharged residents,[7] it is logical that residents (when they are able, and family members or a guardian if they are not) should have such a decision-making role. Residents have the right to choose (or refuse) specific treatments and services provided by nursing facilities, once the facility has ensured that the patient (or his/her guardian) is fully informed about his/her functional status, medical, and/or rehabilitation needs.

Therapeutic and Mechanically Altered Diets

The majority of skilled nursing residents are likely to have a chronic disease or condition (e.g., diabetes or high blood pressure) that requires a prescribed diet. There are many different types of therapeutic* or mechanically altered** diets with varying degrees of restriction and complexity. Armed with the necessary dietetic knowledge, food service managers and dieticians must balance considerations of seasoning, nutrition, taste, texture, and variety to produce meals that residents will consume in quantities that provide adequate nutrition and satisfaction. In addition to preparing and serving special diets, staff members teach and reinforce the benefits, and necessities, of these special diets. At the same time, staff members try to honor the resident's choices.

In the past, nursing facilities have been criticized for using what is perceived to be a predominantly "medical model" approach to the organization and provision of care. Compared to patient-centered care, the medical model focuses more on treatment and is less likely to consider the resident's personal preferences. Because a therapeutic diet can negatively affect individual food consumption patterns and lead to unplanned weight loss, it is possible that a medically-recommended diet could have deleterious effects on both quality of life and physical health status. As Dorner, Niedert, and Welch[9] have pointed out:

> *A diet that is not palatable or acceptable to the individual can lead to poor food and fluid intake, which results in weight loss and undernutrition, followed by a spiral of negative health effects. Often, a more liberalized nutrition intervention that allows an older adult to participate in his or her diet-related decisions can provide for the person's nutrient*

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* Therapeutic diets are used to help treat/manage certain chronic diseases (e.g., diabetes and hypertension).

** A mechanically altered diet includes foods that may be pureed or softened to help patients who have trouble chewing and/or swallowing.

needs and allow alterations contingent on medical conditions while simultaneously increasing the desire to eat and enjoyment of food. This ultimately decreases the risks of weight loss, undernutrition, and other potential negative effects of poor nutrition and hydration.

The American Dietetic Association recommends liberalizing therapeutic diets when possible,[8] but this remains challenging in some ways. Honoring resident choice, following prescribed therapeutic diets, maintaining resident health, and complying with state and federal regulations are individual variables that are not mutually exclusive. Nursing facilities have to take appropriate steps to assure that dietary restrictions considered medically necessary are followed. But within these boundaries, nursing facilities are challenged to identify multiple options that will allow the maximum degree of individual choice in food and beverage selections throughout the day.

Health Conditions Can Affect One's Ability/Desire to Eat

Catastrophic health events take a heavy toll on our ability to consume and enjoy food. While in the treatment phase of an acute illness, patients are more likely to be at risk for malnutrition and dehydration. They are also more likely to experience depression, which also can decrease appetite. Close attention must be paid to these factors as people who are ill or rehabilitating return to their homes or enter any long-term care setting.

"Long-term care facilities provide 'supportive social services for people who have functional limitations or chronic health conditions and who need ongoing healthcare or assistance with normal activities of daily living.'"[8,9] By definition, nursing facility residents have healthcare conditions that may impact their ability to feed themselves and/or consume enough calories or fluids to stay healthy. Some residents may have added difficulty due to their medications, age-related sensory losses, and/or decreased physical function or cognitive abilities.

Medications and Side Effects

Nursing facility residents take an average of eight prescription medications a day.[10] Medications from almost every category can have profound effects on one's ability to consume and enjoy food. Many medications may decrease appetite, sense of taste and smell, or cause gastrointestinal disturbances. It is difficult to find normal day-to-day pleasure in eating with these side effects. The commentary by Christopher M. Herman, MD, in this issue of the Journal addresses the medical aspects of dietary management among nursing home residents.[11]

Age-Related Loss of Senses

In addition to the side effects of certain medications, normal aging can affect our sense of taste and smell. As we grow older, our sense of taste and smell begins to diminish, and this worsens as we reach the age 70 and beyond.[12,13] Taste and smell greatly affect our desire and ability to nourish our bodies by telling our brains that it is time to eat and digest food. Without these signals, many residents do not consume enough nutrients.

For this reason, long-term care facilities often use flavor enhancers, primarily powdered odor enhancers mixed with soups, gravies, eggs, vegetables, grits or cereals, sauces, or pastas, such as macaroni. The work of Susan Schiffman[14-17] at the Duke University Medical Center has been an important stimulus for further experimentation with flavor enhancement as a way of assuring the desired nutritional intake of long-term care residents who have experienced sensory losses of taste and smell in their older years. In her work on these problems, Schiffman has shown that older persons living in long-term care facilities consume more food when flavor enhancement is used, and the increased consumption is associated with improved immune function and functional status related to nutrient intake.[15]

Functional Limitations, Tube Feeding, and Feeding Assistance

Most people who are admitted to a nursing facility are admitted after a surgery or a sudden illness. These health events can cause unique problems in relation to nutrition and fluid intake. For example, many persons who suffer strokes may have limited abilities to speak, swallow, and/or use their arms and hands. In this case, speech therapists, occupational therapists, nursing staff, and physical therapists in the skilled nursing facility work diligently to restore these abilities, but for some the loss is permanent.

According to federal data for North Carolina skilled nursing facilities, only 47% of nursing facility residents are able to eat independently. Twenty-eight percent eat with some assistance, and 25% are totally dependent on someone else to feed them.[2] About 10% of residents are tube-fed.[18] While all efforts are made to avoid feeding tubes, some severe circumstances make their use necessary, as described in the commentary by Timothy S. Carey, MD, in this issue of the Journal.[19]

For some residents who experience a loss in motor function that interferes with independent feeding, complete rehabilitation may be possible, while others may need specially trained nursing assistants to provide ongoing feeding assistance. This ongoing assistance can be frustrating to the resident because it is an additional loss of personal independence, may seem unnatural to be fed as an adult, and is time-consuming. According to the Commonwealth Fund study by Burger, Kayser-Jones, and Prince-Bell, a dependent resident requires a minimum of 20-30 minutes to assist him/her with eating and still make the experience satisfying to the resident.[20] The heavy staffing requirements of providing a highly personalized approach to eating for these populations is a constant challenge to all skilled nursing facilities and a potential source of dissatisfaction expressed by both residents, families, and guardians. In addition to knowing how to help residents eat, staff members must know how to ease resident frustration and offer support as being fed by someone else can be a difficult, but necessary, process to sustain life.

Dementia

Another medical condition that can present unique nutritional challenges is dementia. The resident with dementia may greatly decrease his/her consumption of food by simply being unable to remember to eat. For example, the resident may become distracted and leave the table without eating enough or at all. With advanced dementia, the resident may forget how to hold food in their mouth, how to chew, and how to swallow. This may become a part of an encompassing condition commonly referred to as "failure to thrive."

Trained nursing facility staff must employ special feeding techniques and cues to get residents who suffer from dementia to eat enough. Facilities also use snacks and activities to increase consumption. Staff may target residents who have dementia or reduced consumption with recreational opportunities that offer food and beverages as an integral part of these activities in an effort to increase nutritional and fluid intake. The commentary by Heidi K. White, MD, MHS, in this issue of the Journal provides a thorough discussion of nutrition issues related to the care of persons with advanced dementia.[21]

Logistical and Technical Aspects of Meeting the Nutritional Needs of Residents

Preparing food within the constraints of a congregate healthcare setting is one of the most challenging aspects of long-term care facility management. Operational budgets, the use of safe and sanitary equipment, and proper storage and access to the appropriate quantity and quality of food supplies are often under-estimated daily challenges of a food service department. Facilities must involve registered dieticians and food service managers, who are trained to interface with the operation of an institutional kitchen. The registered dietician and food service managers plan menus with many considerations, including seasonal food options and regional and cultural preferences. Facilities strive to prepare tasty, nutritionally-balanced meals in large quantities three times a day, 365 days a year. North Carolina's long-term care facilities serve an average of 32 food items to each resident every day.

Food choice does not present the challenge at one's home that it does in a nursing facility. In the average facility, about 90 people are served three meals a day along with periodic snacks.[2] Accommodating large numbers of special requests can easily overwhelm the dietary department. There is no realistic way to accommodate 90 or more menu changes at each meal. Upon admission and throughout their stay, residents and families hold discussions with care planners regarding food and beverage preferences. Many times these preferences are uncomplicated and easily accommodated. Finding the balance between medical/nutritional need and resident preference is an on-going effort of nursing home staff that requires individualized attention, creative thinking, and shared decision-making between staff and residents and their family members.

> *"Food choice does not present the challenge at one's home that it does in a nursing facility."*

Working within State and Federal Regulations

Maintaining the health and safety of each resident is the goal of each long-term care facility. As mentioned previously, meeting the individual resident needs and preferences, family expectations, and doctor's orders, while abiding by state and federal regulations, can be challenging. Long-term care is one of the most regulated segments of the United State healthcare system, and nursing facilities strictly adhere to rules and regulations. A commentary by Cindy H. DePorter, MSSW, in this issue of the Journal explains the regulations that pertain to nutrition and fluid intake among nursing home residents.[22]

Facility staff members counsel and educate the residents and family members about the risks of not following a prescribed therapeutic diet. For example, a resident at risk for choking may ask for food that is restricted according to his/her nutritional care plan. Nursing facility staff must explain the risks involved with eating such foods to the resident and/or family. The facility could be held legally responsible if the resident choked on the food that the resident's physician had restricted. While eating restricted food now and then may seem harmless, it could present a significant health risk to residents who are prescribed therapeutic or mechanical diets. In a nursing facility, the negotiation of risks, choice, and benefits are carried out on a minute-to-minute basis.

While mindful of the regulations, facilities try to creatively satisfy the needs, priorities, and preferences of residents and families. For example, many residents want their families to bring them food from home. Nursing facilities permit families to bring home-cooked meals to their loved one; however, the food should not be shared with other residents. Skilled nursing facilities cannot risk having other residents exposed to possible food-borne illnesses. Although it is unfortunate, in this example, it is impossible for the facility to guarantee the safety of food preparation that occurs in other locations. A number of long-term care facilities have created special occasions to help provide the residents a variety foods, such as hosting an oyster roast, ordering specialty take-out meals from area restaurants, etc. The commentary by H. Harvin Quidas, et al., in this issue of the Journal describes other ideas that nursing facilities have used to make food and/or the dining experience more interesting to residents.[23]

Conclusion

For all residents in a skilled nursing facility, regardless of medical condition, their life experiences from birth-to-present create needs far beyond the mechanical act of food consumption. Where, when, and how residents wish to dine; their food likes and dislikes; the role of the dining experience as socialization;

and their ability to exert choice and control affect the amount of satisfaction and pleasure they gain from the act of eating.

In these efforts, today's skilled nursing facilities face a number of substantial challenges, but all agree that finding ways to satisfy residents is one of the most important aspects in creating the nursing facility of the future—within which we would all be willing to reside ourselves, or have a loved one reside, were the need to arise. As our society's need and demand for skilled nursing care increases, the capacity of existing facilities will be stretched beyond present expectations. But, as these trends occur, careful attention to how food, nutrition, and hydration issues are managed will have much to do with the ultimate success of our efforts to make long-term care a pleasant and health-enhancing experience. **NCMedJ**

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COMMENTARY

So, Who's Complaining about the Food?

Ombudsman Perspectives on "the Dining Experience" in North Carolina's Nursing Homes

H. Harvin Quidas, Twilla Chavis, Aimee D. Kepler, and Nancy Murphy

The Long Term Care Ombudsman Program was established and authorized by the federal Older Americans Act amendments in 1978 (and codified in North Carolina state law in 1989). This legislation mandated that every state establish a program of professional personnel having the responsibility of advocating for those who reside in long-term care facilities. The legislation charged the Long Term Care Ombudsman with protecting Resident Rights and helping to ensure resident safety and quality of care. In addition, ombudsmen should empower families of residents and the consumers of long-term care services by offering educational programs on long-term care issues and options.

The North Carolina Long Term Care Ombudsman Program is part of the Elder Rights and Special Initiatives Section of the Division of Aging and Adult Services within the North Carolina Department of Health and Human Services. There are 29 Regional Long Term Care Obdudsmen located in the 17 Area Agencies on Aging across the state, with each agency serving multiple counties. The efforts of these regional ombudsmen are extended through a network of over 1,100 "grassroots ombudsmen" who receive training and then volunteer their time in their respective communities as advocates for residents in long-term care facilities. They also work with facility staff and administrators in the interest of assuring a high quality of life for those who reside in these facilities.

One would think that complaints about food, the dining experience and the availability and consumption of fluids would be a major concern and frequent complaint of both residents and the families of residents of long-term care facilities. As Regional Long Term Care Ombudsmen, we receive fewer formal complaints from the residents of nursing homes* or their family members about either dining or hydration than one might expect. But, in any discussion with residents or family members, it is rare that these topics do not emerge in describing the totality of a loved one's experience in a given facility. Food (including regular meals and snacks/refreshments) and fluid intake are very important parts of the *context* within which the resident's total life experience takes place. Not only are meals (and the opportunity to consume snacks) important anchors in the daily routine of nursing home residents, but the quality (viz., taste, smell, appearance, texture) of food and beverages is an important indicator of life satisfaction among those residing in these facilities. Most residents of long-term care facilities, even those who are not ambulatory and have to be served their meals or are assisted with fluid intake, actually look forward to scheduled food- or beverage-related events throughout the day. But, residents differ (as we would expect among any other population) in the relative weight or importance they attribute to various aspects of food and dining. While many residents actually are excited to begin each day with the smells and anticipated tastes of breakfast foods, others are not "morning persons" and would instead focus their attention on lunchtime options or the dinner meal. In other words, much of the daily rhythm and pace of a typical day as a resident of a long-term care facility revolve around

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* These formal complaints about both food/dining or hydration are more frequent from residents of adult care homes or their family members.

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these opportunities for food and drink. The social interactions with other residents and staff associated with meal times or snack times often provide a positive and much-anticipated uplift to what might otherwise be a mundane and boring daily routine.

It, therefore, figures that if one wanted significantly to change how nursing home residents and families view nursing home care, making changes or improvements in the the residents' dining experience or their access to beverages and snacks throughout the day would be an important place to begin. Improvements in dining would ultimately change how the nursing home experience is viewed by persons who are neither residents or family members of residents, but only hear about these aspects of the experience from others.

What Are the Major Complaints about Either Food or Hydration?

Most of the (usually informal) complaints we Ombudsmen hear about food, food service, or hydration in North Carolina's nursing homes come from residents themselves. Most of these complaints are about matters that are beyond the ability of the Ombudsman to handle. For example, many of the negative comments are about the general taste (flavor) and consistency (manner of preparation) of typical food items. Many North Carolina nursing homes serve populations of older adults who have been raised in rural communities where families are accustomed to raising much of the food they consume. Many residents were used to preparing food using high-fat and sodium flavorings (e.g., ham or "fatback"). Institutional food service staff and dietitians are not likely to prepare food in the same ways, nor are they likely to use artificial flavorings to achieve a similar taste or the appearance of standard food items. The food just isn't what one would have been accustomed to at home. The ombudsman can open a formal complaint if the resident finds the food unsatisfactory, lacking in quantity/appeal/preference, or failing to meet medically indicated directions, etc., and long-term care facilities are generally receptive toward finding a resolution for the resident.

> *"...much of the daily rhythm and pace of a typical day as a resident of a long-term care facility revolve around these opportunities for food and drink..."*

Other complaints about food and the dining experience are highly variable among residents, but a few are frequent enough to seem routine. The presentation of food is extremely important. Many residents do not like several food items served in such a way that they "run together." Since residents do not typically serve themselves from a buffet table or in a family-style arrangement, food placed on a plate by a food service staff member may not look like food the resident would have chosen for him/herself, either in placement on the plate or in quantity of serving. To take another example, bread laying on top of vegetables or meat can become soggy and unappetizing. Sectional plates or trays also have a clear "institutional" food service appearance, and do not evoke feelings of a home-like environment.

With regard to food, one might conclude that *little things make a huge difference* in how a skilled nursing facility is viewed by those who reside there.

Most of the "formal" complaints in this area relate to hydration (or fluid intake). Often these are related to the way in which water pitchers, drinking straws, and cups are placed in resident rooms. Non-ambulatory residents often complain because water is not offered frequently throughout the day; the water pitchers, cups, etc. may be placed on top of a dresser across the room or placed in a window sill out of reach of the resident; milk is served as a beverage on every tray at every meal or just before bedtime, yet many older adults have never consumed milk with meals, or are lactose-intolerant and cannot consume this beverage; or iced tea (which many North Carolina residents have consumed regularly, in a sweetened form, and in substantial quantities throughout their lives) is served with little or no ice in short, round glasses, instead of tall glasses with lots of ice and lemon. Persons who have grown old living in a southern, rural environment are often accustomed to eating a heavier meal in the middle of the day, and a lighter one in the evening. Hence, "soup and sandwich" at noon may be boring and a heavier meal in the evening may not be an easily adapted pattern. Some residents are accustomed to having a bowl of cereal just before bedtime. Adding cereal to the options for pre-bedtime snacks could help assure these residents that living in a long-term care facility is not so radically different from what they experienced when living at home. These are the "cultural differences" that are the source of expectations and valuations of the way nursing homes serve their clientele. Often the steps taken to deal with these expectations are not costly, but require special, even personalized, effort, which can be a burden on already over-burdened staff of these facilities.

Family members have complained that sometimes the pitchers from which water is consumed are not washed and sterilized with any frequency, only refilled. These are standard procedures that should be addressed by any facility in a standardized way, and there are specific regulations pertaining to such matters.

What Are the "Lessons Learned" from Resident and Family Reactions?

It is important to recognize that those of us who have worked in long-term care for many years are seeing positive changes in a wide spectrum of areas related to food, nutrition, and hydration in nursing homes. These changes are welcomed by all stakeholders, especially residents and family members.

One of the most important lessons to be learned from the comments (and often the complaints) of long-term care residents and families is that the allowable (and recognizable) independence of living in these facilities is indicated by the feeling that one can choose from several options with regard to food/dining and beverage consumption. It is often not the number of options, but the fact that a *choice* is possible among types of food, beverage, or time and venue within which consumption of either occurs.

Second, it is important to realize that choices made now may not be the same choices tomorrow or next month. Individual preferences and functional abilities change over time, and it is important to give residents frequent opportunities to reconsider these choices. For example, as the ability to chew certain textures of food change, so do the residents' options for mealtime, and new options should be offered in consultation with nursing and medical professionals involved in the care of these patients.

This underscores the importance of periodic and frequent *assessment* so that facilities can have up-to-date information on the functional status, as well as the preferences, of each resident. For example, we have seen instances where a given resident is unable to feed him/herself using common tableware (fork, knife, or spoon), but the resident can eat using his/her hands. Hence, adapting to this situation by offering "finger food" options, once these functional limitations/abilities are noted, can have a tremendous influence on the nutritional status of the individual resident and contribute to overall life satisfaction. Periodic re-assessment of resident capacities and medical needs is essential to providing the optimal and most life quality-enhancing dining and hydration experience.

Long-term care residents are often treated by multiple healthcare providers, both within and external to the the facility. When one care provider suggests trying a different type of diet, the need for such a diet and the progress of the resident in adapting to it should be reassessed frequently. We have all seen instances where a resident's physician prescribed a temporary therapeutic or mechanically altered diet for a resident who ultimately lost weight because facility staff failed to reassess the resident's needs in an appropriate time frame. Some residents in this situation have remained on termporarily prescribed diets for months longer than they should have. Prescribed dietary plans need frequent reassessment to prevent such occurrences. Dramatic changes in dietary intervention plans can cause undue concern among family members, especially if their loved one does not adapt well to the changes introduced by the prescribed diet. When facility staff make hurried determinations that a resident has difficulty swallowing, or if staff confuse a slow eating pattern for such difficulty, this can often lead to the prescription of a therapeutic diet, which is unappetizing and, therefore, not consumed. Careful assessment of functional abilities, such as swallowing, can often determine the actual problem and lead to changes in the way food is served, not in the texture of the meal itself.

Long-term care facilities have been given high positive marks for efforts to incorporate fresh fruits and vegetables into the planning for meals and snacks served to residents. The acquisition and processing of these food items can be both time-consuming and expensive, but many facilities have made a serious effort to add these elements to their overall food and dining experience. Wherever these efforts have been made, there is widespread appreciation from both residents and family members.

It is our observation that long-term care facilities are constantly innovating and discovering new and better ways to address the food and dining preferences of their residents, often with little or no public acknowledgement of their efforts. There are literally hundreds of examples of facilities going out of their way to serve meals in an attractive and pleasant way, or scheduling special events (like periodic "order out" evenings when pizza and other food items can be ordered from area restaurants to be delivered for a particular meal, or scheduling a "tropical week" during which fruit slushies are served to encourage more fluid consumption in a festive atmosphere). We believe more should be done to recognize and compliment these facilities for these efforts.

Though the Long Term Care Ombudsman Program is often seen as conveying only the "bad news" associated with resident or family complaints, we feel it important to point out the number of times that we actually hear from residents and family members some very positive comments about the way our North Carolina nursing homes have been attempting to make food and the dining experience a positive and enjoyable aspect of everyday life in these settings. One recently discharged resident, who was in a North Carolina nursing home for a post-acute rehabilitation period, asked one of us if she could return to the nursing home on a daily basis and pay for lunch since she enjoyed dining at this facility so much.

Finally, it is our observation that nursing homes are faced with serving the long-term care needs of two very different populations. One of these populations is composed of residents who are cognitively functional and able to express their preferences, and many of these residents are mobile enough to partake in any and all activities related to dining. The other population is composed of residents with limited cognitive and physical functional abilities, for whom individual choices are difficult to express. Family members and residents in the first group are strong advocates for their dining and hydration choices, and staff are responsive. However, the second group of residents have very few advocates on their behalf. The data cards for these patients usually have blank spaces where dietary choices or preferences should be noted. When residents in this category are actually given choices in food/dining or beverage options, family members are pleased and often surprised.

The challenge for long-term care is going to be how to serve these two populations of residents and give some level of choice to both, while attempting to make the experience of living in such facilities feel safe, comfortable, and pleasant. Food and the dining experience are an important part of the totality of the long-term care experience, and we are fortunate in this state to have so many nursing facilities who care enough to address these issues as part of an overall effort to make long-term residence in a nursing home an experience of high quality. **NCMedJ**

North Carolina Division of Aging and Adult Services
Long Term Care Ombudsman Program

NC Division of Aging and Adult Services / 2101 Mail Service Center / Raleigh, North Carolina 27699-2101
919-733-8395 / 919-715-0868 Fax / www.dhhs.state.nc.us/aging/ombud/ombstaff.htm

North Carolina Regional Ombudsmen

Region A
Southwestern Planning Commission
PO Box 850
Bryson City, NC 28713
(828) 488-9211 ext. 3032
Counties served: Cherokee, Clay, Graham, Haywood, Jackson, Macon, and Swain

Region B
Land-of-Sky Regional Council
25 Heritage Drive
Asheville, NC 28806
(828) 251-6622
Toll Free:1-800-727-0557
Counties served: Buncombe, Henderson, Madison, and Transylvania

Region C
Isothermal Commission
PO Box 841
Rutherfordton, NC 28139
(828) 287-2281 ext. 1222
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Counties served: Cleveland, McDowell, Polk, and Rutherford

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High Country Council of Governments
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Boone, NC 28607
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Counties served: Alleghany, Ashe, Avery, Mitchell, Watauga, Wilkes, and Yancey

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Western Piedmont Council of Governments
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Hickory, NC 28603
(828) 485-4213 and (828) 485-4266
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Region F
Centralina Council of Governments
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Charlotte, NC 28235
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Northwest Piedmont Council of Governments
400 W. Fourth Street, Suite 400
Winston-Salem, NC 27101
(336) 761-2111
Counties served: Davie, Forsyth, Stokes, Surry, and Yadkin

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Mid-Carolina Council of Governments
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Lumberton, NC 28358
(910) 618-5533
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Counties served: Bladen, Hoke, Robeson, Scotland, and Richmond

Region O
Cape Fear Council of Governments
1480 Harbour Dr.
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(910) 395-4553 ext. 208
Toll Free: 1-800-218-6575
Counties served: Brunswick, Columbus, New Hanover, and Pender

Region P
Eastern Carolina Council
PO Box 1717
New Bern, NC 28563
(252) 638-3185 ext. 3010 and ext. 3007
Toll Free: 1-800-824-4648
Counties served: Carteret, Craven, Duplin, Greene, Jones, Lenoir, Onslow, Pamlico, and Wayne

Region R
Albemarle Commission
PO Box 646
Hertford, NC 27944
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Counties served: Camden Chowan, Currituck, Dare, Gates, Hyde, Pasquotank, Perquimans, Tyrrell, and Washington

Region Q
Mid East Commission
PO Box Drawer 1787
Washington, NC 27889
(252) 974-1838
Counties served: Beaufort, Bertie, Hertford, Martin, and Pitt

COMMENTARY

What’s New in Long-Term Care Dining?

Nadine A. Pfeiffer, BSN, RN, Denise A. Rogers, Michelle R. Roseman, NHA, MBA, Leslie C. Jarema, NHA, Aimee Reimann, NHA, and Debbie Combs-Jones, MT, MHA

Throughout the years, nursing homes have traditionally been viewed as medically oriented with rigid schedules and limited choices, decorated with institutional-type furnishings and stark white painted walls. Visitors were few. In many cases these views were validated by actual practice. But in the early 1990s, the “medical model” nursing homes began to change as a few culture change philosophies emerged. Facilities started implementing innovative concepts, which are called “enhancements” in North Carolina, to make these facilities more home-like.

The term “culture change” has become synonymous with “environmental transformation” in the realm of culture-change enthusiasts. The concepts are now many, but they all have the same goal. They all implement an enhancement that transforms the medical model into a more home-like model, thus improving resident quality of life. Some opt to follow the named philosophies in their entirety, while others opt to base the changes on a particular model, altered to suit their facility’s individual needs or goals.

One of the original culture-change philosophies was the Eden Alternative,[1] started by Dr. William Thomas. This philosophy focuses on 10 principles to incorporate staff empowerment with team building and to then use plants, animals, and visits by children as the enhancements to complete the environmental transformation of the facility into a more natural and less “institutional” human habitat. This philosophy focuses on improving the quality of life and quality of care for residents and staff.

> *“The ability to choose your own food, socialize with friends, interact with attentive staff members, and enjoy a delicious and healthy meal provides a dignity unmatched by most other services.”*

The WellSpring Model[2,3] was started in 1994 and focuses on a collaborative effort between several nursing homes to cross-train and form a coalition. The homes in this coalition pay a licensing fee and monthly fee to the WellSpring Alliance, which supplies all training materials, clinical training experts, a data reporting system, and technical support during the implementation process. Spearheaded by a nurse practitioner, all staff are trained in eight quality of care modules, and they are managed in each home by a coordinator. Care resource teams, comprised of various staff members, are developed in each home to devise and implement culture-change strategies. The coalition-member homes share the costs of the program. There is continuous review of performance

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data related to resident outcomes in a variety of areas. This model focuses on the quality of care aspect of culture change.

The Pioneer Network[4] is yet another model for culture change. It informally began in 1992 with educational sessions on culture change. The first organized meeting of the movement was held in 1997, and in 2000 the Pioneer Network was officially named and took on its general mission of being a network of people dedicated to facilitating deep-system culture change. This concept directs each nursing home to acknowledge that culture change is an on-going process, base their enhancements on a core set of values, establish a clear vision for change, and establish a mission statement. The implementation of best practices tailored to individual needs is also stressed.

The concept of Person-Centered Planning[5,6] was initiated by the husband and wife team of Eric and Margie Haider (administrator and Director of Nursing at Crestview Nursing Home in Missouri). In 1998, they began a pilot project adopting person-centered planning into the long-term care setting. This philosophy focuses on each individual and offers more freedom, choices, and independence. This model puts the person in the center and provides more individualized care that is in the best interest of the person.

There are six critical components of person-centered planning: (1) supporting personal satisfaction in the lives of residents; (2) creating individualized living spaces; (3) empowering staff as advocates for the residents; (4) respecting individual life patterns, preferences, and needs; (5) providing opportunity for personal growth, development, and contribution; and (6) fostering a connection to the greater community.

According to data from the 2005 North Carolina Nursing Home license renewal applications, 54% of the facilities across North Carolina have self-reported that they embrace these care philosophies, and 19% of those facilities (73) have reported implementing innovations in the dining experience. The following are some best practice dining enhancements that stem from a divergence from the medical model and signify a transformation into true culture change in long-term care.

Best Practice Dining Enhancements in Long-Term Care

Creating a positive mealtime is a balancing act secured through attention to detail, compassion for the residents, and culinary expertise. At Abernethy Laurels in Netwon, North Carolina, the dining experience involves delicious food served by attentive wait staff and is combined with an inviting atmosphere that allows social interaction. In September of 2004, the age-old tray style dining service was replaced by a more personal table side dining program. Residents enter into a remodeled dining room filled with warmth and friendliness, eager to partake in the fare offered by Executive Chef Eddie Williams and his staff. Residents are free to choose from a menu of entrees and side items based on their individual preferences. Meals are served by friendly staff members who engage each resident in informal conversation, while remaining attentive to the individual needs of the diners. This conversation promotes social interaction, as

May I Serve You, Please?

Ted W. Goins, Jr.

A growing number of healthcare professionals are climbing on the bandwagon of "culture change" in long-term care. Resident-centered care and services are replacing the old, institutional, assembly-line approach of the past. Residents get a voice and vote in how they live. A collaborative, team philosophy is replacing the autocratic model. Those who have embraced these changes have created a much better home in which people can live and work. Facilities who don't change will not thrive, and may not even survive.

Lutheran Home–Hickory residents, families, and staff are excited about buffet dining.

Some of the more notable innovations are occurring in food service. The old system is dying: a system characterized by meals served at 7:00 am, 12:00 pm, and 5:00 pm; residents receive the meal the dietician planned whether they like it or not (with few alternates); meals served from a central kitchen in institutional, dome-covered plates often with luke-warm "hot" food, and luke-warm "cold" food. Meals have been served in the worst traditions of institutionalization, encouraged, if not mandated by punitive federal regulations.

A new day is dawning. Resident-centered care is opening eyes and attitudes. Healthcare professionals, state regulators, and others have joined in asking, "Why can't we do this a new way?" The answer is now "why not!"

Lutheran Home–Hickory is a wonderful example. With support from a Long-Term Care Enhancement grant from the state of North Carolina, the Lutheran Home has transformed a once institutional dining room into a "restaurant." Gone are the institutional colors, observation windows from two halls and a nursing station, and trays delivered from a distant kitchen. All have been replaced with a warm décor, wooden blinds to soften the windows, and a restaurant-style buffet at wheelchair height. Depressing, dark, coffee mugs for all liquids have been replaced with clear cups so

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well as offers an insight into the condition and health of each resident. This daily interaction re-connects the staff member with the resident, allowing for specific requirements to be identified and met, while creating an atmosphere of compassion.

In specific instances where a pureed meal is required, the Pureed Food Enhancement Program (PFEP) offers visually appealing and delicious choices. In days gone by, pureed foods were prepared on-site with a blender. This method created a situation where caloric content, nutritional value, taste, color, and texture were compromised. The mechanical alteration resulted in a bland, shapeless, unappetizing meal being served to residents to fulfill the need for pureed food. Residents often will not eat a meal they cannot recognize. Therefore, residents did not meet their individual dietary requirements, sustenance needs, or morale buoyancy. The PFEP presents pureed meals with uncompromised taste, formed in the shapes and colors of the items being served, with measured calories and nutritional values necessary for the well-being of the resident. Imagine a pureed pork chop, in the shape and color of a pork chop that looks so close to its non-pureed counterpart that the resident uses her fork to cut around what appears to be a bone. Spirits can be uplifted through serving a meal containing identifiable items that possess an enticing and aromatic flavor like other tablemates enjoy.

Since instituting table-side dining services, Abernethy Laurels has experienced a phenomenal rise in resident satisfaction with the food quality and atmosphere. Weight loss has been reduced and malnutrition is non-existent. The ability to choose your own food, socialize with friends, interact with attentive staff members, and enjoy a delicious and healthy meal provides a dignity unmatched by most other services. The dining experience is one more example of Abernethy Laurels' mission to "…add life to years."

The Forest at Duke, a continuing care retirement community in Durham, North Carolina, recently completed an addition/renovation project. Thirty-four adult care apartments were added and integrated into the existing Health Care Center. The project created six neighborhoods connected to an interior street with shared common spaces in a virtual village environment. Each neighborhood serves residents with a different set of care needs.

The creation of the new and innovative Health and Wellness Center gave The Forest at Duke the opportunity to offer more normalization of the dining experience in a long-term care setting. Each "neighborhood" has its own "restaurant" with individualized themes and décor. The secured special care unit, *The Riviera*, has a Mediterranean style "outside" café, Niko's Bistro. The intermediate special care unit, *Regency Square*, serves its residents in the Italian themed, Denali's. The skilled residents in the *Olsen* neighborhood dine in The Metro, an American "restaurant." Residents in the *Biltmore*, who have both medical and cognitive challenges, eat in their own home, 1950s-styled kitchen. *Carlton* residents enjoy their meals in an art deco restaurant, The Gatsby. La Maison, a country French restaurant accommodates the *Holbrook* neighborhood.

Each restaurant has natural lighting and a garden view to

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people know what they're drinking. It's the little things that make the difference.

Residents are served their drink of choice and the soup of the day, while they await their meal. Residents then visit the buffet and order what they desire. If resident still has a lifelong aversion to broccoli and orders a double helping of mac 'n cheese—go for it! No one should mandate when and what an older adult should eat.

"No one should mandate when and what an older adult should eat."

The transition has not been easy. In its new approach to redesigning the dining experience, Lutheran Home–Hickory started with lunch, and plans to include breakfast and dinner. Staff members, and even some residents, have found it difficult to discard 43 years of tradition. Persistence pays off. Staff is working to take the same and other dining innovations to the smaller units, including two Alzheimer's-type units, in the 204-bed facility.

The best measure of success came when Administrator Amber McIntosh and the team responsible for the transformation were called to the dining room one day at lunch. The residents, who sought some assistance from activity staff, had prepared an entire meal for the team as a sign of their appreciation. A resident spokesperson reduced the entire team to tears as she thanked them for sharing dignity and a beautiful place to eat. The state of North Carolina can take a great measure of credit through the Long-Term Care Enhancement grant that made this possible.

Meal times are another issue being addressed at Hickory and in many other long-term care facilities. Meal times were set like clockwork, literally. How many of us like to sleep-in occasionally, or finish watching that movie before eating supper? In the nursing home of old you ate at 7:00 am, 12:00 pm, and 5:00 pm, period! Some facilities are finding ways to bend over backward to give residents what they want when they want it. Lutheran Home–Hickory even has a colorful snack cart that makes the rounds of the building. Care for a Moon Pie and a Coke? Now that's livin'!

Lutheran Home–Hickory has helped lead the change/charge for Lutheran Services for the Aging's five nursing facilities and two retirement communities. Each facility

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enhance the dining experience. Signage including the menu of the day is clearly visible for cueing and wayfinding. Elegant table settings are provided, as well as lounge areas that include stocked bars for pre-dining activities. Assistive device rooms are provided to promote the facility's policy of seating all residents in dining room chairs during mealtime. Color coordinated linen napkins and attractive décor are provided, as well as dinner music.

For residents who have been identified to have weight loss, aromatherapy is used to stimulate the appetite. Essential oils known to increase appetite are sprayed in the dining area prior to the meal being served. Research studies are demonstrating the effectiveness of aromatherapy in successfully increasing weight in residents with dementia.[8] The *Biltmore* residents are stimulated by the aroma of coffee, toast, and baked goods cooking in their own kitchen.

For those residents requiring a pureed diet, efforts are made to present them in an attractive way by the use of "food molds" that simulate the food item that has been pureed. To ensure the quality of the food served, they are taste-tested at each meal.

To further encourage independence, choice, socialization, and offer flexibility, any resident in the Health and Wellness Center may dine in any of the "restaurants." Additionally, they may invite family members or friends from outside to join them for meals.

At Rex Rehabilitation and Nursing Care Center in Raleigh, North Carolina, scenic wall murals in several areas have enhanced that facility.[7] Susan Watkins, a restorative nurse, started the transformation by painting her small windowless office with a view of an arched Mediterranean villa balcony over red-tiled roofs that are cascading down hills to a deep blue ocean. With resident input, a beach scene resembling the North Carolina Outer Banks was painted in the big dining room. This mural includes a lighthouse, seagulls, a fishing boat (a resident's request), and a couple seated on a beach. The industrial kitchen in one corner was transformed to look like a crab shack, which made the freezer fit nicely. One wall in a windowless room, which was once a big storage room, now has a huge painted window with a view of the mountains. This pleases the residents who were fond of the mountains. On another wall, a stone fireplace is painted that looks so real one can almost feel the warmth from the fire. The Rehab dining area was turned into a realistic looking French café, and another dining area was turned into a beautiful garden room with a painted gate, stone wall, fountain, and trellis. These murals have made a change in the atmosphere in which the residents gather and eat. They no longer are looking at white walls, but at color, at pleasing scenes, which conjure up memories of favorite pastimes and pleasant experiences.

When Moses Cone Extended Care Center in Greensboro North Carolina, began the Eden Alternative journey in 2002, the first thing they wanted to do was to bring the smell of grandmother's kitchen back to their residents. Since they weren't blessed with the money to re-design their kitchen, they resorted to use of a little ingenuity to achieve their goal and the

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is on their own culture change path, learning from each other and from other innovators. The small 20-bed assisted living residence at Trinity Oaks Retirement Community in Salisbury has installed a buffet serving table to replace another institutional system. Although the dining room is too small for at-the-table choices, residents tell the staff what they desire, and staff serves it from the buffet in the adjoining serving kitchen. This system provides a personalized restaurant-style service, which benefits the residents by adding choices and accommodating preferences. The aroma from the buffet can also help with residents' appetites. This system is an example of how elders and staff can overcome space and other limitations to create a much more enjoyable dining experience. Innovations can work in every nursing and assisted living facility.

Trinity Oaks' Assisted Living residents enjoy dining together.

Food and nutrition are important for every age. We all enjoy a tasty meal in a comfortable environment. No one has to give that up. The future of long-term care may depend on our ability to offer these important quality of life dimensions.

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Wall mural in the dining room at the Rex Rehabilitation and Nursing Care Center result was fantastic. They created a small buffet cart that can be placed directly in the dining room. The buffet brings the wonderful smells, which normally stay in the kitchen, out to the residents. The residents can look and smell the selections at each meal and decide what and how much they want to eat. The resident is then escorted to a seat where he/she receives waited service, enjoys the meal, visits with friends, and requests "seconds" if desired.

The buffet and its wonderful aromas have been extremely successful with residents, and they also netted three unexpected benefits. The aromas increased the residents' appetites, which resulted in a drop in weight loss and an increase in the desire of residents to socialize in the dining room. The third, and perhaps the best, benefit was actually an impact on their visitors. Visitors now regularly come to the Moses Cone Extended Care facility at mealtime, view the buffet, select a meal, and sit with the residents for the type of family gathering they used to experience in their younger days.

The Lutheran Home–Winston-Salem has had remarkable success using flavor enhancers to increase both the enjoyment and levels of food consumption. A large proportion of persons over the age of 65 have smell and/or taste losses sometimes caused by normal aging that can impair nutritional status. There are also many medical conditions that have been reported to cause smell and taste losses in the elderly. These conditions include cancer, Alzheimer's disease, Parkinson's disease, and viral infections. A reduced sense of smell and taste can sometimes be combated by adding flavor enhancers to foods.[9]

Flavor enhancer is defined as a substance that increases the pleasantness of the flavor of another substance. Enhancing food flavors can help our elders maintain appetite and food enjoyment. Long-term care facilities are using flavor enhancers during their cooking process to complement the food product. Some examples of how we are enhancing flavors of foods include using bullion cubes to make sauces and gravies meatier or by using fruit extracts to enhance gelatins or fruit-flavored desserts.

Summary

A number of long-term care facilities in North Carolina have adopted ways to improve the dining experience for long-term care residents. Wall murals and dining room themes help to create a pleasant atmosphere that also might stimulate resident imagination. Aroma therapies are also positive stimulants that increase the appetite and pleasure in eating. Flavor and food presentation are probably some of the most obvious modifications. We can all understand the desire to have our food taste and look good. There are probably even more ideas that could make eating in a nursing home more pleasant and home-like. Efforts like these are critical to stemming weight loss among residents and also to maintaining resident independence to the extent possible. We hope more facilities across the state will use and build on these ideas as they try to maximize their residents' quality of life. **NCMedJ**

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COMMENTARY

The Dining Experience in Nursing Homes

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According to the United States Bureau of the Census Current Population Survey dated March 2000, there were 32.6 million people living in the United States who were at least 65 years old.[1] In North Carolina, 12% of the state's population, or an estimated 1.04 million people, were in this age group. By 2030, this figure is expected to rise to 18% of the population. North Carolina currently has 424 licensed nursing homes with a bed capacity of 42,897 residents.[2] According to the North Carolina Department of Health and Human Services, 60% of people who live to age 65 will need long-term care sometime in their lives; 40% will need nursing home care.[3]

Many aspects of an older adult's life, such as degenerative diseases, functional limitations, medications, and social considerations can result in a decreased sense of independence. In addition to actual loss of independence, many residents in nursing homes experience "learned dependency" from excessive care given by those working in the nursing home setting.[4] These factors have the potential to result in weight loss, dehydration, pressure wounds, and other negative health outcomes. According to the Minimum Data Set (MDS)* information transmitted to the North Carolina Division of Facility Services from January to March 2005, 11.2% of residents had 5% or greater weight loss in the 30 days prior to their assessments.[5]

As mentioned, many factors may influence a long-term care resident's independence and, in turn, their weight. Less obvious among some of these factors may be their combined effect on the dining experience. A positive dining experience should foster independence, promote self-esteem, and make the resident as comfortable and safe as possible, while providing a nourishing, pleasant meal and minimizing negative health outcomes. Providing a positive dining experience to long-term care residents can be challenging. Functional limitations that range from an inability to walk to difficulty swallowing, along with chronic diseases that require therapeutic diets, make it difficult for facilities to provide the type of home-cooked meal each resident might prefer. An effort should be made to maintain each resident's dignity and minimize the possibility of excess dependency during the dining experience.

Rethinking the Dining Room

The American Dietetic Association's *Practical Interventions for the Caregivers of the Eating-Disabled Older Adult* discusses many aspects in which the dining experience can be optimized.[6] These ideas range from mobility issues in the dining room to food presentation. The dining room layout, for example, directly affects the ease of mobility to and from meals. Long-term care facilities should arrange tables and chairs to allow easy access by residents utilizing wheelchairs and walkers. Facilities should also ensure that dining room table height is at a level that will accommodate residents seated in wheelchairs. Even if the dining room is easily accessible by residents in wheelchairs, staff should be encouraged to transfer residents into dining room chairs when possible.

The dining experience can also be enhanced if care facilities present a home-like environment by using tablecloths, cloth napkins, and seasonal centerpieces. Vibrant contrasting colors can be used for tablecloths, placemats, tableware, and/or napkins to increase the nutritive intake of residents with dementia and other patients who may have vision impairments that make it

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* "The Minimum Data Set (MDS) is part of the federally mandated process for clinical assessment of all residents in Medicare or Medicaid certified nursing homes. This process provides a comprehensive assessment of each resident's functional capabilities and helps nursing home staff identify health problems." For more information visit: The Centers for Medicare and Medicaid Services. MDS Quality Indicator and Resident Reports. Available at: http://www.cms.hhs.gov/states/mdsreports/default.asp.

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difficult to distinguish food from table placements (i.e., plates, cups, etc.).[7] Cloth napkins also make a better protective barrier for clothing than paper napkins do.

The dining experience can also be improved by simply offering the residents beverages and pleasant conversation while they wait for their meal. Age-appropriate music, along with proper lighting and room temperature (per resident preference), are other easy ways to make the dining experience more comfortable and interesting.

Two other ideas that improve the dining experience by promoting independence and choice involve the way meals are presented to residents. Facilities should consider presenting meals in a buffet-style setting or using family-style dining, which also promotes a home-like atmosphere. Both of these options allow residents to have increased independence by allowing residents to create their own menus and determine their own portion size.

Eating with Sensory Loss and Chronic Disease

Residents in North Carolina nursing facilities are admitted with different diagnoses, singly and in combination, which can influence how well they enjoy their dining experience. Sensory losses associated with glaucoma, stroke, arthritis, and other conditions affect a person's ability to consume nutritionally-balanced meals and participate in the social aspects of dining. Many residents cannot see the food placed in front of them, manipulate the utensils very well, or hear conversations at the table. In addition to sensory impairments, chronic diseases and their treatments may contribute to loss of appetite, nausea, vomiting, early satiety, fatigue, lethargy, and decreased ability to feed oneself. In 2003, the North Carolina Long Term Care Ombudsman Program provided 441 training sessions for long-term care staff on sensitivity to sensory losses associated with aging.[8] Staff who received the sensitivity training did not enjoy their dining experience. Many of them wanted to retreat to a private location, felt embarrassment, or simply did not want to eat.

> *"A positive dining experience should foster independence, promote self-esteem, and make the resident as comfortable and safe as possible, while providing a nourishing, pleasant meal and minimizing negative health outcomes."*

In addition to functional challenges, many residents are also prescribed therapeutic diets.* The MDS 2005 data show that 47% of residents received a therapeutic diet, and 42% of nursing home residents received a mechanically-altered** diet.[5] A contributing factor to the high incidence of mechanically-altered diets is the fact that 40% of adults more than 65 years of age have no teeth, and only 2% of adults more than 65 years of age still have all of their natural teeth.[9] Therapeutic diet orders, such as 2gm sodium diets, calorie-controlled diabetic diets, or fat-restricted diets may be too restrictive for the nursing home population and may contribute to existing medical problems through complications, such as weight loss, decreased nutritional status, and diminished quality of life. Some facilities use diet types, such as no concentrated sweets and/or no added salt with recipes for large quantities that can serve most residents in a facility. As a result, these menus can be low in calories, bland in taste, and unappealing. Therapeutic diets may be beneficial for certain disease states in the nursing home setting, but they may result in a decreased calorie intake for those whose health needs do not require as much restriction.[10]

One approach used to combat the feeding challenges caused by chronic disease and functional decline is to provide a liberalized diet. Many nursing homes have embraced a liberalized diet plan, which allows all residents to have a regular diet, with minimal restrictions, such as elimination of a salt packet, altered sweet dessert, or other changes according to the resident's medical condition. In 2002, the American Dietetic Association established a position statement for the support of liberalized diets in nursing facilities.[11] The research demonstrated that therapeutic diets may not be warranted in lieu of the overall effects on a resident's quality of life. Many nursing facilities have adopted liberalized menu plans for their residents who have therapeutic needs secondary to diabetes and other disease states, such as hypertension.

A Team Approach

In addition to providing more liberalized diets, facilities can improve resident dining satisfaction and nutritional health through interdisciplinary care team coordination and communication. Members of the interdisciplinary team include the physician, registered dietitian, physical therapist, occupational therapist, speech therapist, pharmacist, social worker, nursing staff (including registered nurses, licensed practical nurses, and nurse aides), and the activity department. Family and resident involvement in the care planning process is also important. As an example of care team coordination, the registered dietitian

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* Therapeutic diets are used to help treat/manage certain chronic diseases (e.g., diabetes and hypertension).

** A mechanically altered diet includes foods that may be pureed or softened to help patients who have trouble chewing and/or swallowing.

can monitor the consumption of meals for all residents or target those who have a higher risk for malnutrition, dehydration, and other nutrition-related outcomes.[12-13] The registered dietitian can determine if a resident's decreased intake is secondary to drug-nutrient interactions, changes in preferences, or changes in disease state. If drug-nutrient interactions occur, the dietitian may inform the pharmacist who can recommend medications and/or order appetite stimulants to counteract the possible negative outcomes produced by the interactions. Speech therapists can evaluate tolerance to current diet textures and fluid consistencies. As a result of this team approach, a meal can be presented that is individualized to the resident's needs and food preferences.

Dietary and activity team members can play a crucial role in making the dining experience personal for each resident. These departments can create theme/holiday meals, "meal-of-the-month" menus, and other special events. Residents also have the right to consult with the dietary department to design facility menus that express their religious, cultural, and preferred food choices. Facilities should use this information along with Dietary Guidelines for Americans,[14] My Food Pyramid,[15] and the Dietary Reference Intakes[16] to create a nutritious menu. To carry out the provision of nutritionally balanced menus, a facility may spend 7-10% of its total budgeted expenses on food service-related costs.[17]

Self- and Assisted-Feeding

Feeding difficulties occur in 87% of the elderly population.[18] It is the duty of the direct care staff to inform the rehabilitation department when someone is having trouble. Occupational therapists can evaluate a resident's need for adaptive equipment and individualized needs, such as proper positioning. Proper positioning (in a chair or bed) is one of the most useful ways to increased independence and, therefore, should be used during all dining experiences.[19] Improper positioning can increase difficulty in self-feeding or swallowing, increase frustration, fatigue, and decrease the resident's motivation to eat enough food. For residents with functional limitations, self-feeding is a challenge and may decrease socialization at mealtime. Adaptive equipment may minimize the energy required for self-feeding and, in turn, may improve the residents' ability to socialize.[19] An occupational therapist can develop a plan of care for positioning and train direct care staff.

Other feeding difficulties may be related to visual impairment and/or blindness. Residents with these deficits benefit from standardized placement of food, beverages, and service ware on their trays. The positional "clock system" can be used to inform the resident of the physical placement of specific foods in relation to their tray set-up.

Physical therapists can also be an asset by spearheading programs such as a "Walk to Dine" program. In this program, nurse aides and nurses work with physical therapists to assist residents with transfers from their wheelchairs into dining room chairs and work with occupational therapists on proper positioning of residents. Perry Gains, CNA, in Restorative Nursing at Charlotte Health Care Center, notes that minimizing chaos in the dining room by transferring residents into dining room chairs, and thus decreasing the number of wheelchairs and Geri chairs in the room, can help achieve a positive dining experience for everyone. This process decreases the risk of aspiration by allowing optimal positioning and provides an increase in resident dignity during dining. To further increase dignity during dining, residents with similar cognition and table manners or those affected by disease states such as dementia should be seated together. Thus, a resident can socialize with other residents who have similar habits and communication skills. Hearing-impaired residents may be reluctant to eat in noisy, crowded dining rooms because they are unable to hear mealtime conversation, which results in a feeling of isolation. Nursing facilities can limit unnecessary staff conversations, use sound-absorbing materials in the design and décor of the dining room, and ask residents for their individual suggestions on how to address noise reduction.

Improving the social aspect of dining is another way to achieve a positive dining experience. A program entitled "Dining with Dignity" was created to use socialization to increase the intake and independence of residents during meals.[20] The program is based on the enjoyment of meals with friends and families. It targets individuals at risk for malnutrition, dehydration, and pressure wounds and provides them with companionship at meals. Specifically, family members and "volunteer meal companions" are trained to appropriately assist residents during meals.[14] The program trains the volunteers on concepts such as cueing, "hand-over-hand" assistance, the "power of touch," and the importance of pleasant conversation. Residents who receive assistance from families or companions during meals consume a larger portion of their meals and decrease their risk of malnutrition, dehydration, and pressure wounds.[14] This supports the concept that nursing staff, families, and feeding companions should be an important part of the interdisciplinary team. One nursing home resident involved in the "Dining with Dignity" program summarized her reaction to the program in this way, "I socialize with different people and get to meet new people everyday. We have become a big circle of friends." This statement demonstrates how important the dining experience can be for a resident's total long-term residential care.

Summary

The dining experience is an opportunity for residents to experience the independence they once knew and still desire. Through appropriate meal consistencies an optimal dining room setting, and coordination of the total healthcare team, these desires can be reached. The resident benefits from this emphasis on the dining experience, while the interdisciplinary team members gain more insight into the individual needs of residents. The dining experience can be an important part of the clinical care of the resident by assuring appropriate nutritional and fluid intake, and it can help assure a desirable quality of life even while residing in a long-term care facility. **NCMedJ**

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Fluid Intake and Hydration: Critical Indicators of Nursing Home Quality

Robert J. Sullivan, Jr., MD, MPH

After emerging from the primordial sea, humans evolved a sophisticated system for maintaining hydration in order to survive. Despite extremes of environmental stress, internal fluid and electrolyte balance remain remarkably stable. Compensatory mechanisms required to accomplish this feat begin with a sense of thirst, which stimulates fluid consumption.[1] With adequate fluid intake assured, the kidneys retain or discard fluids and electrolytes as appropriate. Under most circumstances, this remarkable mammalian adaptation to life on dry land requires no conscious intervention. In fact, the overwhelming majority of healthy children and adults pursue their daily affairs blissfully unaware of their hydration requirements, or their efforts to meet them.

Such is not the case for infirm elderly individuals. They experience a reduction in the ability to compensate for fluid excess and deficit due to a diminished sensation of thirst[2] coupled with a decline in kidney function. As a result of these changes, for the first time in their lives, older individuals and their caregivers must devote specific attention to fluid intake and elimination.[3] Since changes of aging are subtle, and often are ignored or pass unnoticed, it is not surprising that unrecognized chronic dehydration is a common finding among older adults presenting to emergency departments.[4]

Attention to fluid intake is particularly important for those living in nursing homes. Many of the reasons leading to nursing home placement are associated with significant hydration challenges. Residents with cerebral deterioration or injury may fail to respond to thirst stimuli or be unable to gain access to fluids. Renal function can be reduced by infection, diabetes, kidney stones, and urinary tract outflow obstruction. Medications administered to control illness can adversely influence bodily control systems. As a result of such challenges, mechanisms that maintain hydration may prove inadequate. In response, nursing facility management must establish systems of care to provide ongoing hydration support, and staff must be trained to assume an active role in promoting fluid intake.[5] Failure to manage hydration can be life-threatening and is a common reason for hospitalization.[5] Fortunately, excellent reviews and guidance are available in the medical literature to guide both novice and experienced caregivers.[6]

Initial Evaluation

Immediately upon arrival at a nursing facility, the staff should conduct a comprehensive assessment of the new resident's needs and capabilities. In regard to fluids and hydration, the assessment should document prior requirements for hydration assistance, physical limitations on swallowing, and underlying medical conditions and medications that could present problems. Direct observation during meals and throughout the first day will provide additional information regarding intake and elimination patterns and capabilities. An immediate plan of care must be established to address hydration whenever concerns or problems are documented. Virtually all information necessary to understand hydration requirements is addressed in the Minimum Data Set (MDS).* With this information available, a care plan can be created to assure ongoing stability.

When determining fluid intake requirements, all sources of fluid gain and loss need to be considered. Residents exhale moisture with each breath, and their skin constantly exudes moisture that evaporates from the surface. They lose additional moisture through bowel evacuation and the production of urine as they eliminate waste products of metabolism. They gain some fluid through metabolism of foods, but it does not

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* "The Minimum Data Set (MDS) is part of the federally mandated process for clinical assessment of all residents in Medicare or Medicaid certified nursing homes. This process provides a comprehensive assessment of each resident's functional capabilities and helps nursing home staff identify health problems." For more information visit: The Centers for Medicare and Medicaid Services. MDS Quality Indicator and Resident Reports. Available at: http://www.cms.hhs.gov/states/mdsreports/default.asp.

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equal losses. Thus, a daily intake of at least two or more liters is necessary to sustain equilibrium.

While most residents can successfully continue self-management of fluid intake as they have done throughout their entire lives, the admission assessment is designed to detect risk factors for dehydration. Generic risk factors discovered from research studies include female gender, age over 85, more than four medical conditions, more than four medications, bedridden, laxative use, and chronic infections.[8] Specific risk factors include fluid loss associated with kidney disease or diabetes. Diuretic medications prescribed to control heart failure and hypertension cause a steady loss of fluids. Fluid problems can be sudden and severe if nausea, vomiting, and diarrhea persist for any length of time. Fever will enhance the loss of fluids in the form of sweat. Intake is reduced for residents with swallowing problems associated with Parkinson's disease, strokes, or dementia. Depression, delirium, anxiety, and agitation cause a loss of interest in food and fluids. These, and many more problems, are commonly encountered in nursing home residents.

Top-quality nursing care organizations have a variety of pre-defined care plans established to deal with hydration issues detected in the MDS evaluation process. Plans provide a structure for ongoing resident support, periodic observation, documentation, and notification when problems arise. Nutritionists or dietitians will establish the plan for food and fluid type, volume, and frequency. Speech therapists assess swallowing skills and provide recommendations regarding fluid consistency and optimal feeding position. Occupational therapists address requirements imposed by physical disability and provide solutions, such as the use of straws, "sippy cups," vessel with large handles, or resilient grip materials. Once the degree of supervision and assessment for fluid intake is established, every member of the staff is expected to participate in plan implementation. While the focus of most hydration strategies involves improvement and maintenance of function, the nursing home must also have comprehensive plans available for managing nutrition and hydration for the terminally ill under hospice care.

Daily Monitoring

Success in maintaining hydration requires ongoing attention to the resident's environment and daily demeanor. Staff members should ensure the ready availability of refreshing fluids throughout the day and watch to be sure they are used (see Sidebar on page 298). Hydration is not limited to the dining experience. Residents in nursing facilities must have a wide variety of fluids available hour-by-hour, just as they did prior to entering the nursing home. Staff knowledge of preferences expressed by individuals can guide the choice of fluids offered. That includes juice with breakfast, milk with cereal, coffee or tea with meals, soft drinks and water throughout the day for refreshment, and perhaps wine or beer in the evening. For those capable of ambulation, a water cooler or drinking fountain offers a suitable source for refreshment. Bed-bound residents and those confined to chairs must have pitchers with fresh, cool water and cups within reach. Resident charts should include regular documentation regarding the amount of fluids and foods consumed at mealtime. Where fluids are readily available, most residents will take care of their needs without needing assistance. If staff members observe a decline in intake or function, an evaluation for dehydration should be promptly undertaken. Periodic weight checks are helpful, although changes may reflect problems with nutrition rather than hydration.

Residents with medical or emotional problems associated with dehydration will require more intensive monitoring of intake and urinary output. Intake volume is easy to estimate by measuring the fluids consumed from bedside pitchers and during meals. By contrast, monitoring kidney output is challenging for most ambulatory residents since collecting and measuring urine is neither easy nor pleasant. Demented patients may lack the mental capacity to cooperate. The frequency of visits to the bathroom provides a useful clue regarding the adequacy of renal function. For incontinent patients, experienced staff members often assess urinary concentration and volume when changing diapers. Although hardly quantitative, diaper evaluation does permit detection of major changes in output.

> *"Since the physical manifestations of dehydration are non-specific and often obscured by the aging process and/or illness, it is not surprising that this diagnosis is often overlooked."*

Assessing Suspected Dehydration

Dehydration can develop rapidly in older individuals due to illness and changes in medication or environment. If the air-conditioning should fail on a hot afternoon, all residents need to be encouraged to consume extra fluids. Should the nursing home staff become aware of changes in a resident's appearance in regard to either health or function, immediate evaluation is needed.

Since the physical manifestations of dehydration are non-specific and often obscured by the aging process and/or illness, it is not surprising that this diagnosis is often overlooked.[9] Symptoms of dry mouth, fatigue, weakness, restlessness, loss of appetite, nausea, and vomiting are commonly reported. However, signs of pale dry skin and poor skin turgor can reflect normal aging. A dry mouth is more likely to reflect mouth breathing than lack of fluid intake. Constipation and fecal impaction often occur with dehydration, but commonly occur without it. A drop in blood pressure and a rise in pulse when the resident sits or stands is one method used to detect intravascular volume deficits associated with dehydration.

While physical examination for signs of dehydration is helpful, the single most valuable indicator is a documented drop in urinary volume. The normal urine output exceeds 600cc/day for most adults. When the output falls below 400cc/day, an evaluation is needed. Most residents can successfully collect and submit a 24-hour urine specimen. However, if there is a serious question regarding dehydration, placement of a temporary urinary catheter to document output is worth doing. By having the resident to void prior to catheter placement, the presence of a possible bladder outflow obstruction can be simultaneously documented.

Laboratory tests can assist the evaluation of dehydration provided that baseline levels are available for comparison. A rise in hemoglobin and hematocrit are typical findings accompanied by a rise in the blood urea nitrogen (BUN) and creatinine levels. A normal BUN/creatinine ratio is 10:1. Due to increased urea reabsorption associated with dehydration, the ratio will shift to over 20:1. Finding a urine specific gravity over 1.015 in the absence of urinary glucose indicates the kidneys are working hard to conserve fluids. Checking a urine specimen for sodium concentration is particularly helpful. Documenting a concentration below 25 mEq/L in the absence of renal disease or diuretic therapy is a highly significant indication of a hydration problem. An even more accurate test involves calculating the urinary fractional excretion of sodium by comparing plasma and urine sodium and creatinine concentrations.

Rehydration

If physical findings and/or laboratory tests suggest dehydration, an immediate response is required. The resident's physician should promptly be notified and rehydration efforts initiated. If the resident can ingest fluids by mouth, drinking water, diluted juice, soft drinks, electrolyte solutions (e.g., Gatorade®), soups, coffee, or tea should be encouraged. Careful documentation of fluid intake and output must be maintained until the resident is stable. There is no formula available to estimate the volume of fluid needed. Instead, staff must rely upon clinical evidence of response using the same indicators used for diagnosing dehydration. An increase in arterial pressure, urine output, and urine sodium excretion are reliable signs. Look for a return to prior levels of mental performance and a resumption of typical daily functions as further indication of success.

Creative Hydration Programs

Lanaya Cunningham, RD

The staff at Universal Healthcare and Rehabilitation Center in Concord, North Carolina use a nourishment cart covered with a decorative canopy as part of their hydration program. The dietary staff stocks the cooler on the cart with various juices and milk, plus a variety of snacks including gelatin, ice cream, and pudding, which can also contribute to the total liquid intake of the residents. The cart is pushed from room to room, and beverages and snacks are offered at mid-morning, mid-afternoon, and in the late evening.

The afternoon hydration and nourishment pass at Taylor Extended Care Facility in Sealevel, North Carolina is part of the activity program. The cart is decorated with balloons and has music playing while the staff pushes it through the halls in the mid-afternoon. The staff offers snacks to the residents from the cart, which may consist of ice cream, soft drinks, or juices. The snacks and the music are often coordinated to coincide with the planned activity in the facility that day. The activity staff report that the residents often come into the hallway in the afternoon when they hear the music, and they look forward to receiving a beverage and snack.

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Feeding tubes

Residents who receive food and fluids via a naso-gastric or an enterostomy tube represent a special situation since all nutrition and hydration can be controlled by the nursing staff. Nutritionists will design the protocol for both food and fluid administration. If followed with care and attention, the protocol should ensure stability.

Summary

Hydration issues are important considerations for the elderly and infirm. What was previously taken for granted often becomes the focus of daily attention. Nursing homes must take a proactive stance in designing systems and training staff to deal with hydration. The minimum daily fluid requirements, and the steps necessary to investigate suspected dehydration, should be well known and understood by all members of the staff. **NCMedJ**

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COMMENTARY

Regulating Food Service in North Carolina's Long-Term Care Facilities

Cindy H. DePorter, MSSW

> *Based on a resident's comprehensive assessment, the facility must ensure that a resident: maintains acceptable parameters of nutritional status, such as body weight and protein levels… The facility must [also] provide each resident with sufficient fluid intake to maintain proper hydration and health.*[1] — United States Code of Federal Regulations

The provision of food service to residents is among the many regulated services in long-term care facilities. Long-term care facilities face a challenging task in providing three tasty, nutritious meals a day to their nearly 43,000 residents, each with special needs and preferences. In order to ensure that North Carolina's long-term care facilities provide these meals appropriately, North Carolina's long-term care facilities are regulated by the federal Centers for Medicaid and Medicare Services (CMS) through special delegated authority to the North Carolina Division of Facilities Services (DFS).

To understand how long-term care food services are regulated, one must first understand how these facilities are regulated in general. As part of the Social Security Act, Congress included a minimum set of quality and performance standards to regulate all long-term care facilities certified to receive Medicaid and Medicare funding.[2] This legislation covers everything from resident assessments to survey and certification processes to dietary services.

The duty of enforcing this legislation falls under the Centers for Medicare and Medicaid Services (CMS). CMS is also charged with drafting the specific regulations and manuals needed to implement the law. Title 42 of United States Code of Federal Regulations[1] contains the specific regulations long-term care facilities must comply with in order to qualify for federal reimbursement under Medicaid and Medicare. CMS contracts with each state to inspect facilities, assess their regulatory compliance, and to oversee the licensure process. In North Carolina, the state Division of Facility Services (DFS) performs these functions.

Within the North Carolina DFS, the Licensure and Certification Section's primary responsibility is to ensure that citizens of North Carolina receive safe and adequate healthcare. The Section does this by conducting annual inspections of healthcare facilities, agencies, and clinical laboratories. Eighty percent of the Section's 150 employees are dedicated to performing these inspections, most of which take place in long-term care facilities.

This commentary provides an overview of federal (CMS) regulations pertaining to food service provision in nursing homes* and the criteria by which these services are evaluated. It also discusses how state regulatory processes address issues of food service and hydration in long-term care facilities, along with examples of how most facilities are dealing with common challenges in this area.

Understanding Federal and State Regulations

The federal regulations related to long-term care dining issues can be found in the United States Code of Federal Regulations, §483.15 (Quality of Life); §483.25 (Quality of Care); and §483.35 (Dietary Services).[1] To interpret the regulations, states use the CMS *State Operations Manual*, which includes detailed instructions to surveyors.[3]

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* In this commentary, the term "nursing home" refers to an in-patient facility that provides skilled-nursing care 24 hours-per-day by licensed registered nurses.

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Preserving Resident Quality of Life

> *The facility must promote care for residents in a manner and in an environment that maintains or enhances each resident's dignity and respect in full recognition of his or her individuality.*[1]

Each resident of a long-term care facility has the right to be treated with dignity and respect. Preserving resident dignity involves activities that help residents maintain their self-esteem and self-worth (i.e., assisting with grooming and appearance, promoting independence in dining). CMS expects the dining environment to be pleasant and for residents to have a positive dining experience. The dining room should be clean, people at the same tables should all be served at the same time, and the staff providing dining service should be courteous and helpful (i.e., not yelling across the room for assistance). Residents should not have to wear "bibs," and facilities should not serve food on paper plates or use plastic forks on a regular basis.

"Each resident of a long-term care facility has the right to be treated with dignity and respect."

Tying in directly with the regulation to preserve dignity is a regulation to preserve resident food and beverage choice. Each resident has the right to make choices about his/her life and healthcare in the facility. Their choices include *where* they want to eat (e.g., in their room or in the dining room) and *what* they want to eat. The facility should educate residents about the risks of choosing not to follow a prescribed therapeutic diet. For example, diabetic residents often do not want to eat the 1,800-calorie American Dietetic Association diet. Most facilities have an NCS diet (No Concentrated Sweets) that is intended for diabetic residents. The NCS diet allows residents more food choices and freedom. Facilities also have the flexibility to change the types of foods offered at meals to accommodate the resident's choice.

The resident can choose to eat in his/her room versus in the dining room. If a resident would like to sleep late in the morning without skipping breakfast, this is their right. The facility should work with residents to honor this request and still have some type of breakfast available. It might not be the same breakfast that was served to the other residents at the scheduled mealtime, but as long as it meets the nutritional guidelines, it would be acceptable under federal and state regulations. Family members are also permitted to bring the resident food from home or restaurant. Family members are not permitted to bring food to be served to other long-term care residents.

Maintaining Quality Care

> *Each resident must receive, and the facility must provide, the necessary care and services to attain or maintain the highest practicable physical, mental, and psychosocial well-being, in accordance with the comprehensive assessment and plan of care.*[1]

With regard to dining, providing quality care is geared around the resident's ability to consume foods and fluids. Nursing homes are required to maintain acceptable parameters of nutrition, such as body weight and protein levels, based on the resident's clinical condition and risk status. This means that, if a resident experiences unplanned weight loss, the facility has to assess and implement strategies to ensure that the weight loss is not because of some avoidable issue, such as a resident having mouth pain while he/she eats. The facility has the responsibility of assuring that weight loss is clinically unavoidable. If the resident is losing weight because of a clinical condition, the facility still should assess and attempt interventions to maintain resident weight. Along with this comes the issue of the resident having the right to refuse food. In some instances the resident may have a terminal illness and may opt to refuse food. Regardless of the resident's condition, all residents have the right to refuse food. If this happens, the facility should discuss food refusal with the resident (when possible), the resident's family, and the resident's physician to make sure that the resident's wishes are being honored. The facility should document the discussion in the resident's record and support the decision that was reached.

Dehydration falls under the same regulatory requirements. The facility has to provide sufficient fluid intake to assure proper hydration and health. If residents with dementia cannot maintain their own hydration, facilities must offer fluids to these residents throughout the day, not just at meal times. If a resident decides to refuse liquids, he/she has the right to do so. Facilities should document the resident's desire to refuse liquids in his/her record. Facilities should also document that this choice has been discussed with the resident (when possible), the resident's family, and physician. The resident's wishes should be honored.

Dietary Services

> *The facility must provide each resident with a nourishing, palatable, well-balanced diet that meets the daily nutritional and special dietary needs of each resident.*[1]

Regulations specified under Dietary Services address the following areas of food service provision: staffing, menus and nutritional adequacy, food, therapeutic diets, frequency of meals, assistive devices, sanitary conditions, and feeding tubes.

Staffing

Regulations for dietary services are designed with the general intent for facilities to provide each resident with a nourishing, palatable, well-balanced diet, which also meets the individual daily nutritional and special dietary needs of each resident. CMS requires facilities to have a qualified dietitian as indicated by Dietetic Registration of the American Dietetic Association or have the basis of education, training, and experience to identify residents' dietary needs, appropriately assess and plan, and help implement the dietary program. A qualified dietitian is not required to be at the facility on a full-time basis. Facilities that do not employ a full-time dietitian, must designate a person to serve as the director of food services. The director of food services must receive frequent consultation from a qualified dietitian. The regulations do not specify how often a consultation should occur, but consultations usually occur on a monthly basis. The facility must also employ sufficient support personnel who are competent to carry out the functions of the dietary services. DFS judges whether a facility has sufficient dining staff based on their ability to prepare and provide meals in a timely (e.g., quickly enough to ensure the food is served warm) and in an appropriate manner (e.g., all residents at one table are served at the same time). Facilities determine what works for them in terms of sufficient staffing.

Menus and Nutritional Adequacy

Facilities are required to have menus that meet the nutritional needs of residents in accordance with the recommended dietary allowance of the Food and Nutrition Board of the National Research Council, National Academy of Sciences. In addition, all menus are to be prepared in advance and carefully followed.

Food

Each resident should receive food prepared by methods that conserve its nutritive values, flavor, and appearance. Food must be palatable, attractive, and served at the proper temperature. In other words, the facility has to cook the food in such a manner that it looks, tastes, and smells appetizing. To ensure that food is prepared and served in an appetizing manner, DFS depends, in large part, on the residents' and the residents' families' feedback to survey teams on how the resident and/or family perceives the food. How does the food taste? What does it look like? Does it smell good?

DFS surveyors find that food is a serious concern to residents. Mealtime is a social time and a time when residents interact with each other. DFS survey teams routinely ask resident's how they like the food. The question opens up an important dialog between surveyors and residents and helps establish credibility for surveyors. Meal times are a highlight of many residents' days, and it is important that residents are satisfied with this general category of service offered by the facility in which they live.

Therapeutic Diets

The food has to be prepared in a form designed to meet individual needs. Some residents, for example, have no teeth, and therefore must have their food chopped or pureed (mechanically altered). A physician, in conjunction with the nursing home staff, may prescribe a therapeutic or mechanically altered diet. The facility must have substitution foods of similar nutritive value available to residents who refuse to eat the foods routinely served in their prescribed diets. The staff should offer these substitutions to the resident whenever this occurs.

Frequency of Meals and Snacks

CMS regulations require long-term care facilities to provide three meals a day at regularly scheduled times, which are comparable to mealtimes in the community. There must be no more than 14 hours between a substantial evening meal and breakfast the following day. Each day a snack must be offered at bedtime. When a nourishing snack is provided at bedtime, then the facility may have 16 hours between the evening meal and breakfast the following day, if a resident group agrees to this meal span. Snacks vary from graham crackers and juice to fruit and milk to other types of healthy snacks. The facility must offer snacks to residents each night. Residents also may have their own snacks in the facility. Proper storage is an important consideration to lessen the chance of pests. The key idea related to both meals and snacks is choice. Facilities in North Carolina have gone to great lengths not to impose simple "one-size-fits-all" approaches with regard to both meals and snacks.

Assistive Devices

Assistive devices, or special eating equipment, may help residents who have functional limitations. The facility must provide special eating equipment and utensils for residents who need them. This would include items such as large-handled/easy grip forks and spoons, plate guards that help keep food on the plate, or postural supports that help residents with positioning.

Sanitary Conditions

In addition to federal laws, long-term care facilities must also follow state laws with regard to sanitation and safe food handling. The Departments of Environment and Natural Resources and the Division of Public Health work together to meet this public health need. County inspectors grade all the nursing home food service departments just like they do restaurants.

To comply with federal regulations, long-term care facilities must procure food from sources approved or considered satisfactory by federal, state, or local authorities. Food must be stored, prepared, distributed, and served under sanitary conditions. The facility must also properly dispose of garbage and refuse. Elderly people are often immuno-compromised and, therefore, are more susceptible to food-borne illnesses, so these stringent requirements are applied. However, this does not mean that families cannot bring food into the facility. Many families bring food to residents, and it is an acceptable practice. In addition, facilities may have fresh seasonable vegetables and other seasonal meals as long as they come from approved sources. There are no regulations that prohibit this practice. Facilities have great latitude in being able to provide meals that meet standard nutritional guidelines, but still meet the unique likes and dislikes of their specific resident populations.

Feeding Tubes

Residents who have feeding tubes or are at risk for weight loss or dehydration must also have special protections. Facilities are not to place and feed a resident by naso-gastric tube unless the resident's clinical condition makes it unavoidable, and if a resident requires this type of feeding over the long term, a gastrostomy tube would be considered. These regulations also make sure the facility is providing the correct treatment and services to maintain this form of feeding. This includes placement of the tubes, monitoring of intake for proper nutritive levels, and total management of the feeding tube functionality.

State Survey Teams

DFS survey teams visit each facility periodically (no less than once per year) to ensure that all facilities comply with the regulations pertaining to the operation of a nursing home. Federal survey teams may also visit these same nursing homes. While federal survey teams typically visit a facility only after a state survey team has noted deficiencies, federal survey teams may visit facilities at any time for any reason.

DFS surveys teams generally include four-to-five professionals—a combination of nurses, dietitians, social workers, and pharmacists. The annual surveys inspect the overall care in the nursing home, which includes using a variety of indicators, such as pressure sores, dehydration, abuse, and nutrition. Inspections typically take three days, and DFS conducts at least 15% of the inspections during weekends, evening, and/or early morning hours. Surveyors observe; review facility documentation; and interview residents, families, and staff to make their determinations. To determine if there is a "deficiency," the surveyors consider the outcome, what occurred, why it occurred, how often it occurs, the impact, whether the facility has resolved the problem, if they facility knew there was a problem, etc.

If the survey team finds that a nursing home is out of compliance with any regulation or standard (including patients' rights violations), DFS cites the facility for a violation. The facility must then submit a response/plan of correction to DFS for approval. DFS will conduct another survey to make sure the facility implemented corrective action. If a facility fails to implement corrective action, they may be subject to state and/or federal sanctions and fines. In worst case scenarios, facilities might be required to suspend new admissions, have a temporary manager appointed to operate the facility, or have their license revoked. Fines range from $50.00 to $10,000.00 a day. However, in most cases, the facility corrects the problem promptly and is not sanctioned or fined. Facilities also have the right to appeal any deficincy that they incur.

Summary

Other commentaries in this issue of the *North Carolina Medical Journal* describe innovative food and dining practices in some of our state's long-term care facilities.[4,5] Federal and state regulations do not prohibit these innovations, and DFS supports the concept of "enhancements" of the dining experience in these facilities. The Division of Facilities Services, therefore, encourages facilities to assess and operationalize various dining methods, allowing residents to select their foods, dining times, dining partners, and other preferences. The regulations allow facilities to utilize innovative dining approaches, such as buffet lines, or family-style serving options, which allow residents to order at the table as they would in a restaurant. The regulations do not dictate whether facilities should serve food to residents on trays, in buffet lines, or in a family style. While there are many regulations, they leave room for innovative new ideas as long as these ideas do not compromise resident health or safety.

Food consumption and the dining experience are an integral part of the resident's life in a nursing facility. It is important that resident preferences are being honored, and the dining experience is as pleasant and home-like as possible. The facility's responsibility is to provide adequate nutrition and hydration that assures the resident is at his/her highest level of functioning emotionally, functionally, and physically. Meeting the unique needs of each resident in a facility can be a daunting task, but one of immense importance to the quality long-term care. **NCMedJ**

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COMMENTARY

A Physician's Perspective on the Dining Experience in Long-Term Care

Christopher M. Herman, MD, CMD

Nursing Homes have long been the location where services are provided to individuals who suffer from chronic functional and cognitive impairments. Hopes to "cure" these chronic conditions are unfortunately unrealistic. The goals of a nursing home can be best summarized as one in which the facility cares for its "residents in a manner and in an environment that promotes the maintenance or enhancement of each resident's quality of life."[1] Maintenance and enhancement of quality of life become the focus, not cure.

Since mealtimes are often the highlights of a patient's day, they can become a significant source of improved quality of life, or a source of frustration and complaint, for the patient, family, and facility. Although there are many specialized diets from which to choose, most of these diets are not appropriate for use in a nursing home setting. Often, a more liberalized diet that provides for the patient's nutritional needs while considering the resident's medical conditions can increase the desire to eat and the enjoyment of food. This ultimately decreases the risks of weight loss and undernutrition.[2]

Prescribing Therapeutic Diets

Diets in nursing homes are often chosen for the patients by the attending physician based on the patient's medical condition. These are called "therapeutic diets." Therapeutic diets are defined as diets that are provided to meet the specialized nutritional needs of the patient based on his/her medical condition. The assumption is that the diet will improve the patient's overall health and condition. There are likely hundreds of specialty diets that are available for a patient. Most of them are chosen based on two parameters: texture and nutritional modifications.

Alterations in texture are chosen in order to minimize the risks of complications. One obvious choice would be a pureed or thickened liquid diet. This diet might be chosen for a patient with a cerebrovascular accident that has resulted in some amount of dysphagia (difficulty in swallowing). Physicians prescribe these diets to minimize the risk for aspiration.

Nutritional modifications of the diet include such choices as increasing or decreasing calories or the addition of mineral or vitamin supplements. One example is to choose a cardiac prudent diet for a patient who suffers from coronary artery disease.

Initial orders for a patient's diet are usually contained within the FL-2 form* that the long-term care facility receives from the hospital. The hospital discharge summary may also serve as source of a dietary order that is either confirmed or changed by the patient's attending physician. Once a long-term care facility receives an order for a diet, there are several regulatory concerns. Long-term care facilities will create a written care plan that focuses on the specific needs of the patient. One of these needs will be the dietary restrictions that are set forth by the attending physician. "All diets… shall be ordered by the physician or other legally authorized person and served as ordered." The facility is also responsible to "ensure that each patient is provided with a palatable diet that meets his or her daily nutritional and specialized nutritional needs."[3]

Unfortunately, these types of "prudent" choices by a clinician may not always reach the intended goal of benefiting the patient in a long-term care facility. The use of therapeutic diets in long-term care is often unpalatable and, therefore, associated with weight loss. In fact, the American Dietetic Association recommends that, whenever possible, facilities offer a more liberalized diet to long-term care residents instead of strictly holding to therapeutic diets.[4] Most clinicians would easily come to the same conclusion, but they are often bound by their training and experience.

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* Most facilities require a physician-completed FL-2 form upon admission. The FL-2 form includes the patient's level of care and medical diagnoses and conditions.

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The training of physicians in the dietary needs and options of patients is usually limited. Most of the training occurs in a controlled hospital setting during residency. Physicians are then expected to apply this training to other settings, such as the nursing home. Applying his/her training in a new setting often presents the physician with a challenge in understanding what is best for the patient, based on the medical diagnosis versus the patient's preference. Compliance with a therapeutic diet is often very difficult for those patients with the best of intentions. It is even more challenging for those patients who have spent decades establishing their eating patterns, likes, and dislikes.

Unplanned Weight Loss

Weight loss within long-term care facilities has important clinical and regulatory significance. The prevalence of protein energy malnutrition for residents in nursing home facilities ranges from 17% to 65%.[5] Malnutrition among elderly populations is associated with poor outcomes and is an indicator of risk for increased mortality.[6] Research has shown that most long-term care residents who have evidence of malnutrition are on restricted diets, which might discourage nutrient intake.[7]

Weight loss is a complex issue within nursing homes, but there are several problems that can be identified as contributors. One such problem is that many residents are already nutritionally compromised by the time they are admitted to the nursing home. Acute and chronic medical conditions have often laid waste to their caloric intake. Additionally, medications, smoking, and a decline in taste and smell can all decrease food intake.

It is well established that people consume smaller amounts of food as they age. There are a number of reasons for reduced food intake among elderly people, which range from decreased physical activity to disease conditions to earlier or more powerful signals of satiety. This is called anorexia of aging.

The body of literature that focuses on the systemic effects of illness and food intake has been growing. Many of these studies have focused on cytokines. Cytokines are small proteins that are released by the body in response to most illnesses, such as cancer, heart failure, and infections. These proteins then regulate activities, such as inflammation, blood production, and fighting infection. These studies have shown that cytokines, such as interleukin 1 and 6, tumor necrosis factor, and ciliary neurotrophic factor, tend to cause muscle wasting and can reduce albumin, pre-albumin, and cholesterol.[8] The effects of this anorexia are far reaching, producing systemic effects, such as anemia, immune dysfunction, increased infections, decreased cognition, decreased function, and orthostatic hypotension, to name a few.

When considering the management options for patients in long-term care facilities, it is important to understand that these patients are already at a disadvantage for the previously stated reasons. As a result, facilities should provide residents with adequate calories, eating and fluid intake assistance, along with focusing on treating their underlying medical illnesses.

One situation worth noting concerns the use of supplements to improve the nutritional status of patients. Many would argue that the supplements should be given during meals in order to avoid early satiety rather than giving them prior to a meal. One study sought to answer this question and showed that when nutritional supplements were given an hour before a meal, an older person consumed more calories than when the supplement was given during a meal.[9] It has been shown that glucose infused into the duodenum produces less satiety in older persons.[10] As a result, nutritional supplements that contain carbohydrates are less satiating than supplements that are high in protein.

Some additional suggestions to enhance the dining experience in older adults in nursing homes would include cooking for simplicity by focusing on flavor and appearance of food. Ideally, only a few simple diets would be offered. However such a restrictive focus would require the involvement of the administrative staff, nursing staff, and the medical director.

My experience has shown that most families do not expect a specialized diet to be provided in a nursing home. Many families realize their loved one is already experiencing nutritional decline. For this reason, family members often are happy if the patient can take in any food. However, families of assisted living facility residents have expressed greater concerns when they feel that an adequate therapeutic diet is not available. These concerns are likely based upon the family's perception that the patient's medical illness is not as advanced and, therefore, requires continued diet modification.

Most clinicians have treated patients whose medical conditions have required changing to a less-textured diet, which then resulted in the resident eating less due to the unpleasant sight or consistency of the meal. In order to maintain appropriate and adequate levels of oral intake, clinicians may decide to return the resident to a more "risky," liberally textured diet. This decision necessitates family involvement. Family and staff education are vital for a facility to successfully implement such changes.

Summary

Unfortunately, weight loss is frequently an expected part of a patient's normal nursing home residential trajectory. However, the clinical team should determine if the weight loss is reversible. The patient's clinical condition is often such that weight loss cannot be reversed or improved. Currently, life expectancy for a patient who has been admitted to a nursing home is approximately 2.2 years. These patients have been suffering from multiple medical conditions that have ravaged their body and mind and left them in a frail condition.

Food has many personal meanings to each resident that can improve the quality of a person's few remaining years. While many specialty diets are available to patients in a hospital, many of these diets may not be appropriate for patients who reside in a nursing home. Careful attention should be given to the prescription and preparation of meals in long-term care facilities. A focus on liberalizing diets in long-term care facilities can lead to improved quality of life for many patients. **NCMedJ**

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COMMENTARY

Nutrition in Advanced Alzheimer's Disease

Heidi K. White, MD, MHS

Nursing facilities that care for patients with advanced dementia strive to provide high-quality nutritional care. The standards set forth in federal regulations state, "Based on a resident's comprehensive assessment, the facility must ensure that a resident maintains acceptable parameters of nutritional status, such as body weight and protein levels, unless the resident's clinical condition demonstrates that this is not possible."[1] Alzheimer's disease (AD) frequently involves weight loss,[2-7] which is a strong predictor of mortality.[8] Weight loss and subsequent malnutrition may be an unavoidable part of the natural history of end-stage AD and other dementias. Whether nutritional intervention can delay functional decline and morbidity is largely untested. However, observational data from subjects with AD indicates that weight gain is associated with a reduced risk of mortality.[8] Similar data in institutionalized subjects including those with dementia show that weight gain of even small amounts can improve morbidity and mortality.[9] An understanding of the nutritional consequences of Alzheimer's disease, along with appropriate assessment and a thoughtful approach to intervention, may help to avoid the complications associated with malnutrition, thus preserving a better quality of life until death.

> *"...nutritional intervention that seeks to enhance the hedonic reward during mealtime may significantly benefit AD patients who are at risk for nutritional decline."*

Factors Promoting Weight Loss

Taste and Smell Dysfunction

Taste and smell dysfunction occurs with normal aging and can be exacerbated by medications and disease.[10,11] Although some changes in taste perception have been reported,[12] multiple studies in subjects with mild to moderate Alzheimer's disease have demonstrated deficits in odor identification.[13,14] In addition, odor threshold may become progressively more abnormal as the disease progresses.[15] Olfactory dysfunction may not be specific to Alzheimer's disease; similar olfactory deficits have been noted in Parkinson's disease and vascular dementia.[16]

Inflammatory Mediators

Cytokines,* such as interleukin 6, are an integral part of anorexia-cachexia syndromes in other disease states, such as cancer and heart failure.[17,18] Cytokines, including interleukin 1 and 6, and tumor necrosis factor alpha, play an important role in the inflammatory process that accompanies the hallmark changes of amyloid plaques and neurofibrillary tangles that occur with AD.[19-22] In essence, these inflammatory mediators may produce important changes in the areas of the brain that control appetite.

Abnormal Eating Behavior

Abnormal eating behaviors contribute to weight loss. Typical behaviors include needing frequent verbal cues to complete the eating process, verbally refusing food, pocketing food in the cheeks without swallowing, clenching teeth, and spitting food.[23,24]Abnormal eating behavior may be more subtle, such as a fluctuations in appetite, delusions about food (e.g., believing food is poisoned), increased distractibility at mealtime, and

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* Cytokines are regulatory proteins released by cells of the immune system. These proteins act as intercellular mediators in the production of an immune response.

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changes in food preferences.[25] Destruction of the hippocampus and surrounding cortical areas may explain certain behaviors. In late-stage AD, plaques and tangles have been described in the hypothalamus, the neurologic center of appetite regulation.[26,27]

Dysphagia is a common manifestation of late-stage AD.[28,29] Even in early stage AD, an increased duration of the oral and pharyngeal components of swallowing have been observed.[30]

Balancing Energy Intake and Expenditure

Although inadequate oral intake is likely the primary cause of weight loss in moderate-to-severe AD, increased energy expenditure could contribute to a mismatch between energy intake and energy expenditure that leads to weight loss. While it has been suggested that resting metabolic rate may be elevated in AD, several studies now confirm that there is no evidence to support this.[31,32] The idea that physical activity in the form of behavioral disturbances (e.g., pacing) may contribute to increased energy expenditure has not been supported either.[33] To date, there are no data on AD patients during the dynamic phase of weight loss. It is evident from our work, and that of others, that not all AD patients are losing weight all of the time.[8,34] There can be periods of acute weight loss, a slow gradual weight loss, and variations in weight, which may include periods of substantial weight gain.

It is possible that relatively subtle and, perhaps intermittent, changes in factors, such as a behavioral disturbance that influences both energy intake and energy expenditure, may tip the balance toward weight loss for patients with AD. This imbalance may be multifactorial and intermittent. Rather than one particular cause or abnormality leading to weight loss, AD may lead to a condition in which changes in energy intake and expenditure are not easily compensated. Preliminary data from institutionalized subjects with AD show that Body Mass Index (BMI)** is inversely correlated with a measure of behavioral symptoms, which indicates that lower BMI was associated with higher frequency and severity of behavioral problems.[35]

In summary, both primary and secondary factors may contribute to weight loss in advanced AD.[36] Primary factors, such as those discussed thus far, are attributable to the pathophysiology of Alzheimer's disease and may or may not be amenable to intervention. Secondary factors are not attributable to the pathophysiology of AD, but are commonly encountered conditions that may contribute to weight loss and are perhaps more amenable to intervention (see Figure 1).

Evaluating Weight Loss and Malnutrition

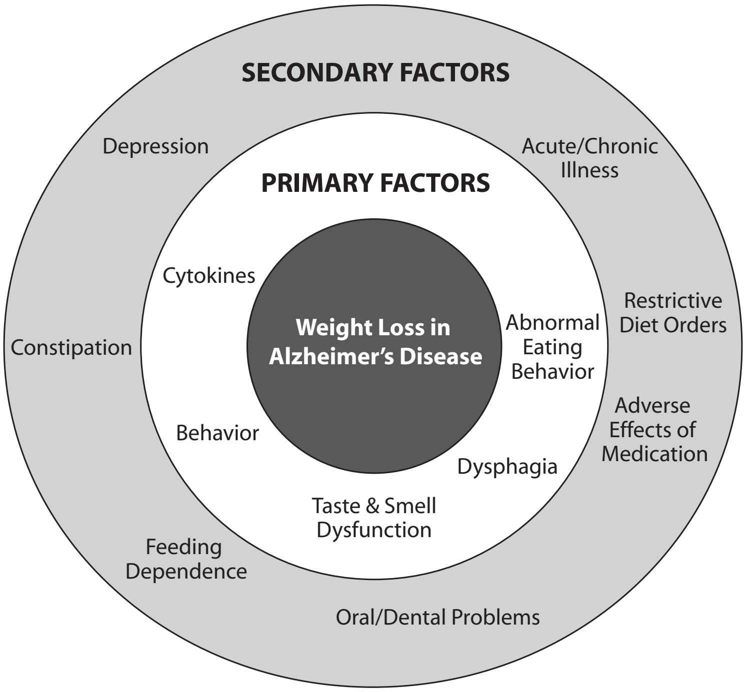
When to Evaluate

Periodic weight measurements are a primary resource for monitoring nutritional status and recognizing change. Most residents of nursing facilities are weighed monthly unless their condition would warrant weekly monitoring. According to parameters set for the Minimum Data Set, weight loss of 5% in one month or 10% in three months is considered of clinical importance and should entail further evaluation. Older adults with a BMI less than or equal to 21 are likely to be malnourished.[37] Conditions such as pressure ulcers that increase nutritional requirements should also prompt evaluation.

Other Illness

Common infections, such as pneumonia or urinary tract infections, will often produce anorexia. Cancer, thyroid dysfunction and other common causes of weight loss are part of the differential diagnosis. Constipation is a common condition in institutionalized individuals because of decreased fluid intake, decreased physical activity, and medication that promotes this condition. Chronic constipation can have a profound impact on appetite, yet be difficult to identify in patients with cognitive impairment. Chronic pain may also be difficult to identify, but

Figure 1.
Weight Loss in Alzheimer's Disease



Primary factors of weight loss are related to the pathophysiology of AD. Secondary factors are common occurrences that may be more amenable to interventions that promote nutritional well-being.

** BMI, weight in kilograms divided by height in meters squared, is a helpful measurement of nutritional status.

can cause anorexia. Depression is another common treatable cause of weight loss in older adults. Each patient should be specifically evaluated for depression and aggressively treated when it is suspected to be present. Depression is also common occurrence in early dementia, but may also be present in more advanced disease.

Medications

Medications should be reviewed. Commonly used drugs can cause many symptoms that potentially limit caloric intake (see Table 1). Acetylcholinesterase inhibitors, which are the primary treatment for the cognitive symptoms of AD, have several potential adverse effects including nausea, vomiting, and anorexia that may contribute to weight loss.[38,39] Additionally, galatamine, an acetylcholinesterase inhibitor, has been associated with an increased incidence of weight loss.[40] Patients with dementia may not be able to voice symptoms attributable to these drugs.

Table 1.
Medications and Induced Symptoms

Medication Type	→	Medication Induced Symptom
NSAIDs, alcohol, nicotine, cholinesterace inhibitors		Anorexia
Toxic levels of drugs (e.g., digoxin, theophylline), antibiotics, NSAIDs		Nausea
Anticholinergics, HIV drugs, antibiotics		Taste and smell dysfunction
Sedatives, opioids		Inattention
Antipsychotics		Movement disorders
Anticholinergics		Dry mouth
Bisphosphonates		Esophagitis
Phenothiazines, haloperidol		Dysphagia[62]
SSRI, antibiotics, laxatives		Diarrhea
Antipsychotics, atypical antipsychotics		Increased appetite

Physical Examination

A thorough physical examination is an important part of the assessment of weight loss and malnutrition. The mouth is a particularly important part of the examination that should not be overlooked. Dental abnormalities such as ill fitting dentures, tooth decay, and abscess formation may contribute to weight loss. Dry mouth and antibiotic use can lead to thrush, a yeast infection that can cause discomfort and unwillingness to eat.

Table 2.
Risk Factors for Aspiration Pneumonia

Risk Factors
Dysphagia
Feeding dependence
Oral Care dependence
Number of decayed teeth
Tube feeding
Multiple medical diagnoses
Number of medications

Dysphagia

Patients with advanced dementia often develop serious difficulties swallowing. They may resist food being placed in the mouth, fail to manage the food bolus once it is in the mouth, or aspirate when swallowing. Caregivers should be encouraged to report changes in eating behavior and signs of dysphagia. Coughing and choking during eating are common signs of aspiration. So called "silent aspiration" occurs when patients with advanced dementia suffer the consequences of aspiration without any identifiable signs. A swallowing evaluation by a speech therapist that includes visualization of the swallow either in a barium study or by fiberoptic techniques can be helpful in determining the presence and severity of swallowing dysfunction. Although this evaluation can be helpful, many patients experience the sequelae of aspiration, but do not demonstrate aspiration on such testing. On the other hand, many patients who clearly aspirate on testing do not seem to suffer obvious consequences of aspiration, such as weight loss or aspiration pneumonia. Risk factors that predispose patients with advanced dementia to aspiration pneumonia are listed in Table 2.[41]

Interventions for Weight Loss in AD

For the most part, getting patients with dementia to eat is a process of trial and error. It is important to make sure that food is available not just at mealtimes, but whenever the patient is inclined to eat. Many patients need supervision, constant reminders, and simple directions to complete a meal. Providing finger foods can be helpful for patients who are challenged by the use of utensils.[42] Appetite and alertness may be better early in the day so breakfast and lunch become more substantial meals. Providing preferred foods can also increase intake.[43] Simplifying the environment so that there are fewer distractions during mealtime may be helpful as well.

Researchers have demonstrated that improving the ambiance during mealtime in a nursing facility by manipulating social and environmental aspects improves food consumption and nutritional status.[44] Studies that have implemented soothing dinner music for dementia patients demonstrate that this intervention can improve mealtime agitation and food intake.[45,46] Taken together, these studies—although few in number and scope of intervention—suggest that a nutritional intervention that seeks to enhance the hedonic reward during mealtime may significantly benefit AD patients who are at risk for nutritional decline.

Feeding a patient, who can no longer feed himself/herself, can be very time consuming, and some patients may respond better to a particular caregiver. Techniques that are particularly effective in feeding a patient should be shared and mimicked by other caregivers. Research indicates that the quality of the relationship between the person being fed and the feeder is an important predictor of food intake.[47] Even severely demented patients respond best to caregivers who are personal, interested, involved, flexible, calm, cooperative, and more willing not to seek control in the relationship.

Maximize Taste and Smell

Dietary restrictions, such as low sodium and low cholesterol, that limit aroma, flavor, and calories should be avoided. Flavor enhancement has been shown to increase food intake and maintain weight in nursing home residents.[48] Facilities and caregivers should take advantage of aromatous foods, which stimulate the physiologic responses that prepare an individual for food intake and stimulate appetite. In addition to mealtimes, activities such as baking bread or popping popcorn can stimulate appetite and provide needed calories.

Nutrition Supplements

Oral liquid supplements should be given between meals to boost calorie consumption.[49] Liquid supplements should not replace food intake, as it could result in decreased calorie consumption.[50]

A routine vitamin/mineral supplement should be considered for all patients with moderate to advanced AD, because inadequacies in micronutrient intake are common among eating-dependent nursing home residents.[51] Like all older adults, most patients with AD will require calcium and vitamin D supplementation. Several studies indicate that even subtle deficits in nutritional status can impact cognitive performance in non-demented older adults.[52-54] Even if nutritional supplementation does not improve cognitive symptoms, nutritional interventions may help to maintain the muscle and bone mass necessary for continued independent physical function and, in more disabled patients, prevent challenging complications, such as pressure ulcers.

Appetite Stimulants

Orexigenic agents (appetite stimulants) are often considered in the treatment of end-stage dementia with nutritional decline. None have been studied for their effectiveness in patients with advanced Alzheimer's disease. Megestrol acetate (a hormone therapy often used to treat certain cancers and other diseases with anorexia cachexia) may be a reasonable choice due to limited data with nursing home patients, but may take several months to have an effect on appetite and weight status.[55,56] Studies of megestrol acetate in patients with cancer and AIDS have only found an increase in fat mass, but no significant increase in lean body mass. No survival advantage has been demonstrated. Side effects include adrenal suppression, fluid retention, deep vein thrombosis, confusion, and impotence. Other agents that have been used to stimulate appetite, but for which there are little or no data regarding their use in advanced dementia include cyproheptadine, dronabinol, testosterone, growth hormone, oxandrolone, and steroids.

When considering the use of an orexigenic agent the origin and causes of the weight loss and the goals of care need to be carefully defined. If dysphagia is the primary issue hindering caloric intake then appetite stimulation may only serve to make the patients condition more uncomfortable. However, if agitation and distractibility are hindering intake, a greater sense of appetite may help the patient to focus attention on eating. The goals of care are also important to consider when making this decision since the benefits of appetite stimulants may be even fewer in advanced dementia than in other disease processes.

Antidepressants

In the situation of otherwise unexplained weight loss, even when symptoms of depression have not been clearly identified, a trial of an anitdepressant may be reasonable. Although tricyclic antidepressants frequently result in weight gain for younger patients who consider this an unpleasant side effect, they may not produce this same effect in frail institutionalized patients. Side effects that include constipation, dry mouth, orthostatic hypotension, and urinary retention make these agents less desirable with the advent of selective seratonin reuptake inhibitors (SSRIs, e.g., sertraline, citalopram). Initial concern that SSRIs may produce weight loss in older adults has not been substantiated.[57] Mirtazapine, a multi-receptor agonist, has been associated with increased appetite and weight gain in younger patients in comparison to SSRIs. However, effectiveness of this agent in producing significant weight gain in frail older adults or patients with dementia is unknown.

Minimizing Aspiration Risk

Altering food and liquid consistency can minimize the risk of aspiration. Semi-solid consistencies are generally tolerated better than liquids. Potentially helpful techniques to minimize the risk of aspiration are upright positioning of the patient during meals and for 30 minutes after meals, tucking the chin during swallowing, swallowing multiple times with each bolus, and keeping the bolus less than one teaspoon. A speech therapist should participate in developing the treatment plan and provide staff education for implementation.

Good oral hygiene reduces the bacterial load in the mouth that can be aspirated and may decrease the risk of pneumonia. A growing number of studies indicate that angiotensive converting enzyme inhibitors may elevate substance P levels and, in so doing, stimulate cough and improve oral sensation, thus decreasing the risk of aspiration and pneumonia.[58]

Feeding Tubes

Even with diligent care, weight loss may continue, and malnutrition may ensue. Both physicians and patients' surrogate decision-makers tend to have high expectations for feeding tube placement to improve nutrition, functional status, and quality of life.[59] These high expectations for improved nutritional and health status are not supported by current research. There have been no randomized clinical trials comparing tube feeding with oral feeding in the severely demented. A review of existing literature by Finucane and colleagues found no evidence to support that tube feeding prevents aspiration pneumonia.[60] In fact, tube feeding does nothing to prevent the aspiration of oral secretions nor can it prevent aspiration from regurgitated gastric contents. Furthermore, Finucane found no evidence to support that tube feeding prevents other infections, the consequences of malnutrition, or pressure ulcers. There was no evidence to support a survival benefit, improved functional status, or greater patient comfort. Adverse events associated with feeding tubes includes aspiration pneumonia, tube occlusion, leakage, and local infection. Although the mortality during percutaneous endoscopic gastrostomy tube placement is low (0-2%), perioperative mortality ranges from 6-24%.

In circumstances where careful hand feeding has not provided adequate nutrition and has resulted in pneumonia or other complications of malnutrition, the possibility of providing food and liquid as tolerated, but allowing a natural death to occur should be considered. For the patient with severe dementia, the decision of whether or not to institute a feeding tube ultimately lies with the patient's family or guardian. However, families and physicians are often aided by advance directives that allow patients with dementia to convey their wishes regarding this issue either before or during the early stages of disease. It is important for healthcare providers to initiate conversation with the patient regarding care at the end of life when cognitive abilities will still allow a meaningful discussion. In most cases, given the current evidence, the decision for careful hand feeding without the use of a feeding tube is very appropriate. Federal regulations should not be seen as a barrier to this course of action as long as the eating problems are properly identified and assessed and reasonable efforts to hand feed are being made.[61] Careful documentation by the physician and other care providers should indicate that nutritional decline is not preventable because of the patient's advanced dementia diagnosis.

Summary Recommendations

A physician should evaluate the patient with advanced AD who is losing weight, has a low BMI, or unmet nutritional needs (e.g., pressure ulcers). A thorough medical history and physical examination should be done. The physician, nutritionist, speech therapist, nurse, direct care worker, and family should contribute to the process of evaluation and the implementation of the nutrition care plan. All of these individuals must work together to ensure that weight loss and malnutrition are recognized, evaluated, and treated. The effectiveness of each intervention must be evaluated. Maintaining nutritional health will not always be possible. All involved should understand the goals of care, which may range from expected improvement in nutritional status to supportive and palliative care in the face of an advanced and terminal condition. The goals of care are likely to evolve as assessments are made and as interventions are evaluated. The nursing home medical director and primary care physicians of individual patients must provide leadership in this process, especially when alternatives to oral feeding are considered. **NCMedJ**

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COMMENTARY

Use of Feeding Tubes in the Care of Long-Term Care Residents

Timothy S. Carey, MD, MPH

One of the most difficult decisions faced by a family caring for a disabled elder is whether or not to place a gastric feeding tube. Recent high-profile media coverage of the Terry Schiavo case has brought this issue into the public arena. Prior to the early 1990s, placement of a feeding tube for direct delivery of nutrition into the stomach, or "enteral feeding," was a surgical procedure requiring general anesthesia and the operating room. During the 1990s, the procedure became simplified, using percutaneous techniques either performed in the endoscopy suite or by interventional radiology. These procedures could be performed using conscious sedation and local anesthesia. Feeding could be initiated within 24 hours. The ease of the procedure was greater, and the immediate complication rate was reduced. Patients who were too ill for the procedure now received enteral feeding. Previously, enteral feeding was often performed through long-term naso-gastric tubes. These tubes frequently clogged or fell out, and were associated with significant patient discomfort. Coincident with the greater ease of gastrostomy tube insertion, the number of tube insertions rose dramatically, almost doubling during the 1990s even after adjustment for the increasing age of the population. Use of feeding tubes was even greater in the southeast, and this rise has continued as increasing numbers of tubes are being placed on an outpatient basis.[1]

Indications for Feeding Tube Placement

Feeding tubes may be placed for a variety of reasons. Some are for acutely ill patients who are in an intensive care unit and are unable to take food by mouth, but who may otherwise have a reasonably good prognosis. This may be the case after trauma or a severe medical illness such as pancreatitis. Gastric feeding tubes are commonly used in head and neck malignancy patients as a 'bridge' around the time of surgery and radiation therapy. More controversial indications include placement of feeding tubes after a cerebrovascular accident (stroke). If the patient otherwise has a fairly good prognosis in terms of level of consciousness and residual functional status, many tubes inserted after strokes can be removed in the year following the event.[2] The most problematic situation in which feeding tubes are used is for elderly adults with neurodegenerative diseases, including cognitive impairment due to Alzheimer's disease and multi-infarct dementia. Unfortunately, these diseases are progressive, and the feeding tube is not part of a rehabilitation plan. There is extreme variability in the use of feeding tubes for this indication around the country. For unclear reasons, the use of feeding tubes is particularly common in the southeastern United States. According to data from the Medicare nursing home Minimum Data Set (MDS), North Carolina ranks sixth in the proportion of severely cognitively impaired elders in long-term care who receive gastric feeding tubes. In North Carolina, 40% of patients with cognitive impairment have feeding tubes, in Alabama the percentage is 47%, but in Maine, only 9%.[3]

> *"Given the substantial uncertainties regarding the benefits of gastric tube feeding, discussions with families should include assisted feeding as an option, as long as all concerned recognize that ongoing weight loss may continue to occur."*

Timothy S. Carey, MD, MPH, is Kenan Professor of Medicine and Director of the Cecil G Sheps Center for Health Services Research at the University of North Carolina at Chapel Hill. He can be reached at tim_carey@unc.edu or at CB 7590, Chapel Hill, NC 27599-7590. Telephone: 919-966-7100.

Risks and Benefits

When wide variation occurs in the utilization of a diagnostic or therapeutic treatment, it's generally due to uncertainty regarding therapeutic benefit, variations in the supply of providers and technology, and varying preferences for treatment.[4] In the case of feeding tubes, providers are often uncertain regarding benefit, and families have variable preferences regarding the pros and cons of this treatment. Yet, over the past decade, moderate amounts of data have been collected and published regarding the utility of gastric feeding tubes in frail elderly with cognitive impairment. Rationales for insertion of these tubes include the prevention of aspiration pneumonia, prolongation of life, or improvement in quality of life. Unfortunately, the benefits of feeding tubes to prevent such complications appear to be quite limited. Alzheimer's disease and related dementing illnesses are conditions that affect the entire brain and the entire body, not just swallowing functions. Patients with gastric feeding tubes continue to have episodes of aspiration pneumonia after insertion.[5] The pneumonia is likely due to aspiration of saliva into the lungs when the patient is asleep, as well as possible aspiration of the very thin liquid that is placed in the stomach through the feeding tube. In addition, healing of decubitus ulcers (bedsores) and improvement in nutritional parameters, such as blood albumin levels, appears to occur for only a minority of patients who receive feeding tubes.[6] Overall, these frail patients have a mortality rate between 30 and 50% over six months, with some studies reporting even worse survival.[7] Some authors recommend that gastric feeding tubes be considered extraordinary treatment since the benefits are limited at best in demented patients.[8] Certainly, families should have a detailed and shared decision-making discussion regarding the very limited benefits of this technology, as well as its significant risks.

The risks of feeding tubes include some risks associated with tube insertion. While the risk of perforation of a structure such as the colon is rare, such complications are potentially catastrophic. Feeding tube removal in the days following insertion can also be extremely risky as peritonitis can result. When a feeding tube falls out or is pulled out (as by a confused patient) in the days following insertion, the patient needs to be emergently transported to the hospital for assessment for peritonitis and re-establishment of the feeding tube using a technique similar to the original endoscopy or a radiologic procedure. Patients may sometimes require arm restraints so that they do not manipulate the gastric feeding tube. These restraints lead to decreased quality of life. Finally, many of the other commentaries in this issue address the social significance of food in our society. When a feeding tube is inserted and oral feeding is ceased, the sensory experience of eating is denied. The social interaction that is so much a part of meals is also absent. While some facilities use tube feeding as a supplement to oral feeding rather than as a replacement, many place patients on a "nothing-by-mouth" status.

Shared Decision-Making and Alternatives to Tube Feeding

Assisted feeding to an amount as much as the elder is able to take is certainly an acceptable alternative to placement of a gastric feeding tube for patients who have some remaining ability to swallow. Given the substantial uncertainties regarding the benefits of gastric tube feeding, discussions with families should include assisted feeding as an option, as long as all concerned recognize that ongoing weight loss may continue to occur.

What are the drivers that have led to the common use of a procedure with such limited evidence of benefit? Assisted feeding takes significant amounts of staff time, much of it one-on-one with the patient. Personnel must be trained, attention to set-up of utensils and foods must be performed, and diets may need to be individualized. Although advantageous to the patient, these interventions are costly to facilities. In contrast, once a feeding tube is inserted, the time involved for a staff member to hang a bag of high calorie liquid takes only a few minutes. Reimbursement to the facility may be increased due to the apparent technical nature of the activity. Labor costs are therefore decreased, reimbursement increased, and the care providers may have the somewhat false illusion that "everything is being done." These cost and reimbursement issues may represent a perverse incentive, leading to increased feeding tube use.[9] Medicare's use of 10% weight loss as a nursing facility quality indicator is laudable, but is not intended to mandate use of tube feedings for patients with end-stage dementia. A palliative approach for such patients, appropriately documented, is certainly acceptable.

Policy interventions to assist families and providers in this extraordinarily difficult clinical situation should include financial incentives to facilities for provision of assisted feeding programs; development of shared-decision making modules for use by patients and providers as they grapple with these difficult decisions; and frank discussions of the limits of technology in its ability to preserve life or improve functional status for this important and frail population. **NCMedJ**

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Members of the North Carolina Institute of Medicine are appointed for five-year terms by the Governor, and each task force convened by the Institute typically includes at least one-third of its membership from among the appointed members. Topics to be addressed through task force efforts are chosen following requests from the Governor, the General Assembly or agencies of state government. In some cases, topics are selected on the basis of requests from a number of stakeholder organizations across the state where this type of analytical process is considered to have potential value.

The North Carolina Institute of Medicine assumed the role of publisher of the *North Carolina Medical Journal* in January 2002 through an agreement with the North Carolina Medical Society, which founded the Journal in 1845. The Institute views the *North Carolina Medical Journal* as an extension of its mission. The Journal provides a forum for stakeholders, healthcare professionals, and policy makers and shapers to study and discuss the most salient health policy issues facing our state. Like many states, North Carolina is grappling with issues such as an increasing number of uninsured, the unmet health needs of the growing Latino population, a critical shortage of nursing personnel, the health risks of tobacco and obesity, rising prescription drugs costs, mental health system reform, the increasing societal burden of chronic illness care, the threat of bioterrorism and the necessity of assuring adequate public health preparedness—all in the midst of an economic downturn. Each of these issues presents unique challenges to healthcare providers and state policy makers. Yet, a fully implemented task force to consider each of these sets of issues is not feasible. The Journal makes it possible to present an organized and balanced overview of some of these issues, six times per year, and allows interested persons the opportunity to engage in the ongoing discussion of these issues throughout the year. The Institute hopes that our readers of the *Journal* will, in this way, become involved in the continuing debate about the most promising avenues for assuring the highest standards of health and healthcare for all North Carolinians.

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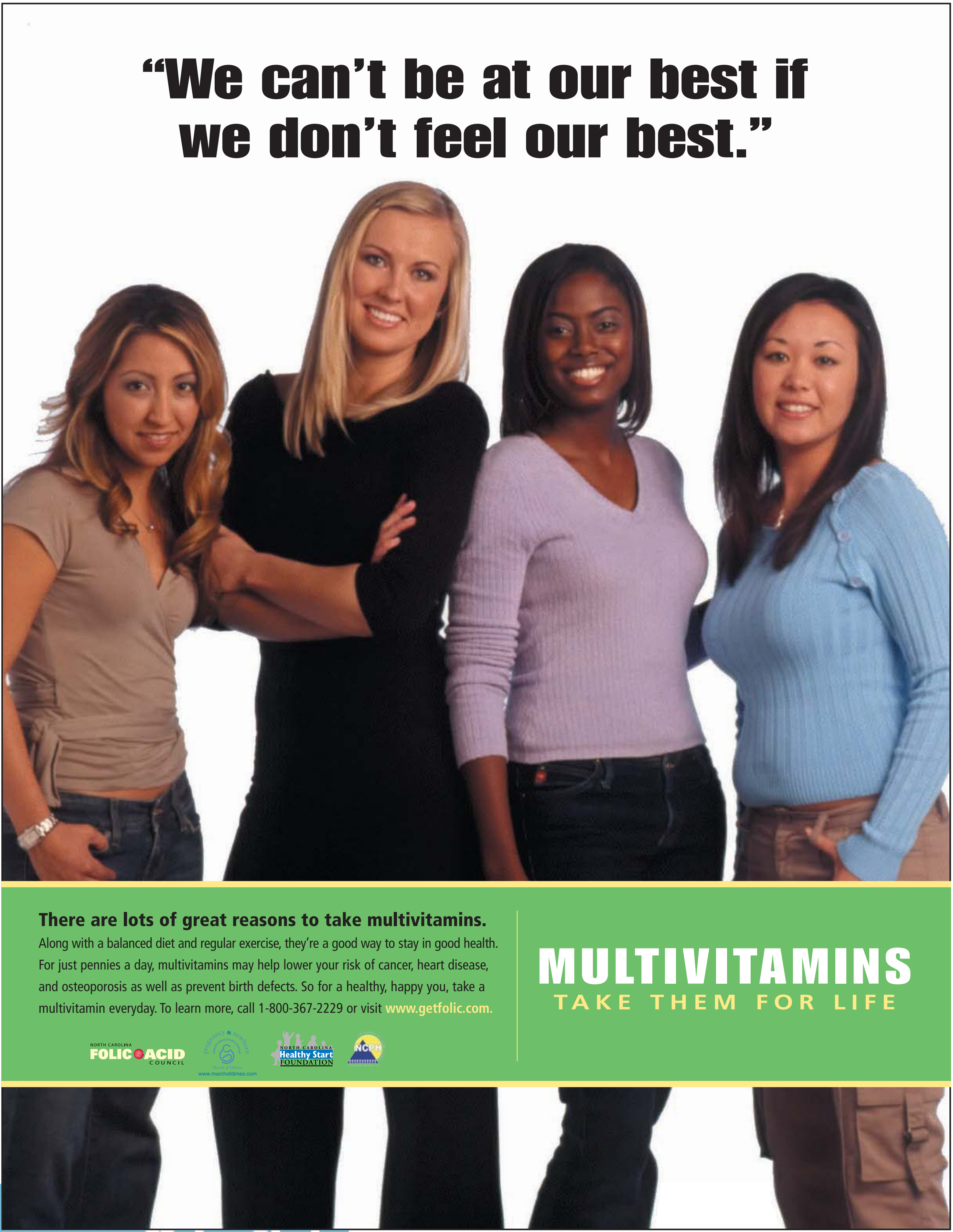
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Patient Flow between Hospitals and Nursing Homes in North Carolina in 2003

The North Carolina Hospital Discharge Data Base consists of more than one million records each year for inpatients discharged from North Carolina hospitals. These records contain information on the source of admission and the discharge status for each patient. This information allows us to describe the volume and characteristics of hospital patients who are transferred directly from and to nursing homes.

During calendar year 2003, there were 1,037,913 inpatient discharges from North Carolina hospitals. Forty-two percent of these hospital patients had their admission source listed as "referral" and 38% had "emergency room" listed. Only 1,411 or 0.1% were identified as being transferred to the hospital directly from a nursing home (skilled nursing facility). Of these 1,411 patients, diseases of the respiratory and circulatory system were the most common principal diagnoses (25% and 18%, respectively), 80% were age 65 and older, 64% were females, and Medicare was the most common expected source of payment (89%).

Seventy-seven percent of all hospital patients in 2003 were discharged to home/self care (routine discharge). Seven percent were discharged to their home under the care of an organized home health services agency. About 7% were transferred to nursing homes: 6.4% or 66,307 to a skilled nursing facility and 0.5% or 4,753 to an intermediate care facility. Another 855 were transferred to "long-term care" and 299 were transferred to a "Medicaid-approved nursing facility."

The following table compares 2003 hospital patients with a routine discharge to those transferred to skilled and intermediate care nursing facilities, by selected patient characteristics.

Percent	**Routine Discharge**	**Discharged to Skilled Nursing Facility**	**Discharged to Intermediate Care Facility**
Age			
Under age 65	75.5	13.9	23.3
65-74	12.0	18.8	14.8
75-84	9.5	37.8	31.8
85+	3.0	29.5	30.1
Gender			
Female	60.4	66.3	65.0
Payer			
Medicare	30.3	89.9	83.3
Other	69.7	10.1	16.7
Principal Diagnosis			
Circulatory system	16.1	15.7	16.2
Respiratory system	9.3	16.9	18.6
Digestive system	8.8	8.0	8.3
Nervous system	4.5	10.8	9.4
Musculoskeletal system	5.1	19.8	6.8
Mental disorder	4.4	1.8	13.3
Pregnancy/delivery/newborn	28.8	0.0	0.6
Other	23.0	27.0	26.8

Contributed by Paul A. Buescher, PhD, and Pedro Luna-Orea, PhD
State Center for Health Statistics, North Carolina Division of Public Health

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The North Carolina Institute of Medicine (NC IOM) with The Cecil G. Sheps Center for Health Services Research at the University of North Carolina at Chapel Hill announces that the position of Vice President of the NC Institute of Medicine is available, on a part-time basis at 50% effort. The Vice President will assist the President of the NC IOM in the administration and oversight of the Institute. The position requires an ability to work with state policy makers, healthcare professionals and trade associations, business and community leaders, and advocacy organizations to involve them in the policy development process, as well as their support in the implementation of key recommendations on health and healthcare issues. Persons seeking this position should have an understanding of health and healthcare issues, extensive experience facilitating diverse groups, public speaking and writing ability, knowledge of the policy analysis process, and fundraising skills. It is desirable that the applicant has quantitative analytical skills necessary to conduct and present results from health policy analyses.

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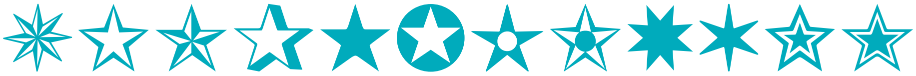
""

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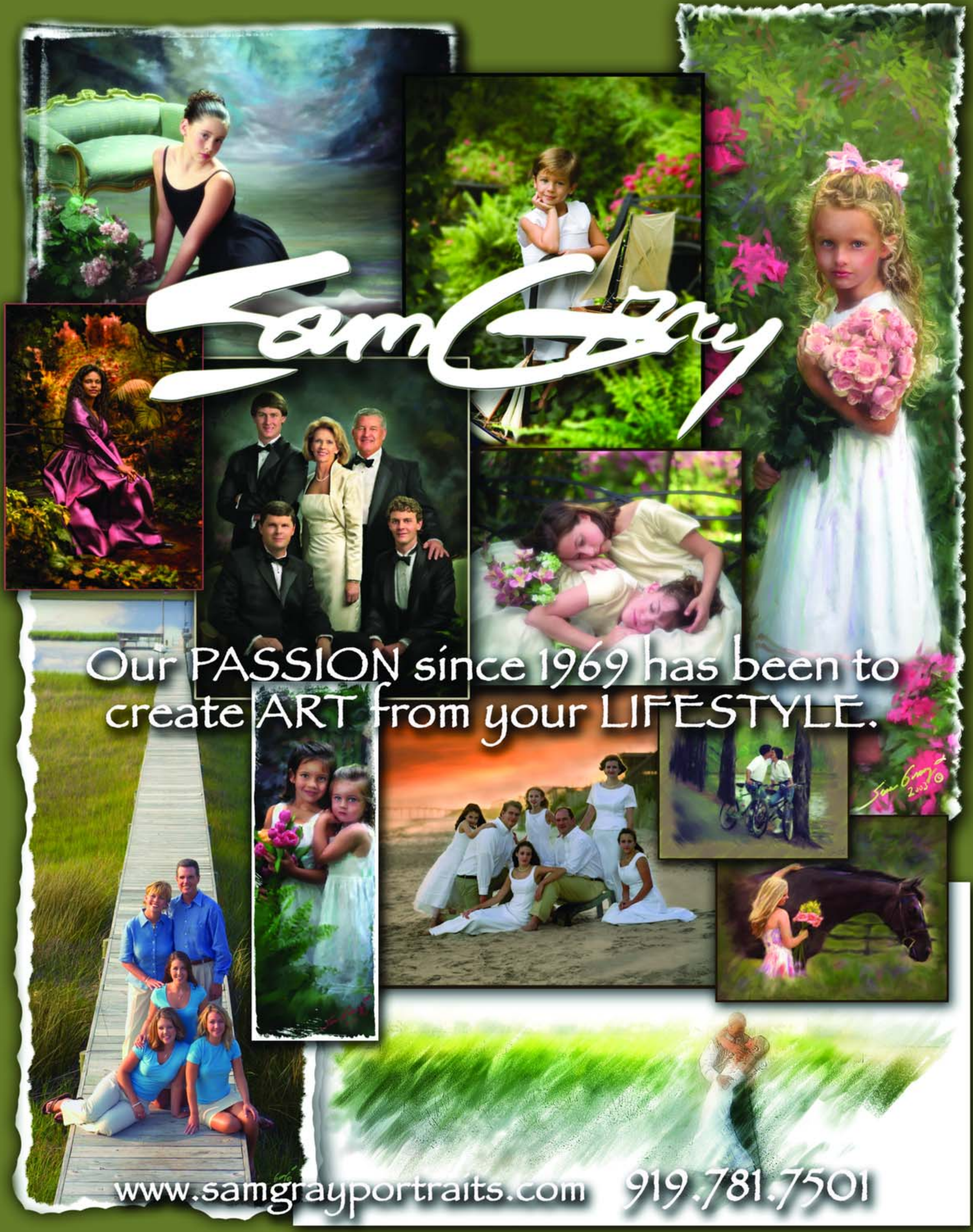
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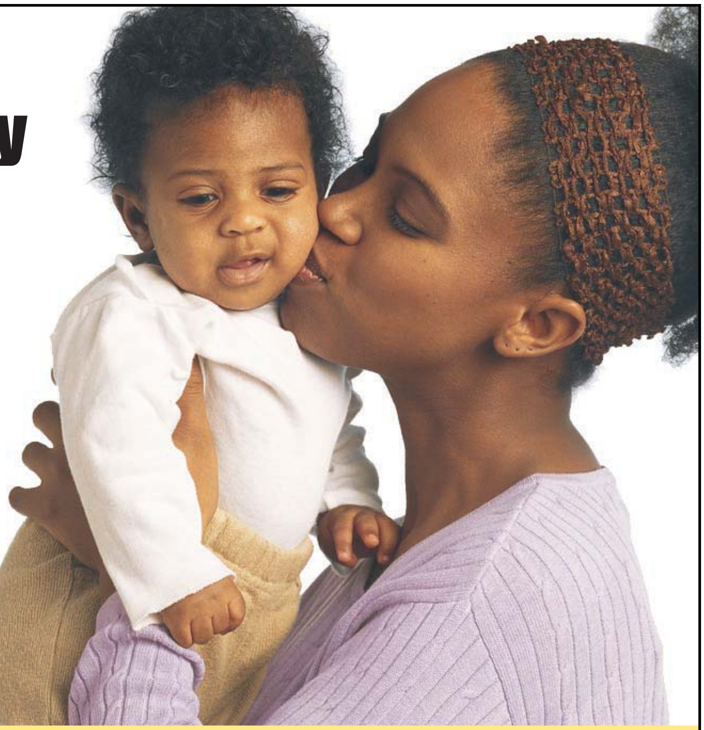

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ARTICLE

Attainment of Goals from National Guidelines among Persons with Type 2 Diabetes:

A Cohort Study in an Academic Family Medicine Setting

Julienne K. Kirk, PharmD, Kenneth R. Huber, MS, and C. Randall Clinch, DO, MS

Abstract

Background: *Cardiovascular disease is the leading cause of mortality in patients with diabetes, but goals for reduction of modifiable cardiovascular risk factors are difficult to achieve in primary care. We evaluated the change in risk factor control for a cohort of patients with diabetes and hyperlipidemia over a four-year period, as well as the change in proportion of patients meeting clinical practice guideline goals.*

Methods: *Medical records were reviewed from a cohort of 86 randomly selected persons with type 2 diabetes in an academic family medicine setting. Data were abstracted to assess the attainment of and change in five treatment goals related to glycemic, blood pressure, and lipid control from 1999-2003. Descriptive statistics were applied to demographic variables. Mean differences in outcomes were assessed with the paired t-test. The McNemar test was used to assess non-parametric variables, and the Wilcoxon signed ranks test was applied to differences achieved in mean goal scores for outcome variables.*

Results: *The mean numbers of treatment goals attained were 2.76 (SD = 0.92) in 1999 and 2.48 (SD = 1.1) in 2003. Significant improvements were noted in the mean values of HbA1c (0.4% decrease, $p = 0.03$), diastolic blood pressure (4.3mmHg decrease, $p < 0.001$), low-density lipoprotein cholesterol (LDL-C; 10.6 mg/dL decrease, $p < 0.01$), and high-density lipoprotein cholesterol (HDL-C; 8.3 mg/dL increase, $p < 0.001$) over the four-year study interval. No significant differences were noted in the percent at goal during the study for HDL-C or for HbA1c. A significant decrease was found in the percent at goal from 1999-2003 for LDL-C (from 79% to 40%, respectively). The decrease in the percent LDL-C at goal was explained by the more stringent practice guideline goals introduced in 2001 for diabetes (i.e., LDL-C < 100 mg/dL).*

Conclusion: *Despite significant improvement in mean values of modifiable risk factors, the percent of patients meeting 2003 guideline goals for HbA1c, systolic blood pressure, and LDL cholesterol did not improve. These findings suggest that patient-level improvements may not be adequate indicators of a practice's achievement of guideline recommendations. Percent attainment of guideline goals may be a useful performance measure of practice-level quality improvement initiatives.*

Key words: *Type 2 diabetes, blood pressure, HbA1c, hyperlipidemia, dyslipidemia, National Cholesterol Education Program (NCEP) Adult Treatment Panel guidelines, LDL cholesterol, body mass index, American Diabetes Association (ADA) Standards of Care, Primary Care*

Introduction

Diabetes has been diagnosed in approximately 13 million people in the United States, with an additional estimated 5.2 million cases remaining undiagnosed.[1] Cardiovascular disease (CVD) is responsible for approximately 65% of diabetes-related deaths, with a two- to four-fold higher CVD death rate noted among adults with diabetes versus those without diabetes.[1] As such, the prevention of CVD is a primary goal in the management of patients with diabetes.

The American Diabetes Association (ADA) has put forth guidelines annually for several of the modifiable risk factors of CVD, including control of glycemia, blood pressure, and blood lipid concentrations.[2] The National Heart, Lung, and Blood Institute (NHLBI) has established widely used clinical guidelines for the screening and treatment of blood lipids [National

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Cholesterol Education Program (NCEP) Expert Panel on Detection, Evaluation, and Treatment of High Blood Cholesterol in Adults].[3,4] Consensus recommendations for blood pressure control have been established by the Joint National Committee (JNC) on Prevention, Detection, Evaluation, and Treatment of High Blood Pressure.[5,6]

Many individuals with diabetes receive treatment in a primary care setting, and published literature indicates goals targeting CVD risk reduction among persons with type 2 diabetes are not being optimized.[7-9] The intent of the current study builds upon a previously published cross-sectional analysis,[7] which described the frequency with which ADA (hemoglobin A1c or HbA1c), NCEP (cholesterol), and JNC (blood pressure) goals were met in a family practice setting for persons with type 2 diabetes. Kirk et al,[7] revealed that overall blood pressure, low density lipoprotein cholesterol (LDL-C), and HbA1c values did not reach the goals for the guidelines in effect in 1999.[3,5,10] Evidence further demonstrating the benefits of achieving and maintaining blood pressure, LDL-C, and glycemic control has accrued since this initial publication.[11-15] Changes in the guidelines related to the control of blood lipids and blood pressure since our first study have led to recommendations for tighter control of these parameters (see Table 1).[2,4,6] The purpose of the current study was to conduct a follow-up analysis on the cohort of persons with diabetes from our previous study, focusing on the attainment of CVD-related guideline parameters (i.e., HbA1c, LDL-C, HDL-C, and blood pressure).

Table 1.
Guidelines for Persons with Diabetes

	Year	
Parmeter	**1999**	**2003**
HbA1c[*]	< 7%	< 7%
Systolic blood pressure[†]	< 130	< 130
Diastolic blood pressure[†]	< 85	< 80
LDL-C[‡]	< 160/< 130/< 100 mg/dL[§]	< 100 mg/dL
HDL-C[‡]	>/= 35 mg/dL	>/= 40 mg/dL

[*] Based on American Diabetes Association guidelines

[†] Based on Joint National Committee for the Detection and Prevention of Hypertension Report, HDL-C = high density lipoprotein, LDL-C= low density lipoprotein

[‡] Based on the National Cholesterol Education Program (NCEP) Expert Panel on Detection, Evaluation, and Treatment of High Blood Cholesterol

[§] LDL-C goals based on risk stratification per NCEP Adult Treatment Panel (ATP) II[3]

Methods

A cross-sectional analysis evaluating CVD risk factors and pharmacotherapy in a randomly selected sample of 124 persons with type 2 diabetes and hyperlipidemia was previously performed.[7] Data were obtained from an academic family medicine clinic in the southeast. Approximately 56,000 patient visits to this clinic are conducted annually, and the mix of insurance coverage includes Medicare (22%), Medicaid (12%), managed care (61%), and self-pay (5%). There are 30 medical residents in training along with three fellows, 15 faculty physicians, three physician assistants, two registered nutritionists, and one pharmacist diabetes educator. Resident physicians, physician assistants, and faculty physicians care for patients seen in this practice.

The methods of this prior study are reported elsewhere.[7] Briefly, medical records were randomly selected using ICD-9 codes for type 2 diabetes and hyperlipidemia. Demographic variables (i.e., patient age, gender, and race) as well as height, weight, personal and family coronary heart disease history, tobacco use, total cholesterol, LDL-C, HDL-C, triglycerides, HbA1c, and systolic and diastolic blood pressure values were abstracted from a structured review of the medical record. The study protocol was approved by the Institutional Review Board. For the current study, follow-up data were available on 86 patients. Seven of the original 124 patients were excluded because they were involved in a clinical trial where management of blood pressure, lipids, or HbA1c was dictated by a study protocol, and 31 of the original patients were lost to follow-up (i.e., patient changed healthcare provider or died).

Descriptive statistics were performed to compute means, standard deviations, frequencies, and percentages for the demographic variables and for the lipid, blood pressure, body mass index, and HbA1c variables. Simple means were calculated for the lipid, blood pressure, and HbA1c variables. Chart data were eligible for abstraction if an office visit was associated with the collection of laboratory data. No patient had more than four eligible office visits for either year studied; missing values were excluded from the analysis. The mean values for the lipid, blood pressure, and HbA1c values were then combined with the appropriate demographic variables to determine if a patient was meeting the goals recommended by the ADA or the NHLBI. The paired samples t-test was used to assess for a difference at the level of the patient in the means of the LDL-C, HDL-C, body mass index, HbA1c, and systolic and diastolic blood pressure values between the two study periods of 1999 and 2003 (two-sided alpha = 0.05). The non-parametric McNemar test was used to assess for a significant difference in the number of patients at the identified goal for LDL-C, HDL-C, HbA1c, and systolic and diastolic blood pressure values between 1999 and 2003 (alpha = 0.05). A "goal score" was computed for each year, 1999 and 2003, with a value of "5" representing a person who attained the recommended goal for each of the five variables under study (i.e., for LDL-C, HDL-C, HbA1c, and systolic and diastolic blood pressure) for that year; a value of "0" represented a patient who met none of the goals for the five variables under study for that year. A histogram was created to depict the distribution of the goal scores for the years 1999 and 2003. The Wilcoxon signed ranks test was used to test for a difference between the mean "goal scores" as well as between the five individual variables from 1999 and 2003 (two-sided alpha = 0.05). All statistical analyses were carried out using SPSS (Version 12.0).

Results

The mean age of our sample was 59.6 years (SD 12.6 years); 53.7% were women. Approximately 54% were African American, and 47% were white. Analyses of those patients from the baseline study lost to follow-up revealed no significant differences from those included in the current study, with the exception of higher mean total cholesterol and triglyceride measures (225 mg/dL versus 207 mg/dL, p = 0.03; 357 mg/dL versus 217 mg/dL, p = 0.03, respectively).

There was an overall low percentage of missing data in the current study. The systolic and diastolic blood pressure variables had no missing data; the HbA1c and HDL-C variables had 1.2% missing data; and the LDL-C variables had 5.8% missing data. Missing data were excluded from analyses.

At the patient level, significant differences were noted at the 2003 follow-up for HbA1c (a 0.4% decrease; p = 0.03), diastolic blood pressure (a 4.3 mmHg decrease; p < 0.001), LDL-C (a 10.6 mg/dL decrease; p < 0.01), and HDL-C (an 8.3 mg/dL increase; p < 0.001). There was a trend toward a significant decrease in systolic blood pressure (a 3.5 mmHg decrease; p = 0.09) (see Table 2). No difference was detected in the body mass index (p = 0.89).

The number and percent of persons with diabetes "at goal" for HbA1c, systolic blood pressure, diastolic blood pressure, LDL-C, and HDL-C are listed in Table 3. While mean LDL-C improved by 10.6mg/dL between 1999 and 2003, the percentage of patients at goal for LDL-C significantly worsened (from 79.1% at goal in 1999 to 39.5% at goal in 2003; p < 0.001). No significant differences were found among the other four variables, though there was a trend toward a significant improvement in the percent at goal for HDL-C (p = 0.09).

Overall, mean goal scores were lower in 2003 than 1999 (p = 0.035). The mean number of goals met in 1999 was 2.8 with a standard deviation (SD) of 0.92; only two patients met all five goals, while nine patients met only one goal (see Figure 1). In 2003, the mean number of goals met was 2.48 (SD 1.1). Similarly, only two patients met all five goals; however, three patients did not meet any of the goals that year. When considering the five individual quality indicator variables of HbA1c, systolic blood pressure, diastolic blood pressure, LDL-C, and HDL-C, the only significant difference noted in goal scores was a decrease in the LDL-C score (p < 0.001) from 1999-2003.

The 1999 NCEP ATP II LDL-C goals were then applied to our 2003 data. When applying these earlier criteria, no significant difference in the percentage of patients at goal for LDL-C was noted in the 2003 data: 83% (71/86) were at goal in 2003 vs. 79% (68/86) in 1999 (Chi-square 2-sided p = 0.19).

Table 2.
Change in Quality Indicators 1999-2003

Indicator	Mean (SD)	Mean (SD)	Difference	95% CI of the Difference
	1999	2003		(Lower, Upper)
HbA1c	8.6 (2.0)	8.2 (1.8)	-0.4	(-0.76, -0.05)
Systolic BP	137.6 (18.6)	134.1 (14.3)	-3.5	(-7.49, 0.55)
Diastolic BP	76.2 (9.3)	71.9 (9.2)	-4.3	(-6.38, -2.22)
LDL-C	125.5 (39.8)	114.9 (40.9)	-10.6	(-18.10, -3.09)
HDL-C	38.9 (11.2)	47.2 (12.1)	8.3	(8.55, 10.25)

SD (standard deviation), CI (Confidence Interval), BP (blood pressure), LDL-C (low-density lipoprotein cholesterol), HDL-C (high-density lipoprotein cholesterol)

Table 3.
Frequency "at Goal" for Quality Indicators 1999 vs. 2003

Indicator	1999 N (%)	2003 using 1999 standards N (%)	2003 using 2003 standards N (%)	Difference in number "at Goal"
	At Goal	At Goal	At Goal	P value[†]
HbA1c	12 (14.1)	*	16 (18.8)	0.33
Systolic BP	32 (37.2)	*	34 (39.5)	0.86
Diastolic BP	72 (83.7)	79 (91.9)	68 (79.1)	< 0.001[‡]
				0.48[§]
LDL-C	68 (79.1)	71 (82.6)	34 (39.5)	0.68[‡]
				< 0.001[§]
HDL-C	53 (61.6)	74 (86)	61 (71.8)	< 0.001[‡]
				0.09[§]

[*] No change in the 2003 standards occurred for this quality indicator, therefore the data are the same as those in the "2003 using 2003 standards" column,

[†] McNemar test

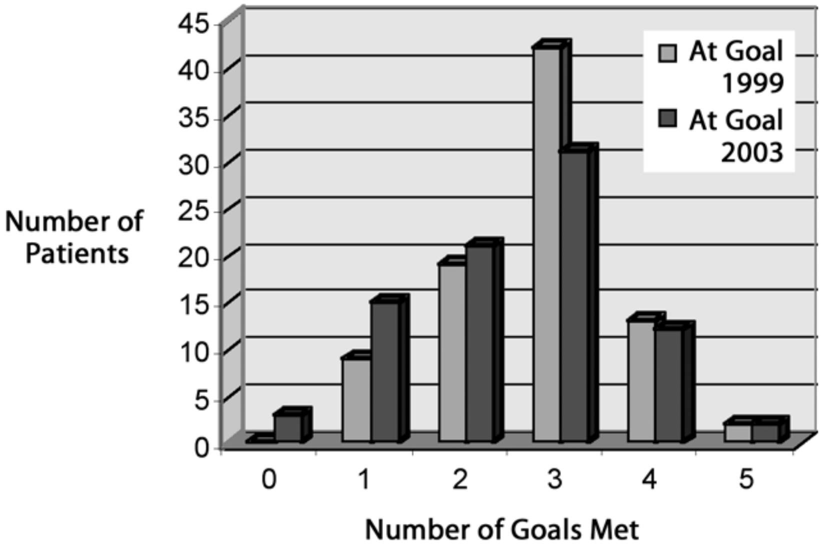
[‡] P value reflects the difference in number at goal for this quality indicator in "1999" vs. "2003 using 1999 standards"

[§] P value reflects the difference in number at goal for this quality indicator in "1999" vs. "2003 using 2003 standards", BP (blood pressure), LDL-C (low-density lipoprotein cholesterol), HDL-C (high-density lipoprotein cholesterol)

Discussion

While improvement with respect to decreased mean HbA1c, diastolic blood pressure, and LDL-C, and increases in the mean HDL-C were achieved over the four-year study interval, the overall number of patients at goal for LDL-C decreased by approximately 40% (see Tables 2 and 3). This paradoxical improvement in patients' mean LDL-C levels despite a decrease

Figure 1.
Number of Cardiovascular Disease-Related Guideline Goals Met (1999 vs. 2003)



in the number of patients at goal for LDL-C in 2003, are explained by the change in the NCEP ATP III guideline with the introduction in 2001 of type 2 diabetes as a coronary artery disease equivalent and the new LDL-C goal of less than 100 mg/dL.

Attainment of goals targeting metabolic endpoints related to cardiovascular disease risk reduction among persons with type 2 diabetes has been studied among primary care providers.[7-9] Some primary care practices have used computer-assisted interventions to improve diabetes care with limited improvement in metabolic outcomes.[16] Compliance with blood pressure or lipid guidelines in cross-sectional data are based primarily on surrogate markers, such as reports of awareness of guideline recommendations,[17] physicians' perceived implementation of guidelines,[18] or performance of recommended screening tests.[19] However, even high rates of risk factor testing (HbA1c, blood pressure, LDL-C) have been shown not to correlate with optimal metabolic control among persons with diabetes.[20] Grant et al., found that high annual testing rates corresponded to only 34% of patients at goal for HbA1c (< 7%), 33% at blood pressure goal (< 130/80), and 46.1% at goal for LDL-C (< 100 mg/dl).[20] Primary care providers are not alone in their difficulty achieving practice guideline goals. Aliyu et al., reported that 38% of cardiologists' patients with established coronary heart disease and no contraindications to statin therapy had sub-optimal management of their dyslipidemia when compared against the NCEP ATP III guidelines.[21]

A previous cross-sectional study assessing ADA-specific lipid treatment goals among adults with type 2 diabetes in a university primary care setting revealed 42% were at goal for HDL-C, and 47% were at goal for LDL-C.[8] In a comparison of national samples of white, African-American, and Mexican-American persons with type 2 diabetes, Harris reported the percent of those with LDL-C values less than 100 mg/dL were 15.4%, 19.6%, and 21.1%, respectively.[22] The percent at goal for HbA1c (i.e., < 7%) for all subjects was 44.6%.[23] In the current study, we found that 71.8% (61/85) of patients were at goal for HDL-C in 2003, while only 39.5% (34/86) were at goal for LDL-C. Only 18.8% (16/85) were at goal for HbA1c (see Table 3). Most patients were at goal for only two of the five variables under study in both 1999 and 2003 (see Figure 1).

A limitation of the current study is its small sample size. The fact that the study patients were from an academic family medicine practice also limits the external validity of the study. While the patients seen in this practice are representative of a mixed population, greater than half of the patients have a managed care plan. Additionally, this follow-up study included only persons with type 2 diabetes and a coexisting diagnosis of hyperlipidemia. It is possible that the percentage of those at goal for HbA1c may differ among persons with type 2 diabetes without hyperlipidemia. Another consideration is the potential confounding effect of the aging of our cohort; treatment goals may be more difficult to achieve with advancing age.

Summary

This longitudinal study, conducted among a sample of persons with type 2 diabetes in an academic family medicine setting, describes the attainment of goals related to metabolic control and CVD risk reduction. The current study highlights the impact that changes in guideline recommendations can have on a practice's achievement of metabolic goals despite improvements at the patient level. We found that patients achieved on average approximately half of the guideline-specific goals related to CVD risk reduction. These results echo those of other investigators in that practice guideline goals are difficult to attain in the primary care setting. Further research is needed to elucidate the barriers related to attaining guideline-specific goals for patients with diabetes in primary care, such as short, infrequent visits; lack of information technology support; and competing demands.[24] Our findings suggest that patient-level improvements may not be adequate indicators of a practice's achievement of guideline recommendations. Percent attainment of guideline goals may be a useful performance measure of practice-level quality improvement initiatives.

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Trends in Up-to-Date Status in Colorectal Cancer Screening, North Carolina, 1998-2002

Jane A. Kim, MD, MPH, Deborah Porterfield, MD, MPH, and Ziya Gizlice, PhD

Abstract

Background: *Rates of colorectal cancer (CRC) screening are rising nationwide. Our purpose was to determine the proportion of North Carolina adults who were up-to-date with CRC screening in 1998-2002 and analyze trends by socio-demographic subgroups.*

Methods: *We examined data from the North Carolina Behavioral Risk Factor Surveillance System. For 1998, 1999, 2001, and 2002, we determined the proportion of respondents 50 years old and older who were up-to-date, defined as a home fecal occult blood test (FOBT) in the past 12 months and/or a sigmoidoscopy or colonoscopy in the past five years. We examined trends in up-to-date status in all respondents and in selected socio-demographic subgroups. We also examined the characteristics of respondents who were up-to-date in 2001-2002.*

Results: *From 1998-2002, the percentage of respondents 50 years old or older who were up-to-date with CRC screening increased from 46.1% to 54.0% (test for trend, $p < 0.0001$). The proportion who were up-to-date increased among those 50-74 years old, those with a high school or college education, and those with incomes less than \$25,000. Proportions that were up-to-date did not significantly increase among African Americans and respondents with less than a high school education. In 2001-2002, we found low percentages that were up-to-date among adults 50-54 years old, Hispanics, and the uninsured.*

Conclusions: *The proportion of North Carolina adults who are up-to-date with CRC screening is increasing, but not across all socio-demographic groups. These results indicate that there are subgroups that need to be reached with screening programs. Efforts to educate the public and providers about CRC screening should continue.*

Introduction

Colorectal cancer (CRC) is a leading cause of cancer in the United States and ranks only behind lung cancer as a cause of cancer death.[1] The American Cancer Society (ACS) estimates that 4,100 new cases and 1,590 deaths from colorectal cancer will occur in North Carolina in 2005.[1] Colorectal cancer screening reduces mortality[2-6] and is cost-effective.[7,8] The United States Preventive Services Task Force, the American Gastroenterological Association, the ACS, and others recommend screening for adults 50 years old or older.[9-11] Multiple modalities can be used for screening: a yearly fecal occult blood test (FOBT), flexible sigmoidoscopy or barium enema every five years, a combination of FOBT and sigmoidoscopy, or colonoscopy every ten years (see Table 1). Despite expert group recommendations and multiple screening modalities, national rates of CRC screening[12,13] remain far below rates for mammography, prostate-specific antigen screening, and Pap smear testing.[14-16]

Although CRC screening rates were low throughout the 1990s, recent data from the national Behavioral Risk Factor Surveillance System (BRFSS) show modest increases in screening rates. From 1999-2001, the percentage of adults 50 years old or older who reported FOBT screening within the past 12 months increased from approximately 19% to 24%, and the percentage reporting a sigmoidoscopy or colonoscopy within the past five years improved from 34% to 39%.[12,13] In 2001, approximately 53% of adults 50 years and older were up-to-date with screening, defined as an FOBT in the past 12 months or

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Table 1.
Colorectal Cancer Screening Guidelines for Average Risk[§] Individuals 50 Years Old or Older[*][9-11]

Any one of the following:
1. Yearly fecal occult blood testing (FOBT)
2. Flexible sigmoidoscopy (FS) every five years
3. Combined yearly FOBT and FS every five years**
4. Colonoscopy every ten years
5. Double-contrast barium enema every five years

[§] Average risk: individuals without a family or personal history of colorectal cancer, personal history of adenomatous polyps, and the absence of an illness, such as inflammatory bowel disease that predisposes individuals to CRC

[*] Recommendations of the American Gastroenterological Association Consortium Panel, United States Preventive Services Task Force, and American Cancer Society (ACS)

[**] ACS recommends the combination of flexible sigmoidoscopy and FOBT over either test alone

a lower endoscopy (colonoscopy or sigmoidoscopy) in the last ten years.[13]

Recent trends in up-to-date status in North Carolina are of interest to the Cancer Prevention and Control Branch of the North Carolina Division of Public Health, which is responsible for surveillance and has implemented CRC screening programs for underserved populations in the past. These trends are also of interest to the Advisory Committee for Cancer Coordination and Control, which makes recommendations on cancer screening and control for North Carolina and is currently writing an updated state plan for cancer control. We were also interested in assessing recent trends in CRC screening to determine if various factors, such as insurance policy changes, state-based legislation, and public awareness campaigns might have resulted in an increased proportion of North Carolinians who were up-to-date with CRC screening. We examined the data from the North Carolina BRFSS for trends in CRC screening rates, including trends across selected socio-demographic subgroups from 1998-2002. We also evaluated the characteristics of those who were up-to-date in 2001-2002 in order to identify populations that might be in need of interventions to improve the performance of CRC screening.

Methods

The BRFSS is a multistage, random-digit-dialed, state-based telephone survey of noninstitutionalized adult United States residents ages 18 and older.[17] The BRFSS consists of a core set of questions with additional optional modules for topics, such as colorectal cancer screening. States have the option to add these additional modules based on the data needs of their state. Colorectal cancer screening questions were mandatory core items in the 1999, 2001, and 2002 BRFSS. The North Carolina Cancer Prevention and Control Branch paid to add questions to the 1998 BRFSS for enhanced surveillance of colorectal cancer screening behavior and needs assessment for public health programs.

During the study period, the North Carolina BRFSS conducted 17,764 interviews. Colorectal cancer screening questions were asked of the 7,642 respondents who were ages 50 years old or older at the time of the interview. Response rates of all eligible individuals with telephones in North Carolina ranged from 56% (2001) to 64% (1998) and were calculated via the CASRO method.[18] The CASRO method calculates the response rate by taking the percentage of complete and partial interviews out of an estimate of all eligible households.

Interviewers asked four questions about whether respondents had ever been screened with sigmoidoscopy/colonoscopy or a home FOBT and, if so, when they received screening (see Box 1). To reflect updated evidence regarding colonoscopy and proctoscopy, endoscopy questions changed in 1999 to ask about screening with "sigmoidoscopy/colonoscopy" instead of "sigmoidoscopy/proctoscopy." For this analysis we refer to both sets of terms as "endoscopy." In 2001, BRFSS changed endoscopy response choices to include endoscopy within the past ten years, the time frame recommended for colonoscopy screening. We defined up-to-date status for the analysis of trends from 1998-2002 as a home FOBT in the past 12 months and/or a sigmoidoscopy or colonoscopy in the past five years. We chose this definition in order to compare trends across years because the ten-year answer choice was not available before 2001.

For each year with data on CRC screening from 1998-2002, we determined the proportion of respondents who were up-to-date with screening for the total number of respondents as well as for the socio-demographic subgroups of gender, age, race, education, and household income. Those who responded "do not know/not sure" or "refused" were excluded. We used a test for trend to determine if there were significant trends in the proportions who were up-to-date with CRC screening. Trends were not calculated for subgroups with less than 100 respondents in a given year.

For 2001 and 2002, we also calculated the percentages who were up-to-date using an alternate definition: FOBT within the past 12 months and/or a sigmoidoscopy/colonoscopy within the past ten years. Given that the national BRFSS now uses the ten-year time interval to determine the percentage of individuals who were screened with lower endoscopy during recommended time intervals,[12] we used this updated definition of up-to-date in order to be consistent with the national definition. This definition of up-to-date includes respondents who were appropriately screened with colonoscopy within the past ten years, but also those who had a sigmoidoscopy five to ten years earlier and were no longer up-to-date with guidelines. To evaluate whether screening according to guidelines increased significantly between 2001 and 2002, we compared the difference in the proportions of respondents who were up-to-date using a t-test.

We combined data from 2001 and 2002, the most recent years for which we had data, and examined the characteristics of respondents who were up-to-date with screening. Combining data from 2001 and 2002 allowed us to determine the proportions who were up-to-date with screening in subgroups, such as the uninsured and Hispanics, groups with small numbers sampled in each individual year.

We used SUDAAN version 8 to calculate rates, averages, standard errors, and 95% confidence intervals.[19] Data from the sample were weighted to adjust for unequal probabilities of selection due to the disproportionate sampling method and due to people living in households with different numbers of telephones and different numbers of adults. The final sample data were also weighted to account for unequal non-response rates among different demographic groups. Two-sided p-values < 0.05 were considered statistically significant. Analyses using BRFSS data are exempt from Institutional Review Board approval because the BRFSS does not have any personal identifiers and is a public health surveillance system. These data were analyzed as part of the surveillance work of the North Carolina Division of Public Health.

Results

Trends in Up-to-Date Status in Colorectal Cancer Screening, 1998-2002

The percentage of respondents 50 years old or older who reported a home FOBT in the past 12 months or endoscopy in the past five years increased from 46.1% [95% confidence interval (CI), 42.2, 50.1] in 1998 to 54% (95% CI, 51.2, 56.7) in 2002 (test for trend, p < 0.0001, see Table 2). Table 2 shows the trend in the percentage of all respondents that were up-to-date from 1998-1999 and 2001-2002, the years in which North Carolina asked questions about CRC screening, and Table 3 presents trends in up-to-date status by socio-demographic subgroups. There were statistically significant positive trends in up-to-date status among males and females, those 50-74 years old, whites, those with a high school or some college education, and those with incomes less than $25,000 (see Table 3). There was a 24 percentage-point increase in up-to-date status among those with incomes less than $15,000 (33% to 57%) and a 13 percentage-point increase from 31% to 44% in the 50-54-year-old age group. In contrast, there were no significant trends in the percentages who were up-to-date among respondents with less than a high school education or a college degree or greater and those with incomes greater than $25,000. Respondents with higher levels of education and income already had high baseline percentages of individuals who were up-to-date in 1998; these groups experienced only small increases over the five-year period.

Box 1

Questions on colorectal cancer screening, 2002 BRFSS (Behavioral Risk Factor Surveillance System)

A blood stool test is a test that may use a special kit at home to determine whether the stool contains blood. Have you ever had this test using a home kit?

A Yes
B No
C Don't know/not sure
D Refused

How long has it been since you had your last blood stool test using a home kit?

A Within the past year
B Within the past two years
C Within the past five years
D Five or more years ago
E Don't know/not sure
F Never
G Refused

Sigmoidoscopy and colonoscopy are exams in which a tube is inserted in the rectum to view the bowel for signs of cancer or other health problems. Have you ever had either of these exams?

A Yes
B No
C Don't know/not sure
D Refused

How long has it been since you had your last sigmoidoscopy or colonoscopy?

A Within the past year
B Within the past two years
C Within the past five years
D Within the past ten years
E Ten or more years ago
F Don't know/not sure
G Refused

Table 2.
Number and Percentage of North Carolina Respondents 50 Years Old or Older Who Were Up-to-Date with Colorectal Cancer Screening,* 1998-2002

	Total Number of Respondents	Percent	95% Confidence Interval
1998	931	46.1	(42.2, 50.1)
1999	1,031	45.2	(41.8, 48.7)
2001	2,473	55.4	(52.5, 58.2)
2002	2,942	54.0	(51.2, 56.7)

Test for trend, 1998-2002: t-value = 4.47, p < 0.0001

* FOBT within past 12 months and/or sigmoidoscopy/colonoscopy within the past five years

Proportions and Characteristics of Up-to-Date Respondents, 2001-2002

For 2001-2002, using the updated definition of up-to-date, which was an FOBT in the past 12 months or sigmoidoscopy/colonoscopy in the past ten years, the percentage of respondents who were up-to-date

Table 3.
Trends in Up-to-Date Status in Colorectal Cancer Screening* by Socio-demographic Groups in North Carolina, 1998-1999, 2001-2002

Demographics	1998 Percent (Total)	1999	2001	2002	Trend Test P Value
Gender					
Male	44.8 (354)	43.3 (385)	54.6 (896)	51.9 (1,082)	0.01
Female	47.1 (577)	46.7 (646)	56.0 (1,577)	55.7 (1,860)	0.001
Age					
50-54	30.9 (162)	39.8 (216)	42.5 (536)	43.9 (624)	0.01
55-64	49.0 (301)	40.0 (306)	57.9 (803)	56.7 (955)	0.003
65-74	51.1 (279)	50.6 (299)	61.9 (643)	60.9 (782)	0.003
75+	49.7 (189)	53.0 (210)	56.8 (491)	52.4 (581)	0.47
Race					
White	45.0 (765)	45.2 (831)	56.4 (2,043)	54.8 (2,046)	0.0001
African-American	51.9 (151)	43.7 (180)	52.5 (350)	53.6 (370)	0.46
Education					
Less than high school	44.8 (269)	37.5 (268)	50.2 (526)	44.7 (655)	0.41
Some high school	44.4 (290)	43.4 (331)	54.4 (753)	57.2 (878)	0.001
Some college	42.6 (196)	49.0 (195)	57.9 (576)	54.3 (609)	0.01
College+	55.5 (169)	54.0 (235)	60.7 (609)	59.9 (788)	0.23
Household Income					
Less than $15,000	33.0 (180)	37.5 (151)	47.3 (311)	57.2 (390)	0.001
$15,000-$24,999	45.3 (190)	46.4 (191)	54.6 (427)	48.1 (473)	0.001
$25,000-$34,999	51.9 (129)	47.3 (133)	59.5 (321)	51.3 (307)	0.62
$35,000-$49,999	57.8 (100)	42.0 (126)	56.9 (292)	57.1 (342)	0.55
$50,000+	43.9 (122)	46.9 (183)	58.5 (521)	60.3 (573)	0.23

* FOBT within past 12 months and/or sigmoidoscopy/colonoscopy within past five years

with CRC screening was 57.4% in 2001 and 56.4% in 2002; this difference was not significant.

In the combined data from 2001 and 2002, approximately 58% of whites were up-to-date compared to 54% of African-Americans and 41% of other minorities, a category that included Asians, American Indians, and native Hawaiian or other Pacific Islanders (see Table 4). Fewer respondents of Hispanic origin were up-to-date with screening (49.9%) compared to those who were not Hispanic (57.0%). Only 45% of respondents 50-54 years old were up-to-date, compared to 59% of those 55-64 years old and 61% of those 65 years old or older. Forty-nine percent of respondents with less than a high school education were up-to-date versus 63% of those who had a college education or beyond. Approximately 59% of those with health insurance were up-to-date with screening, compared to only 34.8% of respondents without health insurance.

Discussion

From 1998-2002, the percentage of North Carolina adults 50 years old or older who were up-to-date with CRC screening increased, but remained low, and positive trends in up-to-date status were present in some, but not all socio-demographic subgroups. In 2001-2002, screening rates continued to improve, but more than 40% of respondents still had not been screened according to guidelines. There were notable disparities in the percentages that were up-to-date in 2001-2002 by race, age, and insurance status.

The proportions of those who were up-to-date in North Carolina are similar to those obtained from the national BRFSS. In the 1999 national BRFSS, 44% of adults 50 years old or older were up-to-date with screening, defined as an FOBT in the past year or a sigmoidoscopy in the past five years,[13] compared to 45.2% of North Carolina respondents. In the 2001 national BRFSS, 53.1% were up-to-date using the updated definition, an FOBT within the past 12 months or lower endoscopy within the past ten years.[20] In North Carolina, approximately 57% of respondents reported screening within these time intervals.

The increase in the percentages of North Carolina respondents who were up-to-date may be due to national and state efforts to promote CRC screening. The Centers for Disease Control and Prevention (CDC) launched multi-media campaigns in 1999 to educate the public and healthcare providers about CRC screening.[21-23] The American Cancer Society also implemented a colorectal cancer screening media campaign in March 1999 and 2000. Activities organized through North Carolina's Cancer Prevention and Control Branch of the North Carolina Division of Public Health included a media campaign to promote screening and regional training sessions for physicians. In addition, the North Carolina Advisory Committee on Cancer Coordination and Control funded a pilot project in 2000 to

Table 4.
Characteristics of North Carolina Respondents 50 Years Old or Older Who Reported FOBT within Past 12 months and/or Sigmoidoscopy/Colonoscopy within the Past Ten Years, 2001-2002

Demographics	Percent (Total)	95% CI
Total	56.9 (5,418)	54.9, 58.9
Sex		
Male	55.2 (1,978)	52.0, 58.4
Female	58.2 (3,440)	55.8, 60.7
Race		
White	58.1 (4,452)	55.9, 60.2
African American	54.2 (720)	48.9, 59.3
Other minorities	41.1 (202)	30.7, 52.4
Hispanic	49.9 (83)	35.0, 64.7
Non-Hispanic	57.0 (5,325)	55.0, 59.0
Age		
50-54	45.4 (1,160)	41.1, 49.8
55-64	59.3 (1,758)	55.9, 62.6
65+	61.2 (2,500)	58.3, 64.0
Education		
Less than high school	49.1 (1,182)	44.9, 53.3
Completed high school	57.5 (1,631)	53.9, 61.0
Some college	59.3 (1,187)	55.2, 63.3
Greater than college	63.1 (1,397)	59.1, 66.9
Income		
Less than $15,000	54.0 (701)	48.2, 59.8
$15,000-$24,999	54.0 (900)	49.2, 58.8
$25,000-$34,999	56.4 (629)	50.7, 62.0
$35,000-$49,999	60.2 (634)	54.5, 65.7
$50,000+	61.8 (1,094)	57.4, 66.0
Health Insurance		
Yes	58.8 (5,014)	56.8, 60.8
No	34.8 (399)	28.3, 41.9

promote CRC screening in six local health departments.

Medicare and the North Carolina General Assembly implemented policy changes in 1998 and 2001 that may have contributed to the increasing proportion of North Carolina respondents who were up-to-date. In January 1998, Medicare began to cover screening FOBT, sigmoidoscopy, and barium enema for average-risk enrollees 50 years old and older. Medicare further broadened its coverage in 2001 to cover screening colonoscopy for average-risk enrollees 50 years old or older.[24] Also in 2001, the North Carolina General Assembly passed legislation mandating that state and private insurance plans cover CRC screening tests.[25] The 2002 North Carolina BRFSS, however, showed only a small increase in up-to-date status compared to previous years. It will be interesting to see whether rates of up-to-date status in subsequent surveys reflect these policy changes.

Although the percentage of North Carolina adults 50 years old and older reporting CRC screening within recommended time intervals is increasing, approximately 46% of adults are not up-to-date with screening. In addition, not all socio-demographic subgroups experienced improvements in up-to-date status. There were significant improvements in whites, those with incomes less than $25,000, and those with a high school or some college education. There was no significant increase in up-to-date status, however, among respondents with less than a high school education and those with incomes between $25,000-$50,000, indicating a possible need for interventions in these populations to help increase levels of screening. In addition, screening among all respondents 50-54 years old improved from 30% to 43% from 1998-2002, but the proportion who were up-to-date among this age group in 2002 was still low. It may be important to target individuals in this age group in order to help them start and continue with screening according to guidelines.

Prior research has found that increasing age, higher levels of education, having health insurance, and being of non-Hispanic background[26-32] are associated with higher rates of CRC screening. The findings from our study are consistent with results from these prior studies. In 2001-2002, North Carolina BRFSS respondents 50-54 years old had low rates of up-to-date screening compared to those of older age, and individuals with low educational attainment and low incomes had lesser rates of up-to-date screening compared to those with higher levels of education and income. Rates of up-to-date screening among the insured were almost twice as high as those among the uninsured. Fewer Hispanics were up-to-date compared to non-Hispanics. Current educational and awareness programs to promote screening may not be reaching the groups who had low percentages of individuals who were up-to-date; poor access to healthcare and lack of income to pay for tests are other possible reasons for these low rates.

African Americans have higher rates of colorectal cancer death and are diagnosed at a more advanced stage more often than whites.[1,33] These disparities may be due in part to low rates of CRC screening in African Americans.[34] In our current study, we found that rates of up-to-date screening among African-Americans did not increase significantly over time, but that the actual rates of up-to-date screening in 2001-2002 were comparable to whites. It is encouraging that African Americans had similar rates of up-to-date status in recent years compared to whites, and the lack of a significant trend may be due in part to sampling error due to small sample sizes in 1998-1999. Efforts to promote CRC screening among African-Americans should continue given their higher rates of mortality and diagnosis in advanced stages of disease.

There are a number of limitations to this study. First, the change in wording from "sigmoidoscopy/proctoscopy" in 1998 to "sigmoidoscopy/colonoscopy" in 1999 may have resulted in higher screening rates in 1999, 2001, and 2002 due to a previously unmeasured use of colonoscopy. The change from proctoscopy to colonoscopy may mean that the increasing trends are due in part to the change in question wording, which could have introduced measurement error and potential bias into our results. The extent to which this change may have affected the results is unclear. Defining up-to-date screening status for the analysis of trends as a sigmoidoscopy or colonoscopy within the past five years may underestimate the actual percentage of those who are up-to-date, since individuals who had colonoscopy between five and ten years ago are in compliance with current guidelines. The BRFSS questions on CRC screening did not distinguish between diagnostic and screening procedures, possibly resulting in overestimates of actual screening rates. Another limitation is that the percentages of up-to-date by socio-demographic characteristics in 2001-2002 are not adjusted for the other variables. Further investigation of these associations with a multivariate model might help define which characteristics are most strongly associated with up-to-date status. This was a telephone survey, so responses were limited to individuals who owned home telephones. The response rates were low, and respondents may have answered differently compared to those who chose not to participate. Another limitation is recall bias; responses were self-reported and may not accurately reflect the actual performance of screening tests. Comparisons of self-report and chart audits, however, have found fair-to-good agreement between patient self-report and medical records.[35-37] And finally, the small numbers of African Americans surveyed in the 1998 and 1999 BRFSS may have affected the accuracy of these estimates.

Conclusions

The percentage of North Carolina adults who are up-to-date with CRC screening is increasing, and state rates of up-to-date status parallel trends seen on the national level. Although this is an encouraging finding, many adults 50 years old or older are still not up-to-date with current guidelines, and some socio-demographic subgroups, such as the uninsured, Hispanics, and those 50-54 years of age, have particularly low rates of individuals who are up-to-date with screening. There is a need for educational programs and screening initiatives for the public and for healthcare providers, especially targeted toward populations who had low percentages of respondents who were up-to-date, in order to improve the performance of colorectal cancer screening in North Carolina.

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John W. Williams, Jr., MD, MHS
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MEDICAL JOURNAL

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POLICY FORUM
Access to Dental Care

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INTRODUCTION

Policy Forum:
Access to Dental Care

Since 2002, when the North Carolina Institute of Medicine began publishing the *North Carolina Medical Journal* as a statewide journal of health policy analysis and debate for all the healthcare professions, key policy makers/shapers, and the interested lay public, we have wanted to highlight the problems of assuring access to primary dental care services in our state. This year, we are fortunate to have a new relationship with the North Carolina Dental Society as an organizational co-sponsor of the Journal. This relationship and the 2005 North Carolina Oral Health Summit, convened by the Oral Health Section of the North Carolina Department of Health and Human Services, were catalysts for the production of this Journal issue. In this issue of the Journal, we summarize the principal themes of these discussions concerning the state of oral health in North Carolina, along with a number of policy options for addressing the shortages of dental workforce supply.

North Carolina, like a number of other states, is facing a significant shortage of practicing dentists. Moreover, problems accessing primary dental care are even more severe in certain rural areas of the state, for those with low incomes or dependence on coverage from the state's Medicaid program, and for persons with special needs, such as persons with disabilities. Few disagree that the number of dentists in our state needs to increase rapidly, and concerted efforts should be made to attract additional dental practitioners to serve underserved areas and populations.

On a positive note, North Carolina is one of the nation's leading states with regard to preventive dental care programs for children, which are primarily offered through the public schools. In addition, community water fluoridation efforts statewide have extended access to this valuable preventive oral health technology to more than 80% of our state's population. Since the 1960s, the prevalence of dental caries in the permanent teeth of 12-17 year olds has declined by more than 80% for whites and 65% for African Americans. Despite these impressive 40-year trends, reported by Drs. Gary Rozier and Rebecca King, serious problems remain. As many as 20-30% of North Carolinians report that they have been unable to access basic dental care services when needed, and one out of three school-age children have untreated dental decay.

While this issue of the *North Carolina Medical Journal* provides an overview of the challenges many people in North Carolina face when trying to access dental care, there are a number of challenges that are not discussed in any detail. For example, we have not provided a detailed discussion of the national faculty shortages for dental schools or community colleges that are preparing needed dental professionals. In addition, we do not discuss some of the highly sensitive issues regarding the expanded use of dental hygienists, which are being utilized in other states. These are issues that may warrant attention, but were beyond the scope of this publication.

Like a number of the health and healthcare policy issues previously addressed in Journal, opinions differ about how best to meet the oral health needs of our population. Short-term and longer-term options are considered, each with costs and likely benefits. We hope that the articles presented here will help explain our state's oral health challenges as policies and programs are developed to meet these important health needs.

Gordon H. DeFriese, PhD
Editor-in-Chief

Kristie Weisner Thompson, MA
Managing Editor

ISSUE BRIEF

Assuring the Accessibility of Basic Dental Care Services:
Issues of Workforce Supply, Organization of Care, and Education

Kristen L. Dubay, MPP, M. Alec Parker, DMD, and Gordon H. DeFriese, PhD

The most common form of dental disease is caries (tooth decay).[1,2] In fact, dental caries is the most common chronic disease among children—five times more common than asthma (59% versus 11%, respectively).[3] Nationally, more than half of all children have dental caries by the second grade.[2,4] In North Carolina, during state fiscal year 2004-2005, 22% of children were found to have untreated tooth decay in kindergarten.[5] Nationally, 30% of adults have untreated tooth decay. [2,6]

Many people do not understand the integral role that oral health plays in a person's general health. Studies are increasingly uncovering associations between chronic oral infections and other conditions, such as diabetes, heart and lung diseases, stroke, low birth weight, and premature births.[1,2] Untreated oral health problems cause unnecessary pain and suffering. They can also decrease the economic productivity of workers through lost work days or distraction, and have a similar negative effect on children's capacity to learn. Individuals with oral health problems may experience a loss of self-esteem, and in some extreme cases, death. Oral and pharyngeal cancers are also significant oral health problems that can lead to serious illness and disfigurement. Further, individuals that delay needed dental care often face higher treatment costs when they do receive care.[1,2]

Most people experience caries and/or periodontal (gum) disease at some point in their lives. Fortunately, most of these problems are preventable and treatable with a combination of self-care, professional care, and community-based initiatives. Community water fluoridation, for example, has significantly reduced the prevalence and severity of dental decay in North Carolina and the nation.[7] Professionally-applied dental sealants, varnishes, and gels, and the use of products containing fluoride, (e.g., toothpaste, mouth rinses, dietary fluoride supplements) effectively prevent dental decay. Self-care practices that include a diet with limited sugars and carbohydrates, regular tooth brushing and flossing, along with regular professional cleanings are also critical to maintaining oral health. Regrettably, many people either cannot access needed dental care, do not know how to access the care they need, or do not realize the importance of dental care to their overall health status.

> *"Studies are increasingly uncovering associations between chronic oral infections and other conditions, such as diabetes, heart and lung diseases, stroke, low birth weight, and premature births."*

Dental care services are one category of healthcare for which there is both the expectation of widespread, if not universal, availability, and yet low levels of consumer demand in comparison with conventional healthcare (i.e., medical) services. Dental care is a segment of overall healthcare where preventive services are of unquestionable primary importance to both the maintenance of health status and the minimization of future costs of treatment. But oral health within communities requires attention to both individual health-promotive behaviors as well

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as collective interventions, such as the assurance of dental care access and the fluoridation of public water supplies.

Patterns of Dental Disease in North Carolina

North Carolina has benefited from more than 30 years of detailed and on-going epidemiological studies documenting the extent and the patterns of dental disease in this state. In addition, the preventive dentistry programs targeted to children in this state set it apart from most others. As a result, it is possible to describe the distribution of dental disease (in terms of need) as well as the success of various programs to address the prevalence of dental disease among North Carolina's children in a way that has made North Carolina the envy of many other states. Drs. Gary Rozier and Rebecca King provide an overview of the history of dental disease trends in North Carolina in a commentary in this issue of the *North Carolina Medical Journal*.[8]

These accomplishments have been realized through an effective and long-term collaboration between the state's Oral Health Section of the North Carolina Department of Health and Human Services (DHHS) and the University of North Carolina at Chapel Hill (UNC-Chapel Hill) School of Public Health. In the 1960s, Drs. John Fulton and John Hughes of the UNC-Chapel Hill School of Public Health worked with state epidemiologists and oral health personnel to develop the first statewide oral health survey.[9] This landmark study demonstrated widespread patterns of untreated dental decay, endentulism, and periodontal disease and served as the stimulus for legislative action to create a major new initiative in dental public health with a particular focus on the oral health of North Carolina's children. The 1960-1963 Fulton-Hughes study was followed 13 years later (in 1976-1977) by a second statewide epidemiological survey conducted by Dr. John Hughes and Dr. Gary Rozier, which enabled the calculation of oral health rates of change in North Carolina.[10] More recently, in 1986-1987 and 2003-2004, Rozier and his colleagues[11,12] at the Oral Health Section of the North Carolina DHHS conducted clinical examinations and questionnaire surveys of 80% of North Carolina school children in kindergarten through 12th grade, which included open-mouth dental screenings by dental professionals. Few states have such a resource to track the accomplishments of dental healthcare and preventive services.

Poverty and Access to Dental Care

Oral health status, like general health status, varies according to sociodemographic factors. For example, people who are low-income, minorities, and/or are less well educated tend to have poorer dental health than others. Low-income children are more likely to experience tooth decay, have a severe experience with tooth decay, and have untreated decay.[3,13]

Between 1999 and 2002, children ages two through 11 with family incomes below 100% of the federal poverty guideline (FPG)* were found to be nearly two times as likely to experience tooth decay as children in families with incomes at or above 200% FPG.[14] Adults and children in poverty were more than twice as likely as their higher-income peers to have untreated tooth decay.[14] Likewise, Latino and African-American children experienced higher rates of tooth decay (treated and untreated) than white children. Poor and minority children are also less likely to receive preventive treatments, such as dental sealants (3% versus 23%, respectively). Similarly, African-American adults are less likely to survive oral and pharyngeal cancers than whites (five-year survival rates are 34% versus 56%, respectively).[1,15]

Education also plays a key role in dental health. Less educated adults are less likely to have a regular oral cancer examination,[17] more likely to experience destructive periodontal disease, and more likely to eventually lose all of their teeth. For example, more than 13% of individuals without a high school diploma have lost all of their teeth, compared to less than 4% of individuals with more than a high school diploma.[1]

Special Analyses of Dental Health Issues in North Carolina

All of these socio-demographic differences in dental health have been addressed at the state-level through a series of meetings/conferences with North Carolina dental health professionals and other interested individuals. In 1989, the North Carolina DHHS was asked by the General Assembly to consider the problem of access to primary dental care by low-income persons in our state, particularly those covered by the state's Medicaid program. Subsequently, the Secretary of the Department, Dr. H. David Bruton, asked the North Carolina Institute of Medicine (IOM) to organize a statewide task force that would examine these issues and make recommendations to address the significant problems low-income individuals and those living in rural and other underserved areas have accessing dental care. The North Carolina IOM Task Force began work in 1998 and completed its report to the North Carolina DHHS and the North Carolina General Assembly in April 1999.[16] The work of the Task Force was generously supported by grants from the Kate B. Reynolds Charitable Trust and The Duke Endowment. The 1999 North Carolina IOM report offered 23 specific recommendations for addressing dental care access issues facing low-income persons in the state. Subsequently, the North Carolina IOM followed-up the work of the Task Force with two meetings, in 2001 and 2003, to discuss the steps that had been taken to fulfill the recommendations from the 1999 report. In April of 2005, the Oral Health Section of the North Carolina DHHS evaluated these issues at the North Carolina Oral Health Summit. The recommendations of the 2005 Summit are highlighted herein where appropriate.

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* According to the federal poverty guidelines in 2000, 100% of FPG for a family of four was an income of $18,000.

Policy Approaches to the Problem of Dental Care Access

Since the mid-1990s, it has become clear that an insufficient number of dentists and dental hygienists have been entering practice in North Carolina. Too few dentists are willing to serve low-income populations, particularly those covered by the state's Medicaid program. A number of possible avenues have been suggested for meeting these challenges. While there is general agreement that dental healthcare is a critical aspect of overall population health and making these services available is fundamental to overall health policy in our state, many of these proposed solutions are controversial.

In North Carolina, as in many other states, there is a growing sense that professional dental care is becoming less and less available, particularly as a number of dental schools across the nation have closed, and as the total number of newly licensed dentists has decreased nationally. The Kate B. Reynolds Charitable Trust, one of the state's leading health-oriented private philanthropies, has made access to dental care for low-income populations a high priority for more than a decade. Some of their programs are described by John Frank, Director of the Trust's Health Care Division, in this issue if the *North Carolina Medical Journal*.[18] Dental care in the United States is clearly among the best in the world for those who can afford it and for those who have regular access to professional care. Unfortunately this is not the case for a sizable proportion of our state's population.

Four basic strategies to improve access have been considered over the previous decade: (1) increasing the dental provider participation in the North Carolina Medicaid program, (2) increasing the supply of dentists, (3) increasing dental care availability for special needs populations, and (4) increasing public awareness of the importance of oral healthcare.

Strategy One: Low-Income Access to Dental Care

Of North Carolina's more than 8.5 million population, approximately 18% are Medicaid recipients—881,356 of whom are less than 21 years old.[19] North Carolina provides dental coverage for all eligible Medicaid recipients (adults and children). Unfortunately, use of these services is low. On average, only 27% of Medicaid recipients visited the dentist in state fiscal year 2004, a percentage that varies by geographic location. In 2005, the percentage of Medicaid recipients who visited a dentist ranged from a low of 17% in Swain County to a high of 36% in Wilkes County.[19] Low-income, uninsured individuals face other barriers to access because the entire financial burden for services is theirs. These individuals often look for free or reduced-cost services and safety net clinics.

Medicaid Payment Rates for Participating Dentists. One of the primary factors responsible for low dental service utilization among Medicaid beneficiaries is the limited participation of dentists in the Medicaid program. In 2004, only 25% of the private practice dentists (855 of 3,446) in North Carolina were considered "active participants" in the program, meaning they billed Medicaid for more than $10,000 in a single year. This is a 33% increase from 2000, but still too few to serve the needs of the Medicaid population, which grew approximately 11% over the same period. The total number of dentists that served at least one Medicaid patient in 2005 is 1,771. Therefore, the current ratio of private dentists participating in the Medicaid program per Medicaid recipient is 1:885.[19] Given this relatively small number of dental professionals practicing in North Carolina, many Medicaid recipients have difficulty finding a dentist who will treat them.

In an effort to prevent dental caries and reduce the need for dental care treatment within the Medicaid population, a program called *Into the Mouths of Babes* (IMB) was developed by the Oral Health Section and introduced across the state. The IMB program provides dental preventive service packages to health departments and physicians' offices serving Medicaid-eligible children. The packages include targeted oral health education for caregivers and a dental screening and fluoride varnish application for high-risk children from birth to age three. Collaboration is also underway with the Early Head Start program to develop educational materials for use with their clientele, to help their clientele access dental preventive services within the medical community, and to help them to find a dental home. Although this program has been effective in preventing dental caries, it is unable to address the low dental care utilization rates among this population.

To address utilization, it is important to understand why dental health professionals may not serve Medicaid patients. One of the main reasons given for low dental provider participation in the North Carolina Medicaid program is low Medicaid reimbursement rates. The North Carolina Medicaid program pays dentists 73% of the UNC-Chapel Hill Dental Faculty Practice's "usual, customary and reasonable" (UCR) charges for a selected list of dental procedures commonly provided to children. These rates were increased in 2003, from 62%. The increase came as a result of a settled lawsuit. The National Health Law Program filed the lawsuit, Antrican v. Bruton, against the North Carolina DHHS on behalf of low-income children, challenging the adequacy of North Carolina's Medicaid dental reimbursement rates. Data indicate that, between 2003 and 2005, the percentage of Medicaid-eligible children ages birth through 21 years with a Medicaid dental visit increased from 29% to 32%, and it is believed that higher Medicaid reimbursement rates may have contributed to this increase. Dr. Mahyar Mofidi offers a review of the North Carolina experience with dentist participation in Medicaid in this issue of the Journal.[20]

Despite the 2003 increase in Medicaid reimbursement rates, there is still a feeling among dentists that rates should increase further and move toward a market-based fee schedule. The UNC-Chapel Hill School of Dentistry fee schedule was initially adopted because it was one generally supported by both dental providers and the Division of Medical Assistance. However, more recently, both groups have begun to discuss the potential benefits of a market-based fee schedule. Dr. Mofidi provides a more detailed explanation of this issue on page 457 of this Journal.[20]

Participants at the 2005 North Carolina Oral Health Summit recommended that moving toward a Medicaid reimbursement rate reflecting the 75th percentile of market-based fees in North Carolina would significantly reduce barriers to access for the Medicaid population. Such a target would indicate that reimbursement rates would be equal to or greater than the rates charged by 75% of dentists in the state. Recently, the North Carolina General Assembly has taken positive steps toward increasing the Medicaid dental reimbursement rates. In the 2005 session, the North Carolina General Assembly appropriated two million dollars in each year of the 2005-2007 biennium to increase Medicaid dental rates. This translates into an approximate increase of $6.4 million/year after factoring in the federal and county shares of Medicaid costs.

Increasing Volunteer Efforts of Dental Professionals in the Care of the Underserved. Beyond the needs of just the Medicaid population, there are important and impressive voluntary efforts on the part of some dental professionals (both dentists and hygienists) to meet the most urgent needs of all those without adequate access to primary dental care. Some of these efforts are in conjunction with clinics operated by federally qualified health centers (FQHCs), while others are through programs offered by "free clinics" in various communities across the state. In this issue of the Journal, Dr. Steve Slott offers a description of some of these voluntary efforts, but with a clear message that more of this type of volunteer effort would be both welcome and likely to have a sizeable impact among our state's population who are most in need of routine dental care.[21]

Strategy Two: Increasing the Supply of Dental Professionals

In addition to the challenges related to low dentist participation in the Medicaid program, dental care access is problematic for many because of the limited supply of dental professionals. In 2004, there were 3,628 licensed, active dentists in North Carolina.[22] This represents a dentist-to-population ratio of 4.2 dentists per 10,000 population—a rate that is well below the national average of 5.7 dentists per 10,000 population. The need for dentists is particularly acute in four eastern, rural counties (Camden, Hyde, Jones and Tyrell) where there is no practicing dentist. In addition, there are three other counties in North Carolina that have only one dentist each (Gates, Graham, and Northampton).[22] Only eight counties have a dentist-to-population ratio equal to or greater than the national average. Seventy-nine counties qualify as federally designated dental health professional shortage areas, meaning that they have a full-time-equivalent dentist-to-population ratio of at least 1:5,000, or between 1:4,000 and 1:5,000, with unusually high needs for dental services or insufficient capacity of existing dental providers.[23]

The number of dental hygienists in North Carolina poses less of a challenge to access. In 2004, there were 4,324 active, licensed dental hygienists in North Carolina, which represents an increase of 18% from state fiscal year 2000 to 2004.[22] In 2004, North Carolina had 5.1 dental hygienists per 10,000 population, a level greater than the national average of 4.4 per 10,000 population. Unfortunately, dental hygienist shortages remain a problem in certain areas of the state. For example, three North Carolina counties (Currituck, Jones, and Northampton) have only one dental hygienist, and in four counties, there is no active dental hygienist (Bertie, Gates, Hyde and Tyrrell).[22]

There are several potential strategies for responding to the shortage of dental health professionals, and they can be divided into short- and long-term strategies. The short-term strategies include making it possible for more out-of-state dentists to enter practice in North Carolina and expanding the role of public health dental hygienists in the provision of educational and preventive dental care services in additional safety net organizations. The long-term strategies include increasing the class size at UNC-Chapel Hill School of Dentistry, developing a new school of dentistry at East Carolina University, and expanding the number of residency training programs and graduates in the specialty of pediatric dentistry.

Attracting Dentists and Hygienists from Out-of-State. In the short run, one strategy for increasing the number of dentists in the state is to make it possible for more out-of-state dentists to practice in North Carolina. Presently, about 40% of all dentists practicing in North Carolina are graduates of dental schools outside of North Carolina.[23] Therefore, dentists educated in other states play a significant role in serving North Carolina residents. It has always been possible for any graduate of an accredited United States dental school to apply for a license to practice in North Carolina. However, prior to 2003, applicants were required to take the North Carolina clinical examinations. These examinations were barriers to out-of-state dentists because they were complicated to schedule and involved extensive logistical and financial commitments of the examinees. As a result, in August 2002, Senate Bill 861 was signed into law (SL2002-37) allowing licensure by credentials for dentists and dental hygienists who have practiced in another state for at least five years without any disciplinary actions. Since that time, 162 dentists (with eight denials) and 182 hygienists (with four denials) have received a North Carolina license by credentials.[23]

The North Carolina State Board of Dental Examiners is further pursuing participation in a Southeast Regional Examination procedure through which dental graduates (dentists and hygienists) who take the clinical examination in any participating state in the region can also apply for a license in North Carolina by reciprocity. The Board of Dental Examiners is also actively pursuing participation in a forthcoming national credentialing examination. Participants at the 2005 North Carolina Oral Health Summit supported all three of these initiatives and felt these were important efforts to improve the state's ability to attract dentists trained in other states.

Expanding the Role of Public Health Dental Hygienists. Another short-term strategy for increasing the capacity dental health professionals in North Carolina is to expand the role of public health dental hygienists to provide educational and preventive dental care services in safety net organizations other than public health department clinics serving low-income populations. In this issue of the Journal, Dr. Rebecca King, Chief of the Oral

Health Section of the North Carolina DHHS, offers a detailed description of dental public health programs in North Carolina.[24] In 1999, the North Carolina General Assembly passed legislation to revise the North Carolina Dental Practice Act to permit specially trained public health dental hygienists to perform preventive clinical services outside the public school setting under the direction of a licensed public health dentist (Sec. 11.65 of HB 168).

Under the North Carolina Dental Practice Act, 32 dental hygienists working in local health departments and one working in a safety net special care clinic, had been specially trained to provide services under the direction of a public health dentist by June 2005. In addition, the North Carolina Oral Health Section was able to use the increased capacity of its qualified state public health dental hygienists (36 people) to expand the reach of its sealant program. In the 2004-2005 school year, the majority of the 6,459 sealants provided to 1,911 children by the North Carolina Oral Health Section were placed by hygienists under the direction of a public health dentist. The successes experienced within the state and local public health programs could also be extended to other safety net providers, such as federally-funded community or migrant health centers, state-funded healthcare clinics, or not-for-profit clinics. These programs serve predominantly Medicaid, low-income, or uninsured populations. Allowing hygienists to provide educational and preventative dental care under the general supervision of a dentist employed at such safety net organizations may extend the safety net organizations' capacities to provide preventive care to underserved populations. Participants at the 2005 North Carolina Oral Health Summit requested that the North Carolina State Board of Dental Examiners reconsider the feasibility of allowing these types of arrangements.

Increasing the Productivity of Dental Education Programs. In the long-run, more significant steps need to be taken to increase the number of dental care providers, particularly dentists, in North Carolina. As North Carolina's population continues to grow, the shortage of dental providers will become even more acute. Currently, the UNC-Chapel Hill School of Dentistry is the only dentistry program in North Carolina, and it accepts 80 students each year. Adding seats to each class at the UNC-Chapel Hill School of Dentistry could positively impact the number of dentists in the state. However, there are a number of challenges to increasing the school's class size. Additional laboratory facilities for the teaching of basic clinical sciences, clinical training facilities, and faculty would be necessary. Such changes would require further funding, which is not readily available.

Increasing the Class Size at UNC-Chapel Hill. In this issue of the *North Carolina Medical Journal*, two commentaries address the complex issues associated with increasing the production of dentists from the UNC-Chapel Hill School of Dentistry. Dr. John Stamm, former Dean of the School of Dentistry at UNC-Chapel Hill, summarizes the current dental workforce situation in the state and recent appropriations by the North Carolina General Assembly to support planning for increasing dental school enrollment in North Carolina. In addition, the new dean of the UNC-Chapel Hill School of Dentistry, Dr. John Williams, describes the complexities of dental workforce issues that bear on the issue of dental class size. His commentary advocates support for an existing plan to expand enrollment at the UNC-Chapel Hill School of Dentistry by 50% (from 80 to 120 students per class).[25]

Developing a New School of Dentistry at East Carolina University. Another option for increasing the production of dentists in the state is to develop a new, second dental school. A commentary in this issue of the Journal, authored by Dr. Michael Lewis, Vice Chancellor for Health Sciences at East Carolina University (ECU) in Greenville, makes the case for a new, "community-oriented" school of dentistry at ECU.[26] The ECU proposal is to develop a school of dentistry that will attract individuals who would like to practice professionally in North Carolina communities that need high-level dental care, and have inadequate dental care access. As exemplified by the Brody School of Medicine and the ECU School of Nursing, ECU has a history and culture of exposing health sciences graduates to strategies for serving underserved populations. Moreover, a sizeable proportion of these graduates are motivated to stay in North Carolina and choose primary care as a career path. Therefore, this strategy could be used to reduce workforce shortages in underserved communities, which would improve access to care for underserved populations. Participants at the 2005 North Carolina Oral Health Summit agreed that there is a need to produce more dentists in this state, and they supported further examination of this issue to determine which of these strategies would be most appropriate and feasible.

Increasing the Number of Fellowship-Trained Pediatric Dentists. Finally, beyond the general dentist under-supply problem, there is a need for more fellowship-trained pediatric dentists in North Carolina. Pediatric dentists are very important because, according to the American Academy of Pediatric Dentistry, they provide a disproportionately higher amount of oral healthcare for underserved children and children receiving Medicaid. A 2000 Task Force report from the American Academy of Pediatric Dentistry found that between 1990 and 1998, the number of trained pediatric dentists in the United States declined from 3,900 to 3,600. This decline was attributed to a lack of pediatric training programs rather than a lack of interest in pediatric dentistry training.[27] The only graduate program for this specialty in North Carolina is at the UNC-Chapel Hill School of Dentistry. In this issue of the Journal, Drs. Michael Roberts and William Vann, Jr., offer an extensive discussion of issues related to the pediatric dental workforce and efforts to increase the supply of pediatric dentists.[28]

As a response to a perceived shortage of pediatric dentists, the Department of Pediatric Dentistry at UNC-Chapel Hill increased enrollment in the early 1990s from two residents per year to three using insecure funding sources. The success of this recent increase in pediatric residency programs has been very valuable, and it is important that it continues. The pediatric workforce is aging, and its future supply is projected to decrease. Additionally, pediatric dentists are still largely concentrated in urban areas and are unavailable in many communities. The 2005 Oral Health Summit participants supported strategies for continuing to increase the supply of pediatric dentists through continual support for increasing the number of pediatric dental residents at The UNC-Chapel Hill School of Dentistry and developing at least one additional pediatric residency program in North Carolina.

Clearly, there is a significant need to increase the number of both general and specialty dentists in North Carolina. However, doing so will require significant financial support. In addition, some of these strategies are controversial, and it will be important to evaluate each option closely before undertaking any of the initiatives.

Strategy Three: Increasing Dental Care Availability for Special Needs Populations

Many special needs patients have unique and more extensive barriers to accessing dental care than other demographic groups. Special needs patients often have cognitive and/or physical disabilities that require special care. Many of these patients live in nursing homes, assisted living facilities, or group homes. Even those living independently or with families in the broader community may have trouble accessing care for reasons such as transportation challenges or finding a provider willing to serve them. Dental professionals face a unique challenge when treating special needs patients because each patient is different. Some patients can be served in a traditional private practice environment, needing no additional time or services, while others must be served at their residence, require specific facility capabilities, and/or take significantly longer to serve than traditional patients.

Barriers to accessing dental health services arise from a variety of factors within the special needs community. For some, oral health is simply overlooked due to the patient's inability to provide self-care or a caregiver's lack of knowledge or training. Most dentists are not trained to deal with the needs of this population. Others find it too onerous, since most of the special needs patients are Medicaid recipients and, thus, services are reimbursed at low rates. Even dentists who treat special needs patients may refuse to treat severely uncooperative or disruptive patients because they lack the expertise or resources needed to care for these patients.[29]

Strategies for better serving the special needs populations were discussed at the 2005 Oral Health Summit. Recommended strategies included developing a data system for gathering information on the amount of training oral health students receive about serving special needs patients; teaching dental professionals techniques that would help practices integrate special needs patients into a more traditional patient base; establishing concentrated special needs clinics with appropriate facility and equipment needs in which dentists could be encouraged to provide part-time services; and developing additional Medicaid reimbursement codes for services to disabled/special needs populations. The commentary in this special issue of the *North Carolina Medical Journal* by Dr. William Milner[30] summarizes the complex issues surrounding the organization and provision of dental care to special needs populations and offers a number of concrete suggestions for how this care might be better managed.

Strategy Four: Increasing Public Awareness of the Importance of Oral Healthcare

Given the low rates of participation in the North Carolina Medicaid dental program by beneficiaries (only 27% of eligible beneficiaries in 2004 had at least one dental visit; the percentage for Medicaid beneficiaries 21 years of age or younger was 31%),[22] there has been a concern that the importance of dental care and good oral health practices needs further emphasis, especially among younger populations covered by this program. This is a problem of widespread significance within the general public. Even among those with dental care insurance, rates of utilization are far less than for conventional medical care. For this reason, it is considered important to continue to emphasize school-based educational programs in health education, which include units on oral health, prevention, and self-care.

Summary: Policy Options for Dental Care Access in North Carolina

As we move into the 21st Century, it is important that North Carolina can assure access to basic (primary) dental healthcare services for all populations. A focal point of this effort is centered around having sufficient numbers of dental healthcare professionals to provide needed services, and that these professionals will be willing to serve those with only a modest ability to pay for their care, especially when these individuals and families are covered by programs like Medicaid.

In this regard, six strategies warrant further consideration and debate as policy options for the future:

- Increasing the numbers of graduating dentists and dental hygienists entering practice in North Carolina, and especially those electing to practice in rural and underserved communities.
- Increasing the numbers of graduate-trained practitioners in general dentistry and pediatric dentistry.
- Allowing public health dental hygienists to perform dental preventive services in clinical settings outside of public health departments in order to extend the reach of these services to those most in need.
- Subsidizing the care provision taking place in remote rural areas or inner cities where those most in need are provided access to basic dental care.
- Training more dentists and hygienists and organizing care delivery programs to meet the needs of special care patients.
- Encouraging a greater level of voluntarism among dental care professionals to serve the needs of low-income populations in special clinical care programs, and through active participation in the North Carolina Medicaid program.

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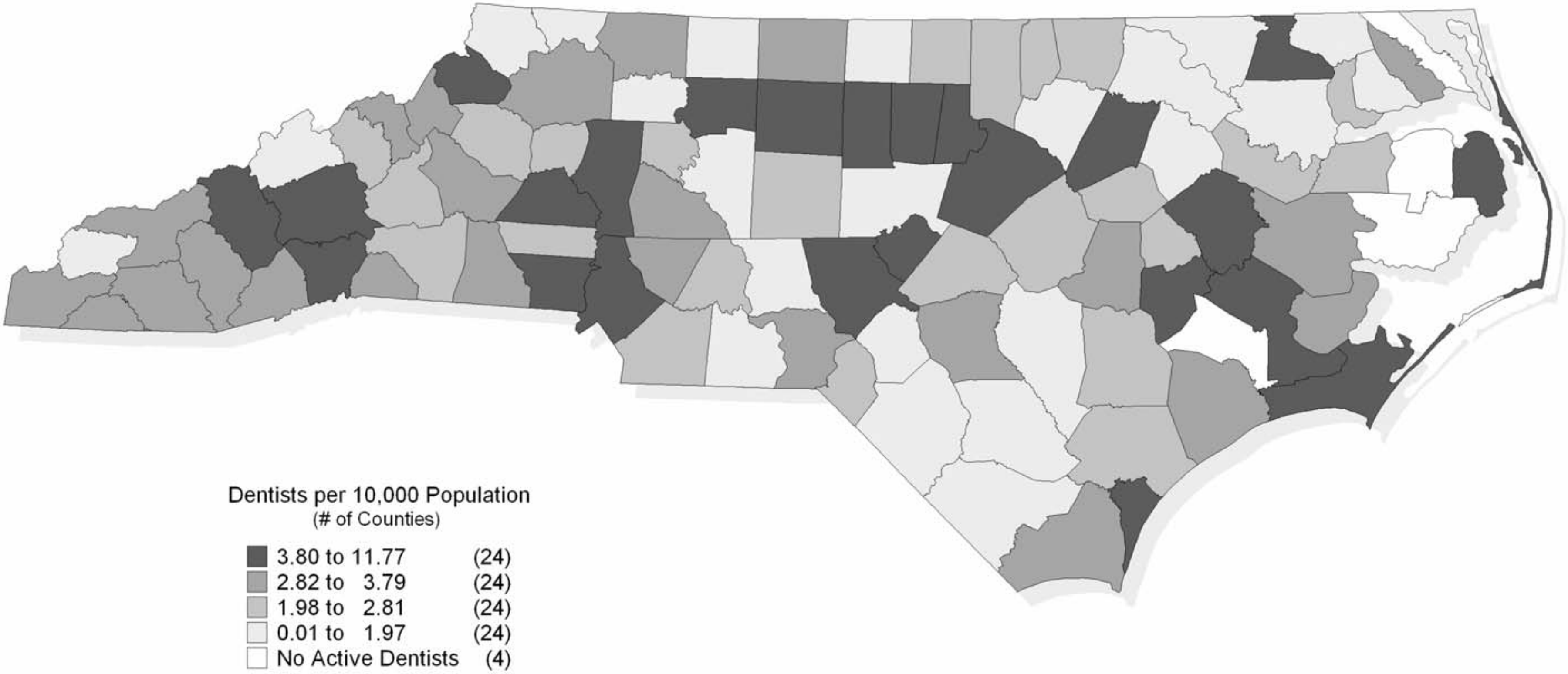
Dentists per 10,000 Population
North Carolina, 2004



Source: North Carolina Health Professions Data System, with data derived from the NC State Board of Dental Examiners, 2004.

Produced by: North Carolina Health Professions Data System, and the Southeast Regional Center for Health Workforce Studies, Cecil G. Sheps Center for Health Services Research, University of North Carolina at Chapel Hill.

*Dentists included are active or have unknown activity status.

Defining the Need for Dental Care in North Carolina:
Contributions of Public Health Surveillance of Dental Diseases and Conditions

R. Gary Rozier, DDS, MPH, and Rebecca S. King, DDS, MPH

A long-standing principle held by epidemiologists who study the health status of human populations is that any disease can demonstrate important variation among people with different characteristics, across different geographic locations, and over time. Substantial fluctuations in the amount of disease can occur as the relative importance of diseases rises and falls, usually in response to scientific breakthroughs and widespread application of effective interventions, but often for unknown reasons.

The prevalence of dental diseases and their consequences are particularly prone to change because of the complex and interacting nature of their many biological, environmental, and social determinants. Dental diseases were at record highs during the first half of the 20th Century.[1] Few people went unaffected, and most could expect to loose some of their teeth by middle age. In the early 1960s, almost 3,000 students graduated from high school in North Carolina having lost all their teeth to the ravages of dental disease.[2] In the mid-1970s, the number of missing teeth among those in their sixth decade of life was two and one-half times greater than the number of filled or decayed teeth.[3]

National trends through the 1990s demonstrated several significant advances in oral health status during the last half of the 20th Century.[1,4] Primary among these changes were substantial declines in dental caries (tooth decay) in permanent teeth beginning in childhood and extending through young adulthood, modest reductions in destructive periodontal (gum) disease, and improvements in tooth loss and oral cancer mortality. Even with these improvements, however, dental disease still is recognized as a silent epidemic, with dental caries and periodontal diseases being among the most common of all diseases. Particularly hard hit are the poor, minorities, those living in remote geographic areas and those with special healthcare needs, creating large disparities in disease and in access to preventive and treatment services.

Important changes in public health practice, the field of dentistry, and the North Carolina population have occurred during the last few decades that should substantially affect the oral health of North Carolina residents. In this commentary, we briefly review the current status of dental diseases and trends that have direct relevance to issues involving access to dental care. Available data require us to focus primarily on children. We will use both clinically determined disease status as well as indicators self-reported in questionnaire surveys of the North Carolina population.

> *"After decades of remarkable improvements in the prevalence of tooth decay, the trend line seems to be leveling off or possibly increasing for primary tooth decay."*

North Carolina Oral Health Assessment Systems

A core function of dental public health is to monitor the burden of oral diseases and the availability of preventive and treatment services. The Institute of Medicine (IOM) of the National Academy of Sciences recommends that public health "…regularly and systematically collect, assemble, analyze, and make available information on the health of the community, including studies on health status, community health needs,

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and epidemiological and other studies of health problems."[5] The oral health surveillance system for North Carolina is one of the more comprehensive in the nation and is responsive to this IOM recommendation and historical precedents for public health practice.

The surveillance for oral health in North Carolina consists of several major elements. Periodically, a scientific sample representative of the entire state or subgroups of its population are selected to participate in dental examinations and interviews. Four of these surveys have been conducted, all with large samples and good response rates. The first two of the four surveys provided estimates for dental disease for the North Carolina population of all ages in 1960-1963[6] and 1976-1977.[3] The second two provide comparable estimates for school children in kindergarten through 12th grade in 1986-1987[7] and 2003-2004.[8] The North Carolina Oral Health Section also conducts annual surveillance of dental caries and its treatment in kindergarten and fifth grade. Assessments began in the 1996-1997 school year and continue with open-mouth dental screenings by trained dental professionals of about 80% of all children in these grades in almost all of North Carolina's counties.[9]

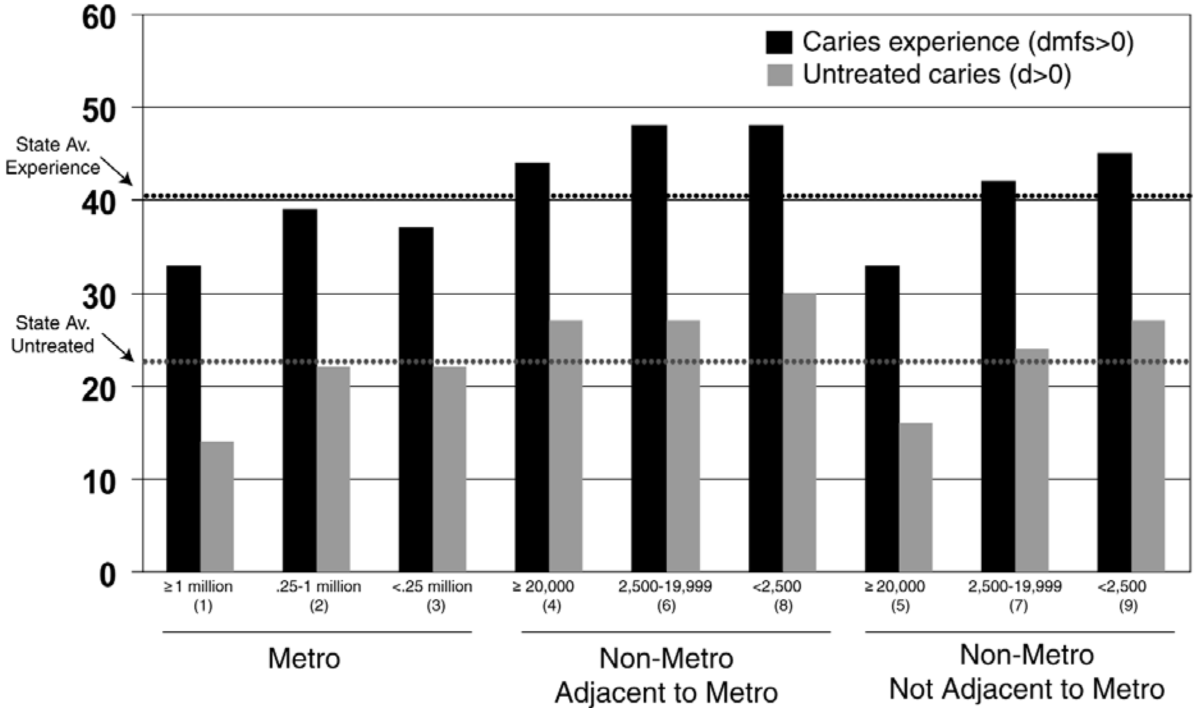
North Carolina participates in the Behavioral Risk Factor Surveillance System (BRFSS), a random telephone survey of the state's residents 18 years of age and older.[10] This survey, done in all states, provides information on dental use and outcomes in North Carolina that is collected in a routine, standardized manner at the state level and for a few larger counties. This system was expanded in January 2005 by the Child Health Assessment and Monitoring Program (CHAMP) survey.[11,12] CHAMP is the first telephone survey of its kind in North Carolina to measure access to dental care, dental utilization, and outcomes of children from birth to 17 years of age, thus providing a seamless account of dental care access and outcomes for the entire state from birth into adulthood.

Other components of the oral health surveillance system for North Carolina include detailed information about water fluoridation and oral cancer incidence and mortality, but information from these elements of the system is not included in this commentary.

Oral Health Status of North Carolina's Population

Key indicators for the oral health of North Carolinians are presented in Table 1 (see page 440), most of which are taken from the 2003-2004 survey of school children. Several findings are evident from these data. First, a large percentage of children

Figure 1.
Percent with Caries Experience and Untreated Caries by North Carolina County Rural-Urban Continuum Codes, Kindergarten Students, 2003-2004



(1) Anson, Cabarrus, Gaston, Mecklenburg; (2) Alexander, Brunswick, Buncombe, Burke, Caldwell, Catawba, Chatham, Cumberland, Davie, Forsyth, Franklin, Haywood, Henderson, Hoke, Johnston, Madison, New Hanover, Orange, Pender, Person, Randolph, Rockingham, Stokes, Yadkin; (3) Alamance, Edgecombe, Greene, Nash, Pitt, Wayne, Onslow; (4) Carteret, Cleveland, Davidson, Halifax, Harnett, Iredell, Lee, Lenoir, Lincoln, Moore, Richmond, Robeson, Rowan, Rutherford, Surry, Vance, Wilson; (5) Craven, Dare; (6) Beauford, Bladen, Columbus, Duplin, Granville, Jackson, Martin, McDowell, Montgomery, Sampson, Scotland, Stanley, Transylvania, Watauga, Wilkes; (7) Hertford, Macon, Washington; (8) Avery, Caswell, Gates, Jones, Polk, Swain, Yancey, Warren; (9) Alleghany, Ashe, Bertie, Cherokee, Clay, Graham, Hyde, Mitchell, Northampton, Pamlico, Tyrrell.

are affected by tooth decay, and the severity, as measured by the mean number of decayed, missing, and filled surfaces per child (dfs or DMFS), among those affected is high. Second, a large percentage of parents report that they believe that their children need dental treatment, such as fillings, teeth pulled, or cleanings. This self-reported need is supported by actual clinically determined need through the oral health survey in 2003-2004. About 31% of North Carolina children have untreated decay in primary

Table 1.
Oral Health Status Indicators for North Carolina, 2003-2005

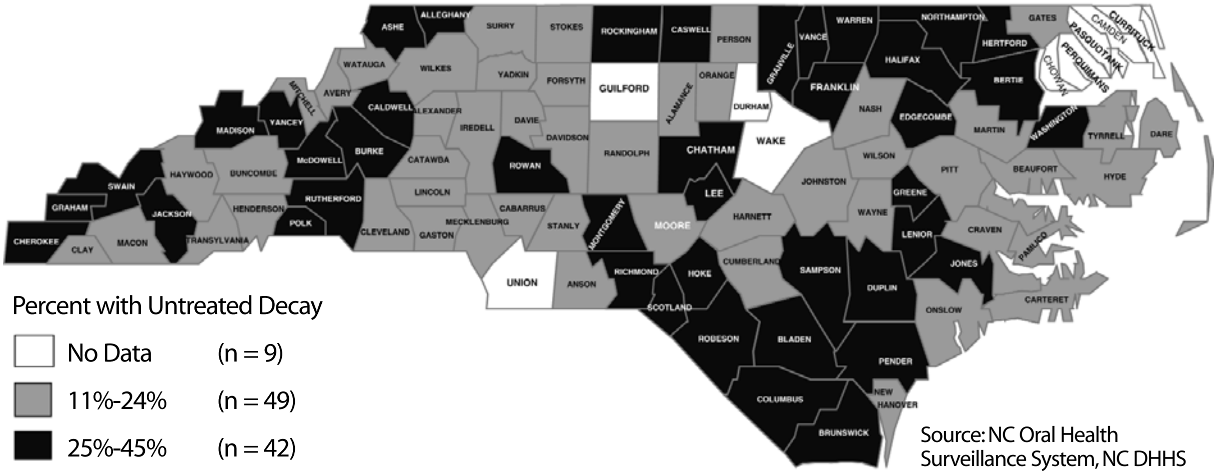
Condition	Overall[†]	Non-Hispanic White	Non-Hispanic African American	Hispanic
Disease Experience				
% any caries in primary teeth (5-9 year olds)	53.7	49.8	55.1	65.0
Mean dfs per child with any caries (5-9 year olds)	8.8	8.5	8.1	11.0
% any caries in permanent teeth (6-17 year olds)	37.5	35.7	41.6	35.7
Mean DMFS per child with any caries (6-17 year olds)	4.4	4.1	5.1	3.9
% any caries in either tooth type (5-17 year olds)	55.8	53.2	58.2	61.3
% clinical evidence of incisor trauma (6-17 year olds)	11.8	10.6	14.1	8.6
% parent reporting serious trauma (5-17 year olds)	10.7	11.5	9.3	8.6
Untreated Disease				
% with 90% of untreated primary tooth decay (5-9 year olds)	19.7	16.9	22.1	28.8
% with any untreated primary tooth decay (5-9 year olds)	30.8	25.7	37.0	41.4
Mean decayed primary tooth surfaces per child among those with any decay (5-9 year olds)	5.1	4.6	5.3	5.8
% with 90% of untreated permanent tooth decay (6-17 year olds)	10.0	9.1	11.4	10.7
% with any untreated permanent tooth decay (6-17 year olds)	13.4	10.6	18.2	16.5
Mean decayed permanent surfaces per child among those with any decay (6-17 year olds)	2.6	2.2	2.9	2.8
Demand				
% parents reporting child needs treatment (5-17 year olds)	51.5	42.4	67.5	60.3
% parent reporting wanted care, but did not get it (5-17 year olds)	60.1	65.8	49.6	72.2
% children ever experienced dental pain in lifetime (kindergarten-third grade)	23.5	19.1	28.2	32.2
% children experienced dental pain at least once in last 3 mos. (grades 4-12)	31.0	28.8	36.4	26.5
Outcomes				
% children's health rated fair or poor by parent 1-4 year olds	6.6	‡	‡	‡
5-17 year olds	16.4	10.9	22.5	36.3
% adults with tooth loss (18 years and older)				
Some tooth loss because of tooth decay or gum disease, but not all	44.7	41.6	58.0	25.2
Complete tooth loss because of tooth decay or gum disease	9.3	9.5	11.0	3.9

[†] Denominator includes all race and ethnic groups.

[‡] Preliminary estimates from CHAMP, 2005. Sample sizes do not permit estimates by race or ethnicity.

Notes: All estimates are from the 2003-2004 oral health survey of schoolchildren except parents' perceptions of oral health of children one to four years of age and tooth loss, which are from the CHAMP[11] and BRFSS,[10] respectively.

Figure 2.
Percent of Kindergarten Students with Untreated Dental Caries by County, 2003-2004



Source: NC Oral Health Surveillance System, NC DHHS

(baby) teeth; 13% in permanent teeth. A third interpretation from data presented in Table 1 is that untreated tooth decay is highly concentrated in a small percentage of children. With regard to outcomes, a large percentage of adults overall lose teeth because of dental disease, and this is highly age-dependent, probably reflecting inadequate access to dental care and values held years ago. Finally, disparities by race and ethnicity exist for most of the indicators, with Hispanics being much worse than whites on many important indicators. African Americans have indicators that usually fell between those of the other two groups.

Surveillance data on caries experience and untreated dental caries in kindergarten students are presented in Figure 1 according to a scheme used by the federal government to classify United States counties according to their rurality.[13] Each county in North Carolina has been classified according to the population size of its metropolitan (metro) area if it has one, and nonmetropolitan (nonmetro) area according to its degree of urbanization and adjacency to a metro area. A nonmetro county is defined as adjacent to a metro county if it physically adjoins one of the state's metro areas and has a least 2% of its employed labor force commuting to central metro counties. Both dental caries experience and untreated tooth decay differ by population size of the county and its adjacency to a metro area. Children in nonmetro counties that are adjacent to a metro county have more caries experience and untreated decay than children in other types of counties, regardless of population size. Between 40% and 50% of children in these nonmetro counties of all three size categories show obvious signs of tooth decay, and close to 30% have some untreated decay. Within each of the three metro and nonmetro classifications, caries experience and untreated decay generally increase as the population size decreases, particularly in those counties not adjacent to metro areas.

A county-specific geographic distribution of untreated decay in kindergarten students is displayed in Figure 2. As many as one out of every four kindergarten students in 42 counties begin school with untreated decay. This number is as high as one out of every three students in a dozen of these counties. Most of the counties with students who experience large amounts of caries and receive a small amount of treatment are located in northeastern, southeastern, or western counties.

Trends in Dental Diseases in North Carolina

Remarkable improvements in dental caries have occurred in the permanent dentition of school-aged children in North Carolina over the last 40 years. Trends in 12-17-year-old children are presented as an example of these improvements (see Figure 3). Lifetime caries experience is presented as the mean of the person-level count of decayed, missing, and filled teeth (i.e., the DMFT index, a standard epidemiologic tool designed for these

Figure 3.
Trends in Dental Caries (DMFT) in 12-17-Year-Old Children, North Carolina

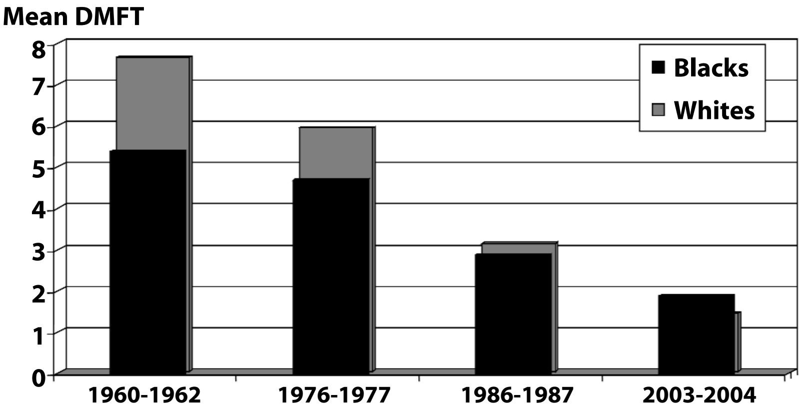
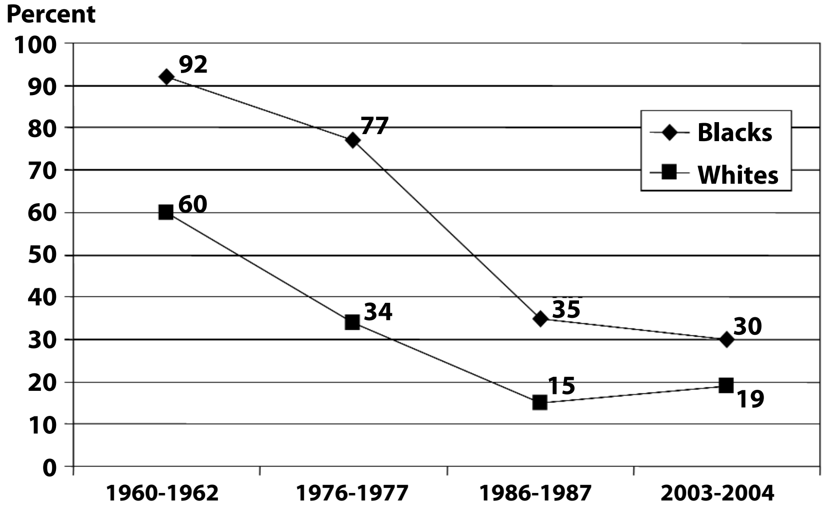


Figure 4.
Trends in Untreated Decay (%DT/DMFT), in 5-17-Year-Old Children, North Carolina



purposes). The mean DMFT score per person declined by 82% in white adolescents between 1960-1962 and 2003-2004 from 7.6 per person to a low of 1.4. A reduction of 65% occurred in black adolescents. The decrease in mean DMFT per person from 5.4 to 1.9 is likewise impressive. Along with the decline in the occurrence of tooth decay, the proportion that is untreated also has declined, and by a substantial amount (see Figure 4). Most of this change occurred, however, between 1960-1962 and 1986-1987. The amount of untreated decay did not change much between 1986-1987 and 2003-2004 (see Figure 4).

Trends in primary tooth decay are not as favorable as for permanent teeth. After years of decline, trendlines in the prevalence of caries in primary teeth have leveled off or appear to have even increased in some groups of children between 1986-1987 and 2003-2004 (see Figure 5). The increase is particularly striking for children whose caregivers have less than a high school education. Surveillance data suggest that most of this increase probably occurred in children born in the mid- to late-1990s and, thus, entered kindergarten in the early 2000s and thereafter.

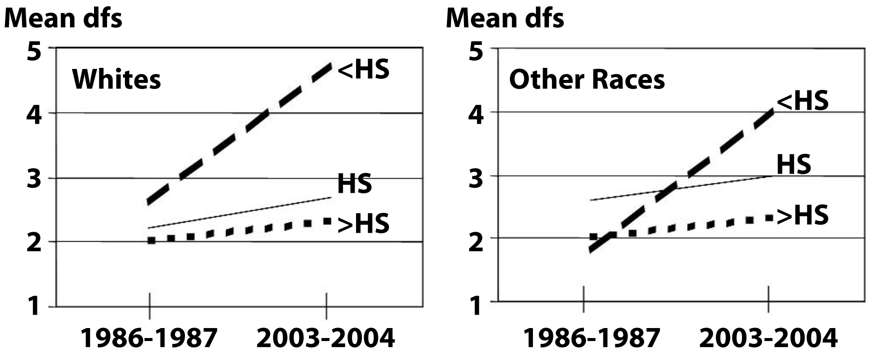
Discussion of Key Findings from Oral Health Surveillance

The key indicators reviewed in this commentary suggest that substantial improvements in the prevalence and severity of tooth decay, the major dental disease affecting children and young adults in North Carolina, have occurred over the last 40 years. Multiple factors are likely to have contributed to these changes in disease status. A comparison of a few of the possible dental experiences of adolescents born in the 1950s with those born in the 1990s, roughly the cohorts being compared in 1960-1963 and 2003-2004 as 12-17 year olds in Figure 3, reveals major differences.

Of significance is the increase in preventive programs. In the 1950s, only 15% of the North Carolina population was drinking fluoridated water, while other public health preventive programs, such as school water fluoridation and fluoride mouthrinse programs in schools were nonexistent. Fluorides were rarely a part of preventive services provided in private dental offices, and less than 20% of children used fluoridated toothpaste. By the 1990s, more than 80% of the population served by municipal drinking water systems was drinking fluoridated water. A significant portion of the remaining child population was exposed to systemic fluorides through the school water fluoridation program, to topical fluorides in public health mouthrinse programs, or applications in dental office settings. A major contribution to the downward trend in tooth decay has been the increase in use of fluoridated toothpaste. By the 1990s, almost everyone who brushed their teeth was using fluoridated toothpaste. Although not presented, our survey results also show that in 2003-2004, close to 60% of adolescents had one or more dental sealants, surpassing the national goal of 50% set for 2010.

The availability of dental services also increased during this 40-year period. In the 1950s, only one dentist for every 4,000 people practiced in the state.[14] They employed fewer than 100 dental hygienists. By the 1990s, the ratio had improved to one dentist for every 2,500 people.[15] Public health workforce supply also increased rather dramatically during this period. In the 1950s, only about

Figure 5.
Trends in Caries (dfs) in 5-9-Year-Old Children, by Parent Education Level, North Carolina



Note: HS = high school

30 public health dentists worked for the state in school-based programs, and the state employed no public health dental hygienists. Only a few local health departments had dental clinics. By the 1990s, a network of more than 100 public health dentists and dental hygienists was providing services in almost every county.

Demand for dental services also likely grew rather dramatically after the 1950s because of changing norms about dental health. The significant increase in dental insurance coverage, which was not available to the earlier cohort of adolescents, but had grown to be more than 50% when the later cohort was growing up, also was likely to be a contributing factor to the increase in demand for care.[16]

These changes in tooth decay mirror trends in dental disease nationwide. Between 1988-1994 and 1999-2002, the two most recent national surveys, a reduction in the prevalence of caries in permanent teeth of up to 10% was observed among persons six to 19 years of age and up to 6% among dentate adults 20 years of age and older.[4] While we do not have recent information about dental caries or periodontal diseases for the adult population of North Carolina, national information suggests that destructive periodontal disease should have improved as well.[17] The North Carolina BRFSS indicates improved tooth retention in adults, an important outcome measure of oral health status. The growing number of people with more teeth can increase the need for dental care, although this need can be counterbalanced by a shift in types of dental procedures from treatment to diagnostic and preventive. While not addressed in this commentary, publications from the North Carolina State Center for Health Statistics suggest declines in oral cancer incidence during the 1990s in most population groups.[18]

This review of surveillance information available for North Carolina also suggests that in the face of these improvements, a large percentage of the population continues to have unmet need and suffer its consequences on oral health-related quality of life. The public's demand for dental services is much more difficult to measure than unmet clinical need or even self-reported need for care. However, responses to the one question asked of parents in the most recent school survey most directly related to demand for dental care suggests that excess demand does exist, ranging from about 21% to 36% depending on race and ethnicity. The extent to which these children and adolescents are able to get dental care in North Carolina depends on a number of factors, many of which present significant barriers to realizing their desire for dental care.

Large disparities in oral health status and access to dental services continue to exist in the state. We chose to present disparities by race and ethnicity, rurality and geographic location, but clear disparities also are apparent by other characteristics of individuals, such as their age and poverty status. The analysis of untreated dental caries found that statewide roughly one out of five children have untreated decay in primary teeth when they start school, but many counties have as many as one of four young children in this condition, 24 counties with one out of three. These counties clearly cluster in sections of the state known to have other health and social disadvantages. Untreated disease also clusters in a small number of people. The ubiquitous distribution of tooth decay among children has shifted so that most are not affected in their permanent teeth at any time during their childhood, and only 10% to 20% of those who are affected have almost all of the untreated disease.

Statistics for dental caries presented in this commentary are for obvious carious lesions. We did not include non-cavitated lesions, nor were radiographs used for any determinations of caries status. The true amount of tooth decay in the North Carolina population is underestimated, probably by about 35% to 40% based on the exclusion of noncavitated lesions alone. Noncavitated lesions are responsive to fluoride therapy and other preventive interventions, which implies the need to continue programs that emphasize preventive strategies that will prevent noncavitated lesions from progressing to the stage that they need restorative intervention.

Implications for Public Health Action

Several conclusions with important implications for public health can be drawn from this review. After decades of remarkable improvements in the prevalence of tooth decay, the trend line seems to be leveling off or possibly increasing for primary tooth decay. Smaller reductions in decay prevalence are evident in the permanent teeth of today's young children than in those in the past. So far, this effect seems to be most pronounced in children born during or after the mid-1990s. These trends are consistent with national trends through 2001, providing some support for the conclusion that these observations in North Carolina reflect actual trends.[4] These emerging trends need to be monitored closely so that we can determine if they represent statistical fluctuations around what are historic low levels of decay, or if we are observing the early signs of a trend toward more disease.

Nevertheless, investigations need to be undertaken into the possible reasons for what appear to be unfavorable trends in dental disease. We may be seeing the early indications of increased disease—the consequence of a reduced availability of preventive dental services, particularly school-based services. The rapid growth of the North Carolina population overall and, more specifically, the number of people at elevated risk for disease, may be straining the capacity of the dental care system to respond to public needs and demands. Key factors related to the demand for dental services, such as the importance the public places on oral health, may also be a contributing factor. A better understanding about why these trends are occurring would help guide public policy.

Progress has been made since the early 1960s in reducing disparities in dental disease and access to care between whites and African Americans living in North Carolina. The growing Hispanic population, who have more disease than its non-Hispanic counterparts, may be eroding the gains made in reducing these disparities. Programs that can help eliminate disparities in dental disease and access to dental care are needed. Approaches will require implementation of innovative strategies, such as: the current *Into the Mouths of Babes* program that encourages physicians to provide preventive dental services for very young, low-income children; expanding existing community-based programs; or restoring discontinued community-based programs that helped us achieve the observed major reductions in dental disease during the 1960s, 1980s, and parts of the 1990s.

Wide concern has been expressed about the lack of access to dental care in North Carolina and nationally, particularly for children from low-income families and for preschool-aged children overall. This concern is bolstered by information abstracted from surveillance systems in North Carolina. Many young, school-aged children have untreated decay, but the overall amount of untreated decay is highly concentrated in a small segment of the population. Untreated decay in older, school-aged children, although less prevalent, is even more concentrated in a small number of children. Addressing the dental needs of these very high-risk children will require intense and concentrated efforts involving multiple strategies.

Finally, the ability to examine trends in dental disease in some detail for North Carolina demonstrates the value of the oral health surveillance system in North Carolina. The surveillance system has matured over the years, but still has limited ability to monitor adult oral health status in general and the oral health status of some minorities, such as American Indians or Asians, who are a small proportion of the state's population, at the level of detail possible with other population groups. The oral health status of adults needs to be brought under surveillance so that the oral health conditions of children being born today can be monitored as they grow into adulthood.

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COMMENTARY

The Dentist Workforce in North Carolina 2005:
A Commentary

John W. Stamm, DDS

This commentary, delivered at the North Carolina Oral Health Summit 2005, presents a basic assessment of the currently active dentist workforce situation in North Carolina. The assessment suggests that North Carolina's dentist workforce supply, while qualitatively excellent, is quantitatively insufficient, ranking North Carolina 47th out of 50 states. In addition, like many states, North Carolina is experiencing significant maldistribution in its supply of dentists. Moreover, the massive projected population growth, changing demographics, disease trends, alterations in demand for care, and potentially significant changes in dental practice styles all further reinforce the view that North Carolina urgently needs to develop substantially increased capacity for enrolling and graduating high quality dentists.

Within acknowledged limitations, the present analysis offers a number of conclusions: *One*, there is an urgent need for dentist workforce expansion in North Carolina based upon the existing dentist shortage, the current maldistribution of dentists, and the very strong North Carolina population growth projected out to 2030 by the United States Census Bureau. *Two*, North Carolina's goal should be to position its dentist-to-population ratio to rank somewhere near the national median of 6.0 dentists per 10,000 population. *Three*, to achieve its need for more dentists, North Carolina should rapidly pursue significant dental student enrollment expansion. *Four*, dental student enrollment growth should be linked with North Carolina Area Health Education Center programs to encourage training in appropriate rural and underserved community settings. *Five*, expansion in dental and dental hygiene enrollment should provide admission priority to academically qualified candidates from rural North Carolina. *Six*, expansion should be considered for General Dental Practice Residency programs and Pediatric Dentistry Specialty programs.

Introduction

The opportunity to examine the status of North Carolina's dental workforce comes at a critical time. On one hand, caries rates among school children and adolescents continue to decline, relatively fewer extractions are being performed, fewer adults are becoming edentulous, and a majority of North Carolina citizens are receiving excellent oral healthcare services. Nevertheless, as one looks forward, the state faces increasingly serious dental, oral, and craniofacial healthcare challenges. For North Carolina's oral healthcare system, whether in the private or public sectors, the current and growing challenge is to provide the population with adequate access to professional dental care in all counties of the state, but especially for rural and economically disadvantaged populations, regardless of where they live. The dental care access problem in North Carolina is acute and getting worse.

"[A] severe shortage of dentists... has emerged in North Carolina. ...North Carolina currently ranks 47th of the 50 states in terms of the dentist-to-population ratio."

Contrast this with the situation nearly 30 years ago, when data from the 1976 North Carolina Dental Disease Prevalence Survey, and the National Health and Nutrition Examination Survey (NHANES), permitted Schonfeld and Warren-Hicks to write, "The dental care system in North Carolina is considerably underutilized in each of the six Health Service Areas due to the low level of demand for dental care. It is expected that this underutilization will result in a drop in productivity in future years due to the four percent annual net increase in dental manpower. The

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North Carolina population has been increasing at an annual rate of one percent."[1] Surveying the North Carolina dental manpower growth between 1972 and 1979, Konrad and DeFriese wrote, "These data show a steady growth in the number of licensed dentists over the period 1972 to 1979. Since the year 1972, the average annual net growth in the supply of dentists in the state has varied between 3.1 and 4.9% per year, with an average net growth rate of about four percent."[2] In contrast, and from the perspective of 2005, it is very clear that North Carolina has changed dramatically since the mid-1970s, and for many persons in the state, gaining access to needed and adequate dental, oral, and craniofacial healthcare has become a more difficult and/or unaffordable proposition.

While acknowledging some over-simplification, the current and likely future access to dental care challenge faced in North Carolina appears to arise from a confluence of four distinct elements or trends:

- *Deterioration of Dental Medicaid.* North Carolina's Medicaid dental reimbursement rates deteriorated during the 1980s and 1990s. Not only that, significant coverage restrictions were also imposed in the early 2000s.
- *Shortage of Dentists.* A severe shortage of dentists has emerged in North Carolina. In the United States, North Carolina currently ranks 47th of the 50 states in terms of the dentist-to-population ratio.
- *Mal-distribution of Dentists.* In North Carolina, as in most other states, and as is true for many other service professions, the distribution of dentists has continued to evolve to the disadvantage of the state's rural populations.
- *Massive Population Growth.* The United States Census Bureau projects that among the states, North Carolina will jump from being the tenth to the seventh largest in population in 25 years. The Census Bureau estimates the 2000-2030 relative population growth will be 29.2% for the United States, but 51.9% for North Carolina.

In consideration of these factors, in 1998, the North Carolina General Assembly charged the North Carolina Department of Health and Human Services (DHHS) with exploring the dental care access issue and recommending strategies for improving the situation. Specifically, the legislature asked the North Carolina DHHS to develop strategies for:

- Assisting dentists in increasing the number of Medicaid patients they treat;
- Increasing Medicaid patients' access to quality dental services;
- Teaching dental professionals how to better integrate Medicaid and other low-income patients into their practices; and
- Expanding the capacity of local health departments and community health centers to provide properly diagnosed and supervised preventive services, such as sealants, fluoride, and basic dental hygiene treatments to low-income patients.

The legislature's charge to the North Carolina DHHS deserves closer attention. Three of the four concerns to be studied, and strategies to be developed, focused on North Carolina Medicaid issues as they related to dentistry. The fourth area of focus was on local health departments and community health centers and their capacity to offer preventive dental services. In the legislature's charge itself, no direct reference was made to the supply of the privately practicing dental workforce in North Carolina. Yet, privately practicing dentists constitute over 95% of the dentist workforce in the state.

On receiving its charge, the North Carolina DHHS contracted out the task of evaluating the four issues identified and recommending appropriate corrective strategies to the North Carolina Institute of Medicine (IOM). The North Carolina IOM formed a high-level, blue-ribbon Task Force on Dental Care Access that undertook the study and released its report in May 1999.[3] The report included 23 recommendations.

Since that time, a good deal has been accomplished in implementing most of these recommendations, or parts thereof. Implementation efforts have included: (1) significant new legislation, (2) changes to dentist licensing procedures by the North Carolina State Board of Dental Examiners, (3) generous funding from the Kate B. Reynolds Charitable Trust for new and expanded community dental clinics, (4) changes in legally permitted duties for dental hygienists in public health clinics, (5) refinement in contract terms for dentists qualifying for support through the state's Office of Research, Demonstrations and Rural Health Program Development, and (6) some additional funds for children's dental care through North Carolina Medicaid. The North Carolina IOM has provided a particularly useful service by issuing follow-up reports in 2001, 2003, and 2005, which tracks the progress made on the original 1999 recommendations.[4,5]

The North Carolina IOM Recommendations on Dental Workforce

In spite of the fact that no direct reference to North Carolina's dental workforce supply appeared in the legislature's original charge to North Carolina DHHS, the North Carolina IOM study recognized that dental workforce supply concerns existed and needed attention. In its 1999 Report, the North Carolina IOM Task Force on Dental Care Access offered nine recommendations for "increasing the supply of dentists and dental hygienists in the state with particular focus on recruiting dental professionals to practice in underserved areas and to treat underserved populations."[3] These appeared as recommendations 4-12 in the report and will not be reproduced here.

Importantly, however, the nine dental workforce recommendations emphasized issues related to, or for the most part restricted themselves to, the Medicaid and the local/community health centers' components of the legislature's original charge to the North Carolina DHHS. Two important exceptions were the recommendation that the North Carolina State Board of Dental Examiners (SBDE) establish a licensure-by-credentials pathway, and that the SBDE also consider whether existing regional (i.e., multi-state) dental examining boards could form yet another pathway to dental licensure in North Carolina. The first of those two pathways has been implemented.[6] The second of these two pathways appears on track for future implementation. But, the North Carolina IOM was not charged to undertake a comprehensive dental workforce study, and it did not do so. As a result, several large-scale dental workforce issues, with important public policy implications for North Carolina, were not addressed in the North Carolina IOM Report.

The North Carolina Legislature Begins to Address Concerns over Dental Workforce Supply

The legislature's major response to the 1999 North Carolina IOM Report was the 2001 introduction and passage of Senate Bill 861, which, among other achievements, set into motion a study to evaluate the feasibility of increasing North Carolina's capacity to train dentists.[6] Specifically, the legislature charged the University of North Carolina Board of Governors to evaluate alternative approaches for enrolling, training, and graduating more dental students in North Carolina. The Board recruited a team of external consultants to conduct the study and generate a report with recommendations for the Board.[7] The Board of Governors received, whetted, and formally approved the report and delivered it to the legislature in July 2002.

The consultants' recommendations contained in the Board of Governors report called for a significant and rapid enrollment increase, from 80 to 105 dental students, at the University of North Carolina at Chapel Hill (UNC-Chapel Hill). There has been concrete follow-up on this recommendation, and UNC-Chapel Hill has submitted an enrollment expansion plan, through the Board of Trustees and the Board of Governors, to the North Carolina legislature. The legislature has, in turn, authorized planning funds for this initiative, which has now been expanded to increase enrollment by 50 students per class, specifically by going from 80 to 130 admitted dental students per year.

The Board of Governors' study for the legislature also recommended that the General Dentistry Residency Program at East Carolina University (ECU) be significantly expanded, and that ECU consider the establishment of a pediatric dental residency program. The Board's report further recommended that ECU evaluate the feasibility of establishing a dental hygiene program. Subsequently, ECU submitted a request for planning funds to expand their General Dental Practice Residency Program, but the legislature did not appropriate funds for their request. To date, it appears that ECU has not acted to implement the other recommendations related to training programs in pediatric dentistry and dental hygiene.

Dental Workforce in North Carolina 2005: A Brief Overview

On January 1, 2004, North Carolina had 3,483 active in-state dentists and 4,052 in-state licensed dental hygienists.[10] In that same year, North Carolina's dentists practiced in 96 of the state's 100 counties. Still referencing the start of 2004, North Carolina's dentist-to-population ratio stood at 4.1 dentists per 10,000 people, compared to the national figure of 6.0 dentists per 10,000 people. An examination of dentist-to-population ratios in all 50 states in 2004 revealed that North Carolina's dentist-to-population ratio ranked 47th out of 50 states.[11] Table 1 provides some basic information for placing the state's dental workforce concerns into a relevant context.

Table 1.
Dental Workforce Context, North Carolina, 2004

North Carolina population in 2003—8.4 million

Population Growth 1990-2000:
North Carolina—21.4%
United States—13.1%

Annual North Carolina dental expenditures $1.65 billion

3,483 active in-state dentists (81% generalists)

Distribution (96 counties have one or more dentists)

North Carolina has 4.1 dentists per 10,000 population
(National figure is 6.0 per 10,000)

North Carolina's dentist-to-population ratio ranks 47th among 50 states

4,052 in-state licensed dental hygienists

Table 2 provides more detailed information about the rate of growth in the dentist workforce in both North Carolina and the United States between 1976 and 2003. These data indicate North Carolina's dentist-to-population ratio has been virtually flat since 1987. Moreover, the national dentist-to-population ratio has been consistently 40-50% higher than North Carolina's.

Turning to the stock of dental hygienists in North Carolina, Table 3 shows that the number of active dental hygienists has grown from 1,368 dental hygienists in 1979 to 4,052 in January

Table 2.
Dentist Workforce, United Sates and North Carolina, 1976-2003

	United States			North Carolina		
Year	**Population** *(millions)*	**Active Dentists**	**Dentist-to-Population Ratio** *(per 10,000 population)*	**Population** *(millions)*	**Active Dentists**	**Dentist-to-Population Ratio** *(per 10,000 population)*
1976	217.6	110,300	5.1	5.6	1,900	3.4
1987	242.3	137,800	5.7	6.4	2,600	4.1
1992	254.9	152,900	6.0	6.6	2,700	4.1
1995	264.6	158,600	6.0	7.2	2,900	4.0
2000	281.5	166,000	5.9	7.8	3,100	4.0
2003	290.3	173,600	6.0	8.5	3,500	4.1

Table 3.
Active Dental Hygienists per 10,000 Persons in North Carolina, 1979-2003

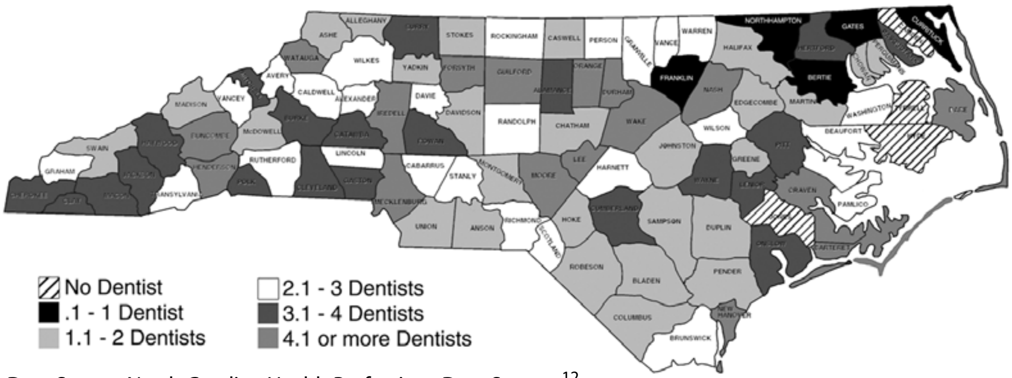
Year	Licensed Dentists per 10,000 Population	Active Dental Hygienists per 10,000 Population	Active Hygienists	Dental Hygienists-Dentist Ratio
1979	3.8	2.4	1,368	0.62
1989	4.1	3.3	2,190	0.82
1998	4.0	4.5	3,395	1.12
2003	4.1	4.8	4,052	1.18
Change Percentage (1979-2003)	7.9%	100%	199.3%	

2004, a 199.3% increase. In terms of the ratio of dental hygienists per 10,000 population, this too has grown from 2.4 in 1979 to 4.8 in 2004, a 100% increase in the ratio. In contrast, the dentist-to-population ratio grew by only 7.9% over the same period. These two disparate growth rates account for the improvement in the ratio of dental hygienists-to-dentists. In 1979, there were 0.62 dental hygienists for every licensed in-state dentist. By January 2004, the ratio had changed, indicating 1.17 dental hygienists for every North Carolina active, in-state dentist.

The Distribution of Dentists in North Carolina

Beyond concerns about the adequacy in the overall supply of dentists in North Carolina, the dental care access problem is significantly compounded by the uneven distribution (hence, the availability) of dentists across the state's 100 counties. Figure 1 indicates the number of dentists per 10,000 people in each of the state's counties, as reported for 2003.[12] Most revealing is that only eight North Carolina counties have a dentist-to-population ratio that approaches or exceeds the United Sates average of 6.0 dentists per 10,000 people. This explains, in large measure, why 79 North Carolina counties are federally designated dental shortage areas.[13] In North Carolina, 28 counties are served by two dentists or fewer per 10,000 population. These workforce distribution concerns need to be evaluated against the continuing high population growth in North Carolina, and the expected impact of that population growth in terms of the future availability of professional dental services in both urban and rural counties.

Figure 1.
Number of North Carolina Dentists per 10,000 Population, by County, 2003



Data Source: North Carolina Health Professions Data System.[12]

Productivity and Quality Increases by Dentists and the Dental Team

Almost all good economic analyses of dental workforce supply recognize that it is the supply of dental services, not simply the supply of dentists, dental hygienists, dental assistants, and dental technicians, that is critical to the population. This is a valid and important distinction. In recent decades, the dental team has demonstrated continuing increases in service productivity (and quality) per unit of time. In acknowledging the significance of productivity and quality increases, these have their weakest impact where the stock of dentists is low and/or where the available dentists are aging and may be past their most productive years. While it is only speculation, it does appear that older dentists close to retirement constitute a substantial proportion of the supply of dentists in rural North Carolina counties.

Access to Dental Care in the Face of North Carolina's Population Growth

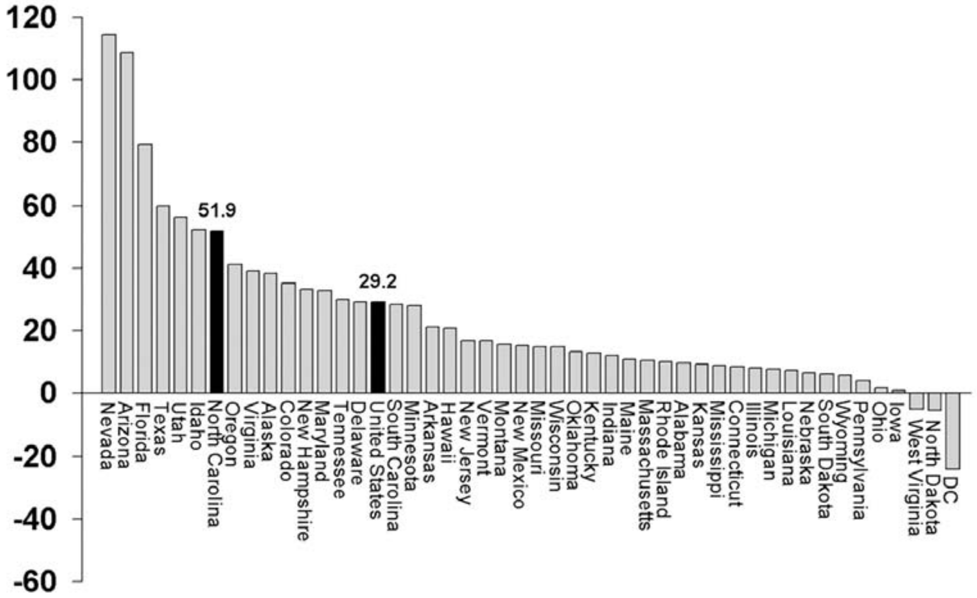
Beyond the dentist workforce shortage and dental care access concerns in 2005, the projected population growth in the state will greatly magnify the problems that currently exist. The challenge of providing future dental care services for North Carolina's population will, therefore, become more formidable with each passing year. North Carolina is currently the tenth largest state, on top of which it is also one of the fastest growing states.[8] Already during the 1990-2000 decade, United States Census Bureau data show that North Carolina's population grew by 21.4%, compared to the United Sates population that grew by only 13.1% for the same period.[9]

Looking ahead, the continuing population changes for North Carolina are even more dramatic. Figure 2, adapted from recent United States Census Bureau estimates, illustrates that in terms of absolute population growth during 2000-2030, North Carolina will experience the 5th largest population increase among the 50 states.[15] Based on these estimates, North Carolina's population is projected to be 4.2 million larger in 2030 than in 2000. It is remarkable that, for the period 2000-2030, the total United Sates population is expected to grow by 29.2%, while over the same period North Carolina's population is projected to grow by 51.9%.[15]

Assuming that the United States Census Bureau provides the most reliable population projections available, the preliminary implications for the dental workforce needed by North Carolinians in 2030 are staggering. Two scenarios may be considered. Under the first scenario, North Carolina will continue to rank 47th out of 50 states and maintain its dentist-to-population ratio of 4.1 per 10,000 population. Just 25 years from now, to maintain the current ratio, North Carolina will require approximately 5,500 active dentists, in contrast to the 3,606 active as of January 1, 2005.[16] Under the second scenario, in which the national dentist-to-population ratio norm is adopted for North Carolina, the state will need 6,320 active dentists in 2030.

The impact of dentists retiring from active practice deserves more explicit consideration when considering future dentist workforce needs. Assuming a typical 35-year career span for dentists and a rectangular age distribution, it becomes apparent that approximately 3.0% of active dentists retire or otherwise leave dental practice each year. In North Carolina, this suggests that approximately 95-105 dentists each year leave active practice, with that number going up as the workforce slowly expands. To place the impact of dentists retiring from practice into perspective, the UNC-Chapel Hill School of Dentistry currently graduates 75-80 dentists per year, not enough to replace those leaving practice. This situation has existed for some time. These and other issues cited above deserve careful and intensive attention as North Carolina considers its need for more dental education capacity.

Figure 2.
Absolute Population Growth (in thousands) by State: 2000-2030



Adapted from US Census Bureau, Population Division Interim State Population Projections, 2005. Internet Release Date: April 21, 2005.

Discussion

In calling for an increase of the dentist workforce in North Carolina, together with incentive measures to promote enhanced access to dental services for rural and underserved populations, the rise of contrary perspectives can be expected. In part, this may arise because workforce and population projections are imperfect, by definition. In a similar vein, some may suggest that dentists' productivity increases have not been sufficiently considered. That is true; though the current access-to-care concerns have arisen even while dentists' productivity, nationally, grew 1.12% per year during the 1990-2002 period.[17] (One assumes North Carolina dentists exhibited similar productivity growth during that period.) Moreover, as was indicated previously, productivity increases have less impact where there is a significant dentist shortage involved. Others may point out that career/practice styles may be changing, in part by the continuing influx of women in the dental profession. Some may question why in-migration of dentists has not been separately considered in the current overview. Also not accounted for are the state's large African American, Hispanic and retired elderly populations, all of whom appear likely to be underserved and may be assumed to exhibit above-average dental needs. In short, while a formally constructed dental workforce analysis would be more illuminating, the following points appear to be a fair and robust reflection of the current dentist workforce concerns facing North Carolina.

- North Carolina ranks 47th out of 50 states in terms of the dentist-to-population ratio.
- The United States has 6.0 dentists per 10,000 persons; North Carolina has 4.1 dentists per 10,000 people. The

national ratio is close to 46% better than North Carolina's.

- North Carolina has only eight counties whose dentist-to-population ratio approaches or exceeds the national average of 6.0 per 10,000.
- 79 North Carolina counties are 'federally designated dental shortage areas'.
- The North Carolina dental hygiene workforce has expanded progressively during the past 25 years, considerably exceeding the growth rate of the North Carolina dentist supply.
- The United Sates Census Bureau projects North Carolina as the nation's fifth fastest growing state, becoming the seventh most populous state by 2030, implying significant future growth in dental service needs.

It is apparent that the North Carolina General Assembly continues to be sensitive to the public policy dimensions of the dentist workforce shortage in North Carolina. Specifically, the legislature has gone beyond its initiatives in 1998 and 2001 (encompassed in Senate Bill 861), and has appropriated $2.0 million in fiscal year 2005-2006 planning funds with the goal of rapidly and cost-effectively expanding dental school enrollment in North Carolina.

The legislature also continues to rely on the North Carolina Area Health Education Centers system to help ensure that dental student practitioners gain rural and community-based dental care experiences. These student rotations are typically focused on North Carolina rural health clinics, but also on state mental health centers, on Indian Health Service facilities, military and coast guard installations, as well as Veterans Affairs (VA) hospitals.

Aside from the powerful and appropriate influence of market forces, the size of the future dental workforce needed in North Carolina will be largely defined by two additional considerations. The first of these is that North Carolina's current position as 47th out of 50 states with respect to dentist-to-population ratios must be rectified. A preferred ranking would see North Carolina positioned around the middle of the range, say 25th out of the 50 states. The second consideration, as already shown, is the state's projected population growth, which significantly exceeds the national growth rate, and thus may push North Carolina into becoming the seventh most populous state in just 25 years. With a 2030 estimated population of 12.2 million, this alone will account for 4.2 million more people than in North Carolina's 2000 census. Essentially, the current dental workforce shortage, overlayered with a North Carolina population estimated to be 51.9% higher than in 2000, dramatizes the need for a substantially larger and responsive oral healthcare workforce.

North Carolina has considerable dental education capacity. In 2005, the state operated 12 dental hygiene programs, 11 of which are based in the Community College System. In addition, there are 15 dental assistant education programs, 14 of which are community college-based, and there is one community college-based dental technology program. The state's dental school is based at UNC-Chapel Hill, where the maximum current annual enrollment is 80 dental students. Interestingly, it would appear that all of these programs function at a sub-optimal size. A recent economics study by the American Dental Association determined that the economies of scale in university-based dental education were such that the lowest per-student costs were approached as a dental school's total enrollments entered the 800-1,300 DDSE* range.[14] The DDSE estimated for the UNC-Chapel Hill School of Dentistry at the time this paper is published is approximately 526.

This commentary on North Carolina's dentist workforce status has focused largely on the availability and distribution of general dentists, because that is where the dental care access problem is the most acute. It is recognized, however, that dental assistants, dental hygienists and dental technicians are also key members of the dental team, and all contribute to the quality and productivity of dental care services delivered. For that reason this commentary has offered a relatively brief glimpse at the growth of North Carolina's dental hygiene work force, relative to that of dentists.

In the same vein, and with respect to advanced dental education, North Carolina currently has four general dental practice residency programs, located in Charlotte, Winston-Salem, Greenville, and Chapel Hill. A fifth general dental practice residency program is being considered for the Asheville area. The University of North Carolina also trains specialists for all dental specialties recognized by the American Dental Association. At the current time, there appears to be a need in the state for more pediatric dentists, as well as for dentists trained to serve the special needs of the ever growing elderly population, a significant proportion of whom are medically compromised and/or dependent on extensive pharmaceutical regimens. Access to dental care for institutionalized seniors is marginal at best. The supply and distribution of dental specialists in North Carolina may well deserve a future workforce study.

Conclusions

This commentary has presented a basic analysis of the current dentist workforce situation in North Carolina. The assessment offered does not represent a formal, fully specified and nuanced workforce study. Taking into account this limitation, the analysis suggests that North Carolina's dentist workforce supply, while qualitatively excellent, is quantitatively insufficient, ranking North Carolina nearly last out of 50 states. Such a position is generally perceived as undesirable with respect to healthcare policy norms.

Moreover, the massive projected population growth, changing demographics, disease trends, alterations in demand for care, and potentially significant changes in dental practice styles all

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* DDSE is the DDS Undergraduate Equivalent. It is obtained by weighting each category of students by a teaching intensity factor, and summing the resultant weighted components. E.g., DDSE = (1.0 x undergraduate DDS enrollment) + (1.7 x dental specialty enrollment) + (1.7 x non-clinical graduate student enrollment) + (0.6 x allied dental enrollment) + (1.2 x non-specialty advanced dental education enrollment).

further reinforce the view that North Carolina urgently needs to develop substantially increased capacity for enrolling and graduating high-quality dentists. Committing to an enrollment increase program, together with increased community-based training experiences, would directly improve dental care access for people in North Carolina, would also contribute to greater economic development in the state, and would lead to positive distributional benefits.

Within acknowledged limitations, the current assessment of the dentist workforce status in North Carolina permits the following conclusions:

- Significant dental workforce expansion in North Carolina is justified by the existing dentist shortage, the current maldistribution of dentists, and the very strong population growth projected out to 2030 for North Carolina by the United States Census Bureau.
- In terms of dentist supply, North Carolina's goal should be to climb from its current 47th position to rank near 25th out of the 50 states with respect to the dentist-to-population ratio.
- Significant dental student enrollment expansion in North Carolina is necessary and should seek to capitalize on the acknowledged economies of scale achievable by encouraging institutions to enroll students up into the 800-1,300 DDSE range.
- Dental and dental hygiene student enrollment expansion must include additional linkages with North Carolina AHEC to help facilitate increased training capacity and to encourage dental training in appropriate rural and community settings.
- Dental and dental hygiene student enrollment expansion should make it possible to provide admission priority to academically qualified candidates from rural North Carolina.
- Expansion of general dental practice residency programs and pediatric dentistry specialty programs should be strongly encouraged.

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Editorial Note: Dr. Stamm uses figures from the North Carolina State Board of Dental Examiners, which report the numbers of dentists active as of January each year. The Issue Brief in this issue of the Journal uses figures from the NC Health Professions Data System provided by the Cecil G. Sheps Center for Health Services Research, which reports active dentists through October of each year. Because the numbers are collected and reported ten months apart, the numbers of dentists and dental hygienists reported in this commentary may differ from those in other papers in this issue of the *North Carolina Medical Journal*. These differences are not considered to have significant implications for the policy analyses or conclusions drawn from their use in any case.

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COMMENTARY

Access to Dental Care for Young Children in North Carolina:

History and Current Status of Workforce Issues

Michael W. Roberts, DDS, MScD, and William F. Vann, Jr., DMD, MS, PhD

Dental caries is considered the most prevalent childhood illness with a prevalence of over 44%, surpassing asthma (11%). Among preschool children, dental caries is considered a major health problem, and this issue has recently come under scrutiny by policy makers, physicians, investigators, and public health officials. This played a central role in the fact that the year 2000 Surgeon General's Workshop and Conference was dedicated to children's oral health issues.

The access to dental care for children in North Carolina mirrors the national picture or is worse. The circumstances in North Carolina are complicated by workforce issues as well as the fact that a substantial number of children are eligible for Medicaid or are uninsured. The purpose of this commentary is to review factors impacting access to dental care for children with a special emphasis on young, preschool children. We also review recent efforts to address the issues and point out several challenges on the horizon.

The Third National Health and Nutrition Examination Survey (1988-1991) found that nearly 80% of two-to-five-year-old children below the poverty level have experienced caries.[1,2] The United States Surgeon General's Conference in 2000 underscored the scope of the nationwide problem of access to dental care for children, especially low-income and minority families, and those with special healthcare needs. Reasons cited include the lack of dental professionals trained to see special populations and/or accepting Medicaid clients. Children lose an estimated 52 million hours a year from school due to dental pain and related care.[3]

In response to a perceived developing national workforce concern, the American Academy of Pediatric Dentistry (AAPD) formed a "Task Force on Work Force Issues" in 1998 that published a white paper summarizing its deliberations.[4] The Task Force noted that since the late 1980s, there has been a growing shortage of pediatric dentists in many geographic locations of the United States. These concerns were substantiated with data; by 1998, the number of trained pediatric dentists in private practice, public institutions, and dental education had declined to 3,600 from approximately 3,900 in 1990. The Task Force concluded that the root cause of the shortage was because the number of pediatric dentistry training positions and graduates was not adequate to offset deaths and retirements.

The dearth of training positions in the specialty was the subject of an American Dental Education Association's (ADEA) request to Congress and is described in their "Primary Care in General and Pediatric Dentistry Programs FY 2000 Appropriations Request" to increase the funds to support additional Title VII grants. This request noted that "the United States is not training enough pediatric dental healthcare providers to meet the increasing need for pediatric oral health services."[5]

While accurate projections of workforce issues in a dynamic society are difficult, Waldman[6] projected a need for an additional 3,000 pediatric dentists to meet the dental care needs of the children in the United States by the year 2020. A National Symposium of Pediatric Dental Educators and AAPD leaders examined the specialty workforce issues in 1998 and set a goal to increase training positions by ten per year from 2000-2010. To accomplish this goal, the AAPD urged existing residency programs to look for creative ways to increase their training numbers. The AAPD also focused its advocacy efforts toward increasing Title VII funding for program expansion and new program start-ups and encouraging hospitals and dental schools to apply for these grants. These efforts have been successful: the number of first-year trainee positions grew from 181 in 1997 to 278 in 2005.[7] This increase of over 30% was achieved through the establishment of seven new residency programs and wide-spread program expansion across the United States.

While national workforce data have made a dramatic swing since 1998, some concerns remain. The AAPD estimates that approximately one-third of dental care to children is provided by pediatric dentists, noting that specialists deliver a disproportion-

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ately higher amount of oral healthcare for Medicaid and medically compromised children. Currently the number of children in the United States is increasing, and the ratio of dentists-to-population is decreasing, a circumstance that has potential to further overload the demand on pediatric specialists.

Access Issues for Children in North Carolina

Improved access to dental care for children in North Carolina was the top priority of the North Carolina Academy of Pediatric Dentistry throughout the decade of the 1990s. Their efforts were focused on improving dentists' participation in Medicaid by attempting to increase procedure reimbursement rates. In 1999 the North Carolina Institute of Medicine (IOM) Task Force on Dental Care Access issued a report to the North Carolina General Assembly and to the Secretary of the North Carolina Department of Health and Human Services identifying inadequate access to dental care as being commonplace among children of families living in poverty.[8] This problem is especially notable among children birth through five years of age. Approximately 25% of all children entering kindergarten each year in North Carolina have untreated dental decay.[7,8] And, among parents who feel that their children have unmet healthcare needs, 57% report the unmet need is for dental care, a percentage almost two-times greater than that reported for medical care.[8]

Many would argue that North Carolina has a statewide dental workforce shortage, magnified by a workforce misdistribution. The fact is North Carolina ranks 47th nationally in the supply of dentists.[9] Four of its 100 counties have no dentists in practice, and 79 counties qualify as federally recognized dental professional shortage areas.[10]

> *"Currently the number of children in the United States is increasing, and the ratio of dentists-to-population is decreasing..."*

The dental access problem for young children in North Carolina is compounded by two factors; (1) low dentist participation in the Medicaid program and (2) the paucity of practicing dentists. In 1998, there were only 47 actively practicing pediatric dentists in North Carolina.

North Carolina IOM's Recommendation Aimed at the Specialist Workforce

Recommendation #13 in the North Carolina IOM Report addressed the issue of training more specialists. It recommended that the number of training positions in the pediatric dentistry residency program at the University of North Carolina at Chapel Hill (UNC-Chapel Hill) School of Dentistry be increased and also recommended that consideration be given to the establishment of additional pediatric dentistry residency programs at other sites.[8]

What about the Addition of New Residency Training Programs?

Following the publication of its report, the North Carolina IOM hosted a meeting of dental directors from East Carolina University, Wake Forest University School of Medicine and the Carolinas Healthcare System [Carolinas Medical Center (CMC)]. Wake Forest University considered initiating a program, but did not go forward. Recently CMC has expressed an intention to develop a program.

The Residency Training Program at UNC-Chapel Hill

The UNC-Chapel Hill School of Dentistry Department of Pediatric Dentistry has been the only residency program in pediatric dentistry in North Carolina since 1955. From 1955-1985, the program was 24 months in length. During this time frame, up to three students/year (a program total of six trainees) were accepted annually, depending on department resources. By 1986, the program had 66 alumni, two-thirds of whom were practicing in North Carolina.

The program length was extended to 36 months in 1986, but the class size was reduced to two residents per year (a program total of six trainees) because resources could not be stretched to support more than a total of six residents. In 1992, the program was awarded a five-year grant from the federal Maternal and Child Health Bureau and recognized as one of three Centers for Excellence in Pediatric Dentistry in the United States. Prior to this time the program never had stable funding, but was supported by a hodge-podge of creative financing mechanisms with reliance on the UNC-Chapel Hill School of Dentistry, the UNC Hospitals, and private resources, which could only sustain very low resident stipends.

The Maternal and Child Health Bureau support has served as a recruitment magnet for exceptional residents. Since 1992, many of these individuals have had the background and sophistication to support their training using a variety of governmental grants. This permitted program expansion of one additional resident per year in most years since 1992 and under this scenario, an extra 11 residents have been trained. Since the advent of the 36-month program, the retention of graduates in North Carolina has been 75%, and this does not include several who left the state for academic appointments.

In 2003, the UNC-Chapel Hill School of Dentistry Department of Pediatric Dentistry was awarded a competitive three-year non-renewable Title VII grant from the federal Heath Resources and Services Administration (HRSA), Bureau of Health Professions to increase the number of pediatric dentistry residency positions by one per year for 2003-2006. As noted previously, these grants are intended to be seed money to initiate new residency programs or increase the number or positions in existing programs.

To summarize, at present there are nine residents (three per year) in training at the UNC-Chapel Hill School of Dentistry, but this number will dwindle to six (two per year) in 2008 unless additional funding is identified and secured to sustain the increase.

Another strategy put in place at the UNC-Chapel Hill School of Dentistry has been to strongly encourage and assist their dental students to complete pediatric residency training outside North Carolina and urge them to return to the state to practice. This strategy has also seen success in the past decade.

As a result of recent cumulative efforts to increase the number of pediatric specialists practicing in the state, the number of private practitioners increased from 47 in 1998 to 92 in 2004, a 96% increase. Notably, five of the pediatric dentists are engaged in community dental clinics within health departments or in Medicaid clinics.[11] While the number of pediatric dentists practicing in North Carolina and the number being trained may be sufficient at present, there is continued concern about the aging of the pediatric workforce and the future increase in the number of children in the state. These trends could have a negative impact on access to dental care.

The North Carolina Dental Medicaid Challenge

Many factors influence the low use of dental services among North Carolina Medicaid recipients. Low dentist participation in the Medicaid program remains an issue. North Carolina has one of the lowest rates of actively participating dentists in the country. Recommendations #1, 2 and 3 of the North Carolina IOM Report addressed issues that would encourage increased dentist participation.[8]

In 2000, a class action law suit (Antrican vs. Burton) was brought by a group of parents against the North Carolina Medicaid Program alleging inadequate access to dental care for their Medicaid-covered children. Settled in 2003, this litigation resulted in reimbursement rate increases for 27 selected dental procedures. This action led to additional dentists agreeing to become Medicaid participants (see Table 1).

Unfortunately, however, the settlement did not include an inflation adjustment clause. Most experts agree that reimbursement levels should reflect the 75th percentile of market-based fees (fees equal to or grater than those of 75% of dentists in the state) to encourage dentist participation.

Although the absolute number of dentists participating in Medicaid increased 4% from 2001 to 2004, the percentage of practicing private dentists who participate in Medicaid remained constant or declined slightly over the same period (49% to 47%).[11]

What Does the Future Hold for Our State?

American Dental Association President-Elect, Robert M. Brandjord, has noted that access to care is the umbrella for the major issues facing dentistry. He stated also that the challenge to dentistry was to motivate the political will of state legislatures and Congress to properly fund access to dental care.[12] A lack of political will in our state would appear to be demonstrated in two recent illustrations:

- Acting on the recommendation of the North Carolina IOM Task Force, during the 1999 General Assembly session, Senators Howard Lee and Beverly Purdue introduced North Carolina Senate Bill 752 to appropriate funds to add three UNC-Chapel Hill School of Dentisty pediatric dentistry residents (one per year) at a sustained state funding level of $100,000 per year. This bill was not passed, and securing funding to support an increased number of training positions in pediatric dentistry at UNC-Chapel Hill remains elusive. Considering its current heavy dependency on federal support through the Maternal and Child Health Bureau

Table 1.
Number and Percentage of Private Dentists Participating in the Medicaid Program

	2001	2002	2003	2004
Total number of private dentists who practice in NC (not including public health dentists)*	3,280	3,381	3,414	3,621
Number of private dentists who "actively" treat Medicaid enrollees**	644	670	712	855
Population of North Carolina***	8,198,173	8,311,778	8,421,050	8,541,263
Number of Medicaid enrolled children under 21 years of age*	536,795	580,990	616,874	643,922
Dentist-to-Medicaid ratio	1:833	1:867	1:846	1:753

* Source: Cecil G. Sheps Center for Health Services Research. North Carolina Health Professions Data System with data derived from the North Carolina Board of Dental Examiners. Chapel Hill, NC: Cecil G. Sheps Center for Health Services Research, University of North Carolina.

** Source: Data provided by North Carolina Division of Medical Assistance. The 1999 IOM Task Force on Dental Care Access Report defined "active participation" in the Medicaid program as those dentists who received more than $10,000 in Medicaid reimbursements in a fiscal year.

*** North Carolina State Demographics online at: http: //demog.state.nc.us/

grant, the program is at high risk of being forced to reduce the number of training positions to even lower levels as federal funding sources evaporate, a prospect with a high likelihood in the future.

- Recently, the General Assembly (Session Law 2005-276) passed a budget that puts all children five years of age or younger covered by North Carolina Health Choice program into the Medicaid program effective January 1, 2006.[13] Medicaid reimbursements for dental procedures are significantly less than North Carolina Health Choice. Younger children have had the most difficulty in establishing a dental home in the past. This legislation has the potential to aggravate the access to dental care issue for affected children.

Summary

The 2000 North Carolina IOM report contained 23 recommendations. To date 16 have been fully or partially implemented. This represents progress, but accomplishing full compliance remains a goal. Absent new training programs in our state, as current federal training grants phase-out, identifying financial support to continue training an adequate number of pediatric dentists for North Carolina will be a challenge. **NCMedJ**

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COMMENTARY

Dentist Participation in Medicaid:
Key to Assuring Access for North Carolina's Most Underserved

Mahyar Mofidi, DMD, MPH

Dental care is essential to overall health.[1] Despite improvements in prevention and oral health status, millions of people still experience preventable dental disease.[1,2] There are glaring and persistent socioeconomic disparities in the distribution of oral health problems with persons from low-income families and minority backgrounds being affected to a much larger extent than their counterparts.[1,2]

Research has documented many factors, both complex and inter-related, that contribute to the persistence of oral health disparities.[1] Inadequate access to regular dental care represents a chronic, significant problem to achieving oral health.[1,2] Even though Medicaid has the potential to markedly improve access to dental care for millions of economically disadvantaged persons, this federal-state program has unfortunately not lived up to its potential. Less than one in every five children enrolled in Medicaid uses preventive services in a given year.[1,2]

> *"Less than one in every five children enrolled in Medicaid uses preventive services in a given year."*

Among the primary reasons for poor utilization of dental services by Medicaid enrollees is scarcity of available dentists.[2] Numerous studies on access to dental care have been completed, including those of dentists who consistently cite three major issues for their lack of participation in the Medicaid program: (1) inadequate reimbursement rates; (2) broken appointments and patient non-compliance; and (3) burdensome paper work associated with Medicaid.[2] Of these, insufficient reimbursement rates, which are often less than what it costs to operate a dental practice, constitute the principal reason for keeping many dentists away from treating Medicaid enrollees.[2-4] In North Carolina, the 1999 North Carolina Institute of Medicine Task Force on Dental Care Access identified a significant increase in reimbursement rates as its number one recommendation for improving access to dental care.[5] It noted that more dentists would be willing to see more Medicaid patients if reimbursement rates were increased.

Increasing Medicaid Reimbursement Rates

Over the past several years, a number of states have developed comprehensive approaches to increase dentist participation in the Medicaid program.[4] Establishing competitive, market-based reimbursement rates has been a central strategy.[4] These efforts appear to have improved both the dentist participation rate in Medicaid and access to dental care for beneficiaries.

What has the experience in North Carolina been? There have been several rate changes since 1999. These payment rates, however, are still below dentists' fees charged to non-Medicaid patients and are not consistent with a market-based approach. Nonetheless, by April 1, 2003, as a result of a dental care law suit settlement, there was a significant reimbursement rate change for many dental procedures benefiting children.[6] The majority of targeted dental services affected by the reimbursement rate change also happen to be available to the adult Medicaid recipients. These services include, but are not limited to, comprehensive exams, radiographic x-rays, fillings, and extractions. Common adult procedures, however, such as scaling and root planning (i.e., deep cleanings) and dentures were not affected by the rate change.

How have increased reimbursement rates impacted dentists' participation in the Medicaid program and, more importantly, the beneficiaries' utilization of dental services? This question is a difficult one to answer as causality sequencing cannot be established with available data. Preliminary evaluations suggest that increased rates have indeed coincided with improved participation and utilization levels.[7] Following is a brief summary of results:

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Dentists' participation

- During 2001 and 2004, there was a 33% increase in the number of dentists "actively participating" in the Medicaid program (from 644 to 855, respectively). The 1999 North Carolina Institute of Medicine Task Force defined "active participation" in the Medicaid program as those dentists who received more than $10,000 in Medicaid reimbursements in a fiscal year.
- Between 2003 and 2004, 143 new dentists began actively participating in the Medicaid program bringing the overall active dentist participation rate to 24%.

Utilization

- The percentage of Medicaid enrollees receiving dental services increased from 20% in 1998 to 27% in 2004.
- From 2001 to 2004, utilization of dental services among children jumped from 28% to 31%, while utilization among adults aged 21-64, went from 24% to 25%.
- Utilization rates for older adults aged 65 and older remained relatively stable, going from 16% in 2001 to 17% in 2004.

Challenges and Concerns Associated with Reimbursement Rates

Notwithstanding the progress in dentist participation and dental access for the enrollees, a number of challenges and concerns associated with increasing reimbursement rates must be mentioned.[7]

- Increase in access to dental care is primarily attributable to those dentists who were participating in the Medicaid program, but who began to serve more patients after the reimbursement changes. While the number of these dentists is on the rise, it is important to note that among all providers who billed for Medicaid procedures in 2004, only half can be considered as "active" providers in the Medicaid program. In addition, over the past several years, the number of all dentists participating in the Medicaid program has remained relatively flat and may be decreasing as a proportion of all dentists in the state.[7]
- Despite an increase in the dental utilization rate for children, the 31% rate for 2004 still lags below utilization levels of children in the general population. For example, children between 200% to less than 400% of the federal poverty guideline (FPG) and children equal to and greater than 400% FPG have 49.4% and 65.2% dental utilization rates, respectively.[4] In addition, among children whose families can afford private dental insurance, 55.8% were reported to have at least one dental visit during the past year.[8] A more reasonable benchmark against which to compare the progress of the North Carolina Medicaid dental program for children may be the Healthy People 2010 goal that at least 57% of children from low-income families receive a preventive dental visit each year.[9]
- There has been little change in older adults' utilization levels. In fact, dental utilization rates for older adults in the Medicaid program falls far behind those of their counterparts in the general population. In a national study, among older adults with private insurance coverage, 65% reported at least one dental visit during the past year, while among those without private dental coverage, 33.9% had at least one visit.[8]
- The reimbursement rates for certain frequently used and needed services for Medicaid-eligible adults, such as deep cleaning and dentures are low.[7] For example, Medicaid pays $78.11 for a quadrant scaling and root planning, while the standard fee at University of North Carolina at Chapel Hill (UNC-Chapel Hill) dental faculty practice for the same procedure is $196. Medicaid also pays $309 for a complete denture, whereas the fee charged by UNC-Chapel Hill is $903. Such low reimbursement rates may discourage dentists from treating Medicaid-eligible adults who, in turn, without adequate access will be vulnerable to experiencing oral health problems.
- Although the state has taken action to address reimbursement concerns, stakeholders agree that a more comprehensive approach that strives to mirror market-based fees and regularly accounts for inflation is needed.[7] States such as Alabama, Michigan, and Tennessee have established competitive Medicaid reimbursement rates to significantly improve access to dental care.[4] For example, dentists in Tennessee are reimbursed at the 75th percentile of the East South Central region's fees, as determined by the American Dental Association's Survey of Dental Fees. The 75th percentile fee level for a particular region indicates that 75% of dentists in that market are charging that amount or less for a particular service, and 25% of dentists are charging more than that amount for that particular service. States that come close to the 75th percentile fee have experienced positive outcomes. For example, the number of Medicaid-participating dentists in Tennessee increased from about 380 before the rate change to approximately 700 participating dentists after the rate change. Access to dental care rose from 24% to 47%, approaching a range that is seen in the private sector in Tennessee.

At the 2005 North Carolina Oral Health Summit, it was generally agreed that, as an ultimate goal, Medicaid rates should reflect the 75th percentile of market-based fees in North Carolina.[10] Subsequent to the Oral Health Summit, the North Carolina General Assembly appropriated $2.0 million in each year of the biennium to increase Medicaid dental rates.[10] It remains to be seen whether Medicaid payments that approximate private sector markets will result in increased dentist participation in Medicaid and increased access above and beyond current levels.

Nonfinancial Factors in Dentists' Participation in Medicaid

Raising dental reimbursement rates is necessary, though not sufficient, in getting more dentists to treat Medicaid patients. As stated, dentists cite a number of nonfinancial barriers to treating Medicaid patients. Often cited are administrative burdens, including complex provider enrollment procedures, burdensome patient eligibility processes, and prior authorization requirements. Several states have reported that administrative fixes in Medicaid operations combined with funding improvements have led to increased dentist participation.

North Carolina is illustrative. Medicaid now accepts both electronic and paper claims submissions.[11] Prompt payment mechanisms have been implemented, such that dentists are paid in 17 days and 35 days, respectively. To improve dentist participation and reduce Medicaid claim problems, the North Carolina Division of Medical Assistance (DMA) provides information and education to dental offices on how to file Medicaid claims.

A high "no-show" rate among Medicaid enrollees and patient noncompliance also explain dentists' reluctance to participate in Medicaid. These problems have often been attributed to lack of consumer awareness about the importance of oral health and lack of care coordination within the Medicaid program.[12] Two of the North Carolina Institute of Medicine Task Force's recommendations focused on these issues.[5]

No statewide action has been taken with respect to educational activities for Medicaid consumers.[6] North Carolina would be well advised to look at the oral health promotion programs of other states. In Michigan, for example, the state, collaborating with the Michigan Dental Association, developed an educational publication, *Don't Wait Until it Hurts*, to encourage enrolled beneficiaries to seek preventive dental care.[12] Other states have used a more targeted approach, focusing on populations that are at greater risk.[12] In Maine and Michigan, caregivers of children who have not had a dental visit in the previous year receive periodic reminder mailings to encourage them to schedule a dental exam for their children.

As for care coordination, case management services are needed to help some Medicaid beneficiaries access dental care services and adhere to treatment plans and oral hygiene protocols. The North Carolina DMA has pilot-tested dental care coordination models in some counties.[10] It has found that there are currently insufficient numbers of care coordinators to provide adequate dental care coordination for all Medicaid recipients. Again, our state would be well advised to learn from the experiences of other states. Medicaid agencies in some states have established innovative strategies to enhance care coordination, which include targeting preschool children in Head Start and Early Head Start programs and their families.[12] In Alabama, to improve patient attendance, a "Rights and Responsibilities" packet, which describes the patient's responsibilities and sanctions if the patient misses an appointment, has been developed for use by dentists.[12]

Among the suggestions offered at the 2005 North Carolina Oral Health Summit regarding dental care coordination, was to extend care coordination to beneficiaries with an enhanced risk for dental caries or for complications from dental disease.[10] Studies will be needed to assess whether more intense and organized assistance to beneficiaries will result in increased access to dental care.

Success in increasing dentist participation in the Medicaid program also hinges on successful outreach efforts targeting dentists.[4] Over the past several years, the North Carolina Dental Society, whose membership includes approximately 86% of private dentists in the state, has been at the forefront of encouraging private dentists to treat patients on Medicaid.[7] Through newsletters and statewide and regional meetings, the Dental Society has been actively promoting changes, financial (e.g., rate changes) and administrative (e.g., enhanced claim filing systems), which have been implemented within the Medicaid dental program.[7] In a joint effort with the DMA, a Frequently Asked Questions (FAQ) document, which addresses common provider questions and concerns, was developed and subsequently promoted within the membership. Similarly, seminars and workshops have been conducted not only to respond to provider inquiries and address misconceptions about Medicaid, but also to share the positive relationship that exists between the Dental Society and DMA. These and other outreach activities need to continue in an effort to increase dentist participation in Medicaid and improve access to dental care.

Provider Attitudes and Behaviors

An important aspect of dental care access, which has received little attention, is the reportedly negative attitudes and behaviors of some dentists and their staff toward patients who are insured by Medicaid.[13] Stigma associated with those on a public assistance program may keep some dentists away from treating Medicaid clients. It is not known if these dentists would see Medicaid patients even after addressing the financial and nonfinancial factors presented above.

In a North Carolina study, a diverse group of Medicaid beneficiaries explained that, after negotiating one barrier after another (e.g., finding a provider, obtaining convenient appointment times, securing transportation, etc.) to get a dental appointment, they faced what they perceived as judgmental, disrespectful, and discriminatory attitudes and behaviors from dentists and their staff because of either their race and/or public assistance status.[13] For some beneficiaries, such perceived treatment discouraged their efforts to pursue dental care. Quality patient care requires that health professionals be aware of and respond to individual differences among patients, evaluate information about them in an objective, unbiased manner, and develop relationships that promote open and trusting communication. The current proposals aimed at improving access to dental care for Medicaid enrollees (e.g., increased reimbursements, patient education) fall short of addressing the more vexing obstacles to dental care that beneficiaries face. Thus, strategies to improve dental care access for Medicaid enrollees should also focus on cultivation among dentists of more "patient-centered care" that is culturally respectful and responsive to patients' values and needs.

North Carolina Health Choice for Children

In October 1998, North Carolina implemented its State Children's Health Insurance Program (SCHIP), entitled North Carolina Health Choice for Children (NCHC). NCHC offers healthcare coverage to uninsured children who come from working families with incomes that are too high to qualify for Medicaid, but too low to afford private insurance. NCHC provides comprehensive health insurance coverage, including dental, vision, and hearing services. A major feature of NCHC has been reimbursing dentists generally at 90 to 95% of usual, customary, and reasonable fees.[14]

NCHC has greatly improved access to dental care.[14,15] These children have experienced much better access to dental care when compared to children enrolled in Medicaid. Evidence shows that participation in NCHC is associated not only with increased dental utilization and regular dental care, but also reduced unmet dental needs. Improvement in access to dental services for low-income children in North Carolina is consistent with the results that other states have witnessed under SCHIP.[16] The success of state SCHIP programs in increasing access to dental care has been attributed to a variety of factors. Central among these has been paying dentists' fees close or equal to their usual private practice charges.

Despite these reported gains, because of budgetary constraints, the North Carolina General Assembly has recently enacted legislation to transfer coverage of children aged birth to five from NCHC to Medicaid.[10] The General Assembly also passed legislation to reduce all of the NCHC provider payments from the current reimbursement rates to the Medicaid rates for children aged 6-18 by July 1, 2006.[10]

Such actions prompt a number of questions and concerns. For example, how will the new changes impact access to dental care for the affected children? What type of effect will these changes have on dentists? Will affected children lose their usual source of dental care? It would seem that an important first step toward ensuring that low-income children have access to dental care is for the state to adopt the kind of Medicaid fees that will attract sufficient numbers of providers. Without such a commitment, we may well lose the important gains made by NCHC toward reducing the dental access gap for low-income children.

Conclusion

Issues surrounding participation of dentists in the Medicaid program are complex. Accordingly, increasing such participation requires a multifaceted strategy. Stakeholders in North Carolina have taken significant steps toward improving dentist participation in Medicaid. Notable among these has been a consistent increase in Medicaid reimbursement rates, which has been associated with improved participation and access to dental care. But, challenges remain with respect to attracting more dentists. Adequately addressing these and other challenges should significantly improve access to dental care for underserved populations and reduce oral health disparities. **NCMedJ**

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COMMENTARY

Special Care Dentistry Delivers a Formula for Change:
A Model Has Been Developed but Must Be Implemented Statewide

William E. Milner, DDS, MPH

The Reality of Now

Not-so-pretty scenarios are being played out daily in our communities:

- The benefit of a lifetime of dental care rapidly disappears for patients who cannot access a local dentist's office. Longtime dental patients are frequently turned away from practices because of complicating medical conditions, limited mobility, or change in financial status. Lack of on-site care in skilled nursing facilities, group homes, or home health programs forces them to receive only emergency care at best. A lifelong routine of regular checkups and preventive and restorative care is forced to come to an end.
- Unable to clean their own mouths, these compromised residents depend on the facilities or home caretakers for daily preventive care. Almost universally, caretakers shy away from cleaning mouths; they will take care of every other part of the body, but avoid the mouth out of fear that they will hurt the resident or that they will be bitten. What results is a filthy mouth with rapidly progressing root decay and gum disease. It gets worse for the typical dementia, head trauma, or non-communicative stroke patient who cannot say he or she hurts.
- After a few months of little or no oral healthcare, residents are in a constant state of oral infection, a dangerous condition with spin-off effects. Oral bacteria and debris can be aspirated into the lungs, which causes aspiration pneumonia and necessitates costly treatment and trips to the hospital. Diabetics have trouble controlling their disease because of this constant source of infection. Oral bacteria can also enter the blood stream, landing on heart valves and causing infection.
- Families are frustrated with the lack of availability of basic dental care. Caretakers are willing to drive anywhere for help, but help doesn't exist. Those with autism, cerebral palsy, muscular dystrophy, and a dizzying variety of syndromes are left without the hope of care.

Talk to a facility director of nursing, a health coordinator for group homes, or any family member providing care for a home health patient, and you will hear the same scenarios confirmed. Fragile, disabled, dependent North Carolinians deserve better. Luckily a solution is at hand. North Carolina has a tested and proven model of care, the established networks to create a statewide system, and the political will to provide quality, consistent care to its most vulnerable populations.

Four major areas must be considered from a public policy perspective to change this situation.

Table 1.
North Carolina's Rapidly Growing Senior Population

NC ranks 10th among states in the number of persons age 65+.
By 2020, the population 65+ will have grown 71% from the 2000 baseline.
By 2030, there will be 2.2 million 65+ (17.8% of the population).
In 2000, 219,068 persons with disabilities received Medicaid.
Total Nursing Home Residents – 47,336 in over 400 facilities.
Total Group Home Residents (mental/physical disabilities) – 4,520.
Total Home Based Residents (mental/physical disabilities) – 5,364.

A Different Dental Practice and a Provider with a Mission

A new type of dental practice is emerging because of the huge growth in numbers of the older population. To accommodate this demographic and health status shift in the population, the North Carolina Dental Society has initiated a new service area—Special Care Dentistry.

What is it? Special Care Dentistry serves those living in nursing homes, assisted living facilities, group homes, or the community at-large—patients who have intellectual and/or physical disabilities and are medically compromised. There are a few special care practices in the state. This infant area of expertise needs the support of North Carolina's dental care proponents and special care interest organizations in order to expand to serve the state's entire special care population.

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There are two major similarities between a traditional dental practice and a practice dedicated to special care.

- The treatment philosophy is the same. No matter what the disability, all patients deserve the same quality of care that any of us within the community receives.
- The other similarity involves how care is provided. Special Care Dentistry involves the complete dental team—dentist, dental hygienist, dental assistant, and office support staff.

But to be successful, the practice of Special Care Dentistry, whether on a full-time or part-time basis, requires a completely different practice organization.

- For instance, it requires an expanded practice location. Although Special Care Dentistry can be delivered in the fixed-office setting, most special care patients either cannot be easily moved to an office or exhibit behaviors that cannot be managed in a waiting room. Because of this, most patient care takes place at a facility, community center, or in the hospital operating room. Local private practitioners working in a limited number of facilities can provide emergency care and some clinical services, but they cannot provide comprehensive services for the entire special care community.
- It requires different equipment. Equipment needs to be mobile because it needs to go into a variety of settings, such as a long-term care facility, community center, or home. Residents who are sick or who have trache tubes or cumbersome geri-chairs cannot be transported outside to a "Winnebago style" van for care, especially in the middle of winter.
- It requires different reimbursement rates. Because 80% of special care patients depend on Medicaid to pay for their dental care, and Medicaid reimburses at approximately 62% of cost, a special care practice cannot serve the entire community with comprehensive, quality care, and be fiscally sustainable based solely on fee-for-service reimbursement.
- It requires a different legal structure. The most workable structure to emerge is the nonprofit practice. Nonprofit status allows the funding of start-up costs through grants and provides tax deductibility for contributions that help offset the cost of providing care to most patients at Medicaid rates.

Beyond the changes in practice organization and reimbursement, it requires a provider with a specific set of dental and interpersonal skills.

- It requires a different mindset. Direct patient care for special care patients requires more time per patient. It requires special training, flexibility, creativity, and a dedication to serve these difficult patients. In addition, this type of practice is more physically demanding than the traditional practice, both because of moving portable equipment into and out of facilities on a daily basis and treating patients who may be combative.
- It requires extensive communication about care because more individuals are involved in treating or approving treatment plans for the patient. The dental provider in a nursing home works with facility and hospital administrators, physicians, directors of nursing, charge nurses, social workers, other ancillary providers, a variety of responsible parties, those responsible for the daily oral hygiene of the patient, state facility surveyors, and the patient. Communication with these team members adds extra time to the process.
- It requires attention to detail. The nursing home chart is huge compared to the typical dental chart. Twenty percent of special care patients require conscious sedation for treatment. Conscious sedation monitoring by nurses and the dental team greatly extends treatment time. The long list of drugs these patients are taking requires a specialized knowledge of pharmacology. Treatment forms include a variety of permission requirements for guardian, power of attorney, and healthcare power of attorney.

Formula for Change: Expand the Number of Comprehensive, On-Site Programs

Making excuses for intermittent, less than comprehensive care is unacceptable and degrading to special care patients. To serve the special needs populations, dentistry must expand the recruitment efforts and the number of training opportunities for special care dental providers who will serve all patients, no matter their reimbursement source, location, type of dental care needed, or disability.

The nonprofit practice is the most workable model to date. It is a model that can be expanded to accept special needs patient referrals from local practitioners; serve the rapid influx of retirees to North Carolina; relieve the gap in service to those deinstitutionalized by North Carolina's mental health hospital system; and support special care patients, families, local healthcare providers, and organizations representing the special needs patients.

Access Dental Care mobile equipment and truck.

Changes Require a New Breed of Community Practitioner

The growth of this special needs population requires a dental team with special training. Until recently, the few practitioners providing comprehensive special care worked at the University of North Carolina at Chapel Hill (UNC-Chapel Hill) School of Dentistry, in a limited number of hospital dentistry programs, in the state mental retardation hospital system, or in a local private pediatric practice. A few private practice dentists go to a limited number of nursing facilities on their "day off;" most work with few dental staff and carry basic portable equipment. Unfortunately, none of these is sufficient for today's special care dental treatment needs.

Special Care Dental Programs

North Carolina's Special Care Dentistry programs emerged in the late 1990s and have created a sample framework for a statewide system.

- In the mid-1980s, The North Carolina Dental Society created a special care committee to address the treatment needs of patients and education needs of providers.
- In 1997, this committee supported the development of Carolinas Mobile Dentistry (CMD) at Carolinas HealthCare System, Charlotte. It began service to nursing homes in the Charlotte area. CMD covers 1,800 beds.
- In 2000, the North Carolina Dental Society initiated Access Dental Care. This Greensboro non-profit assisted Wake Forest University Baptist Medical Center (WFUBMC) in creating their Special Needs/Portable Dentistry program in 2002. It also teamed with Healthy Cabarrus, Kannapolis to start a branch of Access Dental Care in a four-county region around Concord/ Kannapolis. Access Dental Care has now absorbed the WFUBMC program to serve 4,000 beds and plans an expansion of service to the Triangle region.
- By 2006, the Carolinas Mobile Dentistry and Access Dental Care programs will cover over 7,000 beds.

Table 2.
Access Dental Care Five-Year Summary

Totals from August, 2000 – July, 2005*
Clinical
• 3702 Total Patients in the Practice
• 19,505 Total Patient Visits
• 32,116 Patient Services Provided
Financial
• $2,815,966 billed with an average gross of $98 per patient.
• $1,908,824 paid to date
• Over $903,000 in uncompensated care provided. This amounts to almost two years of net revenue. (80% of our patients are Medicaid beneficiaries)
• 162 Operating Room Patients (MR/DD patients-Medicaid) with an average gross of $1350 per patient.

*Figures do not include the newly acquired WFUMBC program.

The UNC-Chapel Hill School of Dentistry is, first and foremost, a teaching center, not an access to care facility. Its staff's expertise has made it the default special care referral source over the years for local practitioners. The special care population has grown so rapidly and is so difficult to transport that the school cannot continue to provide statewide access to care. To complicate matters, the School of Dentistry has experienced decreases in public funding, limiting its ability to start new teaching programs targeting special care populations. This means that neither dental school students nor faculty members have the opportunity to learn how to treat special needs populations in the community setting. If dental students are not introduced early in the education process to delivering care in community on-site programs, we lose the opportunity to put future practitioners into the special care professional pipeline.

State mental hospital dental staff experience on-the-job training because they handle North Carolina's toughest cognitively disabled patients daily. But, a few years ago, North Carolina decided to initiate a program of de-institutionalization, placing many of these severely and profoundly handicapped residents back into community group homes. Now group home programs are desperately seeking local dental care for these residents, arguably the most difficult to treat in dentistry. Communities without special care providers have no resources to call on.

Some larger hospitals have dentists on staff and/or graduate training programs that care for special care residents, primarily in the operating room setting. These dental teams are also responsible for in-house physician referrals, preparing patients for surgery, and providing oral care to support cancer therapy. To this point, they are at capacity providing in-house care and have not been able to expand to on-site community programs.

There are some dentists providing limited care to long-term care residents. Because of the extreme shortage of comprehensive special care programs, facilities contract with these providers knowing that many of their residents will not get the care they need. Mass examinations are followed by some extractions and denture work. Treatment plans for the remaining residents are provided, and the facility is required to find a dentist willing to provide care. This is a dead-end referral because most local dentists are not trained to deal with these patients.

Some local dentists will continue to treat some special care patients. Pediatric dentists still care for children with disabilities, but their practice volumes have forced them to restrict the number of older special care patients they see. General practitioners have an important role in caring for early dementia patients and the manageable chronically ill.

Formula for Change: Special Care Professional Education

A new model of care requires a new program of education for dental providers. At this point, North Carolina does not have a program that trains special care providers. Short student rotations and courses at the UNC-Chapel Hill School of Dentistry provide exposure to the special care patient, but do not provide the formal training necessary to enter an active practice. A post-graduate residency would allow dentists and hygienists to gain across-the-board dental skills provided in fixed, mobile, and hospital settings. Education for current local practitioners interested in Special Care Dentistry can be supplied by mini-residencies, regular continuing education, and on-site practical experiences.

Residents and their families are asking legitimate questions about the lack of daily oral care. Facility administrators and directors of nursing must finally make oral health and daily oral hygiene a priority. When this happens, special care dental staff can train the facilities' admitting nurses and education coordinators, who can, in turn, maintain a consistent teaching and monitoring process of direct care staff. Charge nurses and nursing aides must understand the ramifications of not providing daily oral hygiene and be held accountable. Failure to do this will, at some time in the future, put the facility at risk (e.g., families will take legal action).

There are a few existing education programs that need to continue. North Carolina Division of Facility Services surveyors, those in charge of ensuring that federal and state Medicaid funds are spent wisely, receive regular training. This training should to be expanded to include other long-term care advocacy groups. Future facility administrators are provided oral health programming information during the North Carolina School of Public Health Administrator in Training course. Every future administrator knows what a comprehensive dental program looks like. University interdisciplinary training should continue giving various future healthcare providers an understanding of oral health issues.

Funding that Matches the Practice

As it is currently structured, Medicaid reimbursement does not address the unique practice nature of special care dental services. Many services required by these patients are not even deemed eligible for reimbursement. Right now, 75-80% of skilled nursing home residents and almost all group home residents depend on Medicaid to reimburse their medical and dental providers.

To correct this inequity and to draw more practitioners into special care practice, higher reimbursement rates must be implemented, taking the following factors into account for special care patients.

- Special care patients take longer to treat. Their behavior must be handled before their dental needs can be treated. All of this requires working with the gamut of care givers and responsible parties. This takes more time that is not reimbursed and allows fewer patients to be treated in a day. (Access Dental Care currently averages 15 patients per day) For example, the autistic patient requires a special treatment regime and environment. It takes many appointments to gain the patient's trust, none of which are reimbursable. The treatment setting must be quiet, consistent, and supportive of parents.
- Patients with special care needs require more expertise to treat. Each new employee, dentist, or auxiliary must spend six months to one year learning to care for these individuals. None of this training experience is reimbursable to organizations.
- On-site programs require travel time and expenses, none of which is reimbursed. Access Dental Care fuel costs have doubled in the past five years. Each team spends approximately two hours each day going to a facility, setting up the dental equipment, breaking down the dental equipment, and returning to the administrative office.
- Communication with responsible parties takes time and is not reimbursed.

Public funding of dental services for the truly needy and vulnerable populations continues to be a problem. Historically dentistry has received 1-2% of total Medicaid funding, and now, in North Carolina, Dental Medicaid rates reimburse at 62 cents on the 2001 dollar. A lawsuit several years ago increased Medicaid rates by 12%, but inflation has now neutralized these gains with no sign of significant increases in the future. Although the overall population is increasing dramatically, the relative numbers of the special needs population are small, and what might seem to be a large increase in reimbursement rates would actually result in a relatively small increase in overall expenditures.

Formula for Change: Innovative Funding of Special Care Dentistry

Existing special care programs have been created through "grassroots" community efforts, with initial funding from grant support. Generous seed money from several North Carolina foundations is the reason for Special Care Dentistry's successful programming to date. Medicaid's inclusion of adult services has given providers the chance to deliver comprehensive care. There is ample financial data to craft an expanded list of reimbursable services for Special Care Dentistry. It should include funding for education priorities, public policy initiatives, program development, and fair fee-for-service reimbursement.

Public Policy Initiatives

Starting a new field of service delivery involves creating a new structure of practice. Old rules must be reviewed, present practices changed to improve service, and future programs created to deal with a changing population. Special care providers are currently treating patients five to six days a week plus trying to develop awareness of special needs in education, research, local program building, and public policy development. It is an overwhelming task. This core of individuals has the expertise to manage this change process, but they need the time. Unfortunately, the present organizations operate on such a thin profit margin, any time spent not treating patients puts them at financial risk. The following action areas need to be implemented.

- Provide support for long-term care provider organizations to establish consistent, quality Special Care Dentistry services.
- Work with communities wanting their own special care dental program. Several North Carolina communities are requesting help, but there is no time available to help them develop a program.
- Create health services research projects that support the development of community programs and ensure the quality of care provided.
- Review North Carolina's existing dental practice laws to allow for the more efficient practice of Special Care Dentistry.

Formula for Change: A Special Care Dentistry Center

Fund a North Carolina Special Care Dentistry Center to coordinate the activities mentioned in this commentary. A part-time dentist, a hygienist, and an office assistant can bring together the necessary parties to do the job right. Funding must be sustainable, giving this group the chance to work on the necessary issues and not spend all their time raising money.

Our Next Step

Many North Carolina foundations, the North Carolina Dental Society, long-term care organizations, individual nursing/group homes, and responsible parties of the mentally and physically disabled have "put their money where their mouths are." North Carolina's long-term care organizations understand the need for change and are asking special care dental providers what they can do to help create a statewide system. Dentistry has developed a successful model for providing care, but now needs the support of other organizations that will benefit from these changes. It is time to agree on a workable business/policy plan and make sure that specific changes are made. North Carolina's future long-term care residents deserve a better quality of life—one that puts the mouth back into the body. **NCMedJ**

For More Information:

To learn more about Access Dental Care and Carolinas Mobile Dentistry, visit their Web pages.

Access Dental Care
www.accessdentalcare.org

Carolinas Mobile Dentistry
www.carolinas.org/services/seniorcare/mobiledentistry.cfm

COMMENTARY

Public Health Dentistry and Dental Education Services:
Meeting the Needs of the Underserved through Community and School-Based Programs

Rebecca S. King, DDS, MPH

One essential role of public health is to reduce the prevalence of disease in populations through proven preventive measures, thereby reducing the need for treatment services. The ongoing problems of the lack of access to quality oral healthcare, along with the difficulty of establishing a "dental home" for all North Carolina citizens, and especially for its children, continues to challenge dental care provider resources in North Carolina. Dentists in private practice deliver the majority of direct patient care services to all segments of the population. However, an increasing amount of care is now being rendered by numerous public health safety net dental clinics. Collaborations of publicly and privately-funded services have directed resources to augment the care provided by dentists in private practice. The collaborations are various combinations of state, local, and federal levels of government, non-profit agencies, faith-based community organizations, and volunteer efforts by concerned citizens. The result is that disadvantaged citizens who previously could not access a dental care provider can now more easily receive dental treatment and preventive services.

Perhaps the overarching description of the efforts of all dental public health and safety net providers is stated in the North Carolina Oral Health Section's mission "to promote conditions in which all North Carolinians can achieve oral health as part of overall health."[1]

With a focus on the three principles of public health—assessment, policy development, and assurance—the North Carolina Oral Health Section and other dental public health agencies have developed strategies to address both the *supply* of available care and the *need* and *demand* for care. Efforts concentrate on:

- Oral health monitoring—assessment and surveillance of treatment and need,
- Dental disease prevention—policy development to reduce need,
- Dental health education and health promotion—assurance to reduce need while increasing demand, and
- Access to dental care—assurance to increase supply.

State Level Strategies: North Carolina Oral Health Section

The North Carolina Oral Health Section is the only public program in the nation that provides statewide dental health prevention and education services specifically for children. The Oral Health Section is in the Division of Public Health, Department of Health and Human Services. Its function is mandated by the North Carolina General Assembly under the statutory authority of G.S. 130A-366, with services delivered at the county level. The majority of staff is funded by 77% state appropriations and 23% Federal Financial Participation. In addition, one county funds four public health dental hygienist positions with county and Smart Start funds, and one county funds a hygienist position with Maternal and Child Health Block Grant funds.

> *"The youngest North Carolina children at risk for tooth decay lack access to preventive oral care, as well as to dental treatment services."*

Too many citizens, particularly children, experience preventable oral diseases. Prevention is the key to improved oral health. No matter how many treatment resources are established in the state, the treatment of dental disease cannot solve the problem.

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The vision is for North Carolina children to be cavity-free forever. The goal of the North Carolina Oral Health Section is to *prevent* dental disease, especially in children. To achieve this goal, the Section's programs are organized into five broad components: (1) Dental Disease Prevention Services, (2) Oral Health Monitoring Systems, (3) Dental Health Education/Health Promotion, (4) Access to Dental Care, and (5) Dental Public Health Residency Program. Section services are based on best practices as defined by the Centers for Disease Control and Prevention (CDC). Because of the limited number of staff, the Section primarily serves elementary school children, in order to have the greatest and longest-lasting impact. Since the 'patient' of dental public health is the community, the majority of the programs are geared toward the general public, including healthcare providers, with specific activities targeted to high-risk elementary and preschool school children. Eighty-three percent of the Section's staff—54 public health dental hygienists and two public health dentists—reside in the counties they serve and provide direct services in cooperation with local health departments. The Section serves over 288,000 children annually.

Programmatic Components of the North Carolina Oral Health Section

Dental Disease Prevention Services

The citizens of North Carolina continue to suffer from several oral diseases, including tooth decay, periodontal disease, and oral cancer. Tooth decay is the most prevalent childhood disease with more than 60% of North Carolina's schoolchildren still experiencing this disease. Several Section activities focus on decay prevention through the use of fluorides and protective dental sealants.

Community water fluoridation. Fluoridation of community water supplies continues to be the most effective evidence-based strategy for preventing dental decay. The CDC promotes community fluoridation as one of the two most effective public health measures to reduce dental decay, the other being school-based dental sealant programs. CDC's Water Fluoridation Reporting System (WFRS) database shows that 85% of North Carolina citizens served by municipal water supplies now receive fluoridated water. The Section provides technical assistance and uses federal Preventive Health and Health Services Block Grant funds to provide financial assistance to water systems wanting to fluoridate or to update older fluoridated water systems. These Block Grant funds have been reduced significantly over the last few years and are currently at risk for elimination by Congress. If that happens, other resources will have to be identified to support fluoridation and other proven dental preventive efforts.

The water systems that are not currently fluoridated are small and/or have structural or logistical problems that make it difficult to fluoridate. Systems that fluoridate often require hiring a water plant operator with a higher level certification than would be required if the system did not fluoridate. The higher level certification commands a higher salary, which is a burden on a small system. If their water comes from multiple sites, these systems can require additional fluoridation equipment, placing an additional financial burden on a small system. Each site of the water systems that add fluoride must be checked at least daily. For example, a water system with six well heads, each requiring its own fluoridation equipment, must have a properly certified operator check each injection point daily. Most future growth in the proportion of the population served by community water fluoridation will be in response to (1) increased population in the fluoridated areas as the state becomes more urban, (2) fluoridated water systems extending into rural areas, and (3) small water systems merging with larger fluoridated systems.

Into the Mouths of Babes (IMB). The youngest North Carolina children at risk for tooth decay lack access to preventive oral care, as well as to dental treatment services. Except for that provided by the relatively few pediatric dentists in North Carolina, dental care for this group is practically nonexistent. A partnership of six North Carolina agencies addressed the issue by developing a medical model for the provision of preventive dental services to Medicaid-covered children under age three. This model, called *Into the Mouths of Babes*, trains physicians and other medical providers to perform an oral screening and refer children for dental treatment if necessary, counsel parents on taking care of their child's teeth, and apply fluoride varnish. Medicaid reimburses the medical provider for these preventive oral procedures up to six times per child before the third birthday.

IMB is part of the Section and continues to partner with the North Carolina Division of Medical Assistance (Medicaid), the North Carolina Pediatric Society, the North Carolina Academy of Family Physicians, and the University of North Carolina at Chapel Hill Schools of Dentistry and Public Health. Representatives from each of these agencies form the IMB Advisory Committee, which partners with the North Carolina Dental Society. IMB trainings occur through collaboration among the Oral Health Section trainer, the North Carolina Academy of Family Physicians, and North Carolina Pediatric Society.

As of June 2005, approximately 400 physician offices, residency programs, and health departments were providing the IMB preventive oral procedures, with approximately 40% of Medicaid-eligible children receiving the services. Section staff are working with Early Head Start to develop new training materials for teachers and educational materials for parents to emphasize the importance of preventing disease in the primary teeth and to seek early dental preventive services.

Because North Carolina data show that dental decay is on the increase in the preschool population, the Section is examining ways to effectively address the dental needs of this vulnerable group of children. Medicaid requires at least 90 days between IMB oral preventive procedures. Eliminating this requirement would allow more scheduling flexibility. In addition, children qualify for the oral preventive services only up to their third birthday. Extending the eligibility to allow children to receive the procedure at the three-year well-child checkup would increase the opportunity to receive all six encounters, resulting in an increased preventive benefit.

Preliminary North Carolina data analysis shows that children having four, five, or six of these fluoride varnish procedures before their third birthday need less treatment for tooth decay. The analysis shows a dose-related response, with some benefit seen even in children having fewer encounters. The proportion of children with repeat visits for IMB oral preventive services has increased, and we hope to see this trend continue. The dissemination of the data demonstrating the effectiveness of these early preventive procedures should encourage more physicians to participate in IMB and more parents of high-risk children to request these services.

Dental Sealant Initiative. The expanded use of protective dental sealants has great potential for reducing the rate of tooth decay, especially in areas of the teeth not as affected by fluorides. The CDC recommends school-based dental sealant programs as one of the two most effective public health measures to reduce dental decay. The Section's sealant initiative has two parts:

- School-based sealant projects are targeted to children in the elementary school setting. The projects are conducted by teams of the Section's public health dentists and dental hygienists, who set up a temporary "Dental Office" in the school. Patient examinations and treatment plans are provided for eligible children by the dentists and public health dental hygienists place sealants for these at-risk children at no cost to the participants.

  This model received a recent boost by one of the recommendations of the 1999 North Carolina Institute of Medicine Task Force on Dental Care Access.[2] The recommendation led to a change in the North Carolina Dental Practice Act,[3] which now allows public health dental hygienists, trained by the Section, to place dental sealants when the public health dentist, who is providing the legally required direction of this activity, is not on-site during the sealant project. Approximately 15,000 sealants are provided annually for children at high risk for tooth decay. While the projects deliver direct preventive services to children who are at high risk for decay, they are also designed to educate children, parents, and others in the community about the need for sealants and to encourage them to ask their private dentists about sealants.
- Sealant promotions that occur in offices of private dentists are a public/private partnership where privately practicing dentists use their facilities to place sealants for eligible children at no cost. Another public/private partnership model uses a private office facility or other site, such as a community college dental clinic, where sealants are placed by both private and public health practitioners working side by side.

Such sealant initiatives illustrate the Section's focus on prevention, coupled with dental health education/promotion and services.

Oral Health Monitoring Systems

The Oral Health Section has always used evidence-based monitoring systems to guide programmatic strategies.

Statewide Oral Epidemiological Surveys. North Carolina is the only state with a series of statewide oral epidemiological surveys dating back to the early 1960s. The Section conducts these surveys about every ten-to-15 years. The most recent survey was conducted in 2003-2004. These surveys assess the oral health needs of the citizens of the state, and the data are used to plan and evaluate the state's dental public health program. They also evaluate the effectiveness of specific public health efforts, such as community fluoridation, dental sealants, and fluoride mouthrinse.

Dental Health Assessment. State dental public health professionals assess more than 134,000 elementary school children each year for oral disease. Their calibrated assessment is useful for identifying and referring those children who need dental care, as well as conducting disease surveillance and tracking disease patterns. This surveillance technique is used annually for kindergarten and fifth grade children in North Carolina. Children who are in need of dental care are identified and, with the help of school nurses, are referred to local providers. The assessment collects data on cavities, past restorative treatment, and sealant prevalence. The collected data allow for the evaluation of goals established as part of overall community health-based objectives.

Dental Health Education/Health Promotion

Statewide school-based education programs include classroom education, videos and other audiovisual tools, educational materials, and interactive exhibits. Portable educational/promotional dental exhibits, educational videos and slides, and media promotion campaigns are used statewide.

Education for professionals includes programs, educational information and materials, and in-service training for teachers and allied health professionals. Other training and instructional materials are provided to healthcare professionals through local organizations, the university system and dental and medical publications. A comprehensive dental health curriculum, *Framework for Dental Health Education*, and innovative on-line educational materials are available to elementary school teachers.

Children's Services. In 2004-2005, almost 151,000 children were provided instruction on topics, such as dental care, sealants, nutrition, oral conditions, fluoride, plaque control, tobacco use, and injury prevention. Section field staff also emphasize teacher training and support so that classroom instruction on dental health will be an ongoing process during the school year.

Adult Services. More than 13,000 adults are provided educational services each year in keeping with the Section's emphasis on preventive dental education and promotion to parents and teachers.

Professional Services. Section staff provide a number of services to health professionals. These services include educational/informational programs for local and state healthcare professional meetings and state and local dental societies, training programs for health department staff and other health professionals, and consultation with healthcare professionals across the state and nation. Section staff work with dental programs in community colleges as part of their public health curriculum. The Section mentors students and residents from the University of North Carolina at Chapel Hill Schools of Public Health and Dentistry.

Consultation Services. Educational consultation is provided by the health educators, upon request, to dental public health staff in addition to teachers and other healthcare providers.

Educational Materials. Approximately 500,000 pieces of educational materials are printed and distributed statewide each year, primarily to schools and health departments.

Educational Exhibits. Almost 5,000 people annually attend and receive information through point-of-contact dental health education exhibits used in various sites. With 11 different topics, the exhibits are used by individuals including Section staff, county staff, Department of Health and Human Services employees, community college staff, and related healthcare professionals.

Access to Dental Care

Access to dental care includes two aspects. These are (1) referral and follow-up for those persons in need of dental care and (2) improved access by the indigent population to dental care funded by third-party reimbursement. One measure of access to dental care in a population is the level of untreated dental cavities. According to the 2003-2004 North Carolina School Oral Health Survey, 19% of white, 30% of black and 38% of other (predominantly Hispanic) North Carolina children had untreated dental cavities. The Section's 2004-2005 kindergarten and fifth grade (K-5) statewide assessment data indicate that 22% of kindergarten children have untreated cavities in primary (baby) teeth, and 5% of fifth grade children have untreated cavities in permanent teeth.

In 2004-2005, almost 8,600 children received needed dental care as a result of follow-up by Section staff. Lack of access to appropriate dental prevention and treatment for the medically indigent is a major and worsening problem. Current access obstacles need to be reduced to improve participation from the private sector. Participation in Medicaid by privately practicing dentists has improved somewhat in the last few years as reimbursement has been increased, and paperwork has been streamlined.

The IMB program has increased access to oral preventive services and referrals for dental treatment for North Carolina's very youngest children. North Carolina 2003 Medicaid data show an eight-fold increase in the number of Medicaid-covered children under age three who received oral preventive services in a *medical* (i.e., physician's) office, with many referred for dental treatment.

The Section's successful collaboration with the North Carolina Dental Society continues with the North Carolina Dental Society-sponsored *Give Kids a Smile!* program. Statewide, dentists participate in and open their private offices to at-risk children for restorative care and sealant delivery. The 2005 *Give Kids a Smile!* Program provided 10,887 sealants for children. A variety of restorative services were provided, including 1,556 fillings. The approximate value of all of the services provided for the children was $1,170,000. The total number of patients treated was 4,832. Approximately 3,000 volunteers gave their time to provide these needed services. Collaborative projects enable public and private partners to work together to have an impact on access to dental care.

The American Academy of Periodontology states that periodontal (gum) disease is a risk factor for preterm and low birth weight babies. Medicaid pays for dental treatment for eligible pregnant women. However, many dental practitioners are reluctant to treat pregnant women. As part of professional education, the Oral Health Section needs to work more closely with the North Carolina Dental Society, UNC-Chapel Hill School of Dentistry, UNC-Chapel Hill School of Public Health, and North Carolina Area Health Education Centers to educate dental practitioners about the importance of addressing the oral health needs of pregnant women. These efforts would help expectant mothers decrease their risk of having low birth weight babies and reduce the transmission of decay-causing bacteria to their newborns.

In 1998, the North Carolina General Assembly charged the North Carolina Department of Health and Human Services to evaluate and recommend strategies to improve access to dental care for the Medicaid population and to improve the Medicaid program's provision of preventive services for their clients. The Secretary of the Department of Health and Human Services asked the North Carolina Institute of Medicine to convene a group to make recommendations to be reported back to the Legislature in April 1999. The resulting 23 recommendations have been reviewed every two years to document progress. The most recent review occurred in an Access to Dental Care Summit sponsored by the Section in April 2005. The Summit gathered community and dental care leaders to discuss potential strategies for improving dental care access, whether by further implementation of the original 1999 recommendations or through new strategies to improve access. The Summit report was published by the North Carolina Institute of Medicine in December 2005 as the "2005 NC Oral Health Summit Proceedings and Proposed Action Plan." If implemented, the updated action plan will help ensure access to dental care for more underserved North Carolinians across the state.

Dental Public Health Residency

The purpose of the North Carolina Dental Public Health Residency program is to allow dental practitioners with formal academic dental public health training, such as a Master's in Public Health (MPH), to gain valuable practical experience in the field of dental public health and to prepare candidates to become board certified in the American Dental Association accredited specialty of Dental Public Health. Dental public health residents participate in the planning, administration, and evaluation of programs that seek to reduce oral disease incidence and to improve the oral health of the community. The Section offers one of only two such residencies in the United States based in a state or local dental public health program. Chapter 130A-11 of the North Carolina Public Health Laws mandates the creation of a state public health residency, while the Residency Advisory Committee is an official committee within the Department of Health and Human Services. The Section's residency program is accredited by the American Dental Association's Committee on Dental Accreditation and as such, adheres to the Association's *Standards for Advanced Specialty Education Programs in Dental Public Health.*

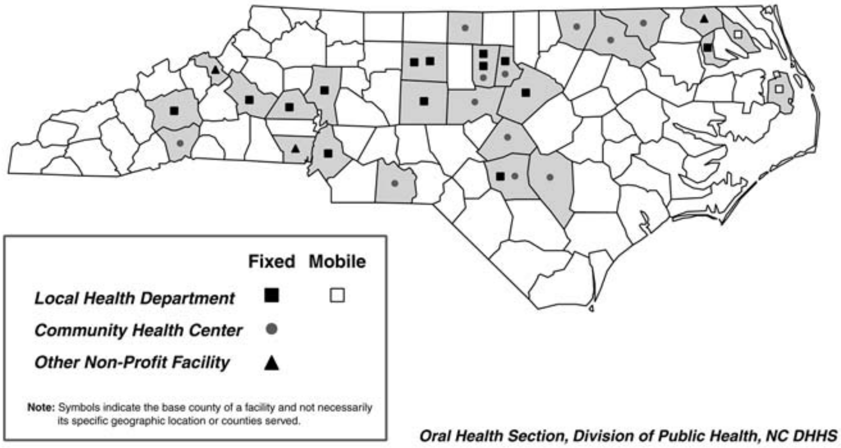
Local Government Strategies

Ninety-four of the 100 counties in the state have established some type of safety net dental care access facility or program, with many programs established within the past ten years.[4]

Most of these programs are operated by local health departments. Many of these programs combine mobile and fixed clinical facilities. They mostly serve children and adults with emergent care needs. Funding for these programs comes from local county budgets, grants, and reimbursement from third-party payers—mainly Medicaid and North Carolina Health Choice (S-CHIP). Recent increases in Medicaid fee-for-service reimbursements help these programs maintain viability. Many of these local programs were planned and implemented with technical assistance from representatives of the Section. Annual data from the community's kindergarten and fifth grade students that is collected by the Section demonstrates the need for these treatment resources and their funding. By providing assessments, referrals, case-management, school-based sealant projects, and education, public health dental hygienists employed by the Section or by county health departments contribute to a comprehensive community-based dental public health program.

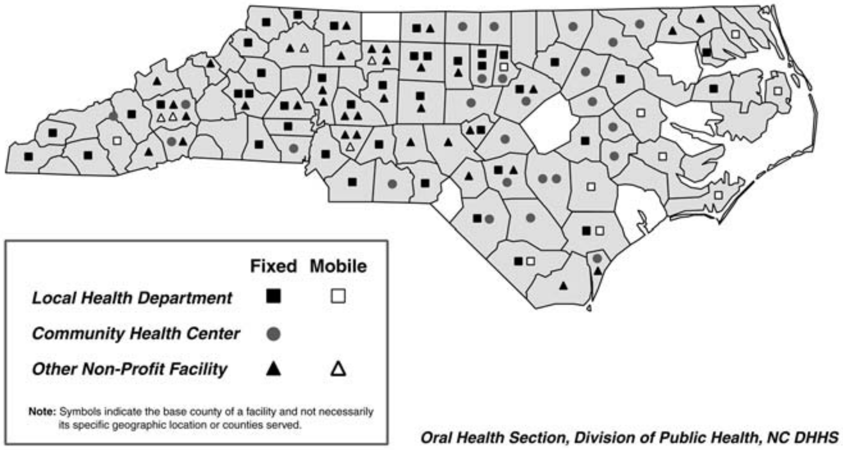
As previously described, one of the recommendations of the 1999 North Carolina Institute of Medicine Task Force on Dental Care Access[3] resulted in recent changes in the North Carolina Dental Practice Act.[4] These changes allow public health dental hygienists employed or contracted by county health departments to provide sealants and other specific preventive and therapeutic services for established patients already treatment-planned by the county's public health dentist, but without the on-site presence of that dentist.

Figure 1.
Dental Care Safety Net Facilites Prior to 1996



Oral Health Section, Division of Public Health, NC DHHS

Figure 2.
Dental Care Safety Net Facilites—October 2005



Oral Health Section, Division of Public Health, NC DHHS

Since 2000, the Section has certified 49 public health dental hygienists employed by local health departments to provide services without the on-site presence of a dentist. Thirty-three of these hygienists still work in dental public health programs. Of these, 17 provide clinical services to patients, and 31 provide community-based services, such as screenings for preschool and school age children.

Federal Funding for Dental Care Programs

Twenty-three federally qualified/community/rural health centers operate dental clinics in North Carolina. These clinics treat citizens in need, especially children, under guidelines established by the Health Resources Services Administration (HRSA). In Dental Health Provider Shortage Areas (DHPSAs), private and public health dentists are eligible to receive professional student loan repayments as an incentive to serve in geographic areas where the lack of access to dental care is documented. Coordinated by the North Carolina Office of Research, Demonstrations, and Rural Health Development, many DHPSAs have attracted and employed dentists to serve their residents. New federal guidelines require the construction of all new centers to include dental clinics.

Nonprofit Agencies and Volunteer Initiatives

Several communities rely on the dental services provided by local nonprofit agencies. Often these agencies collaborate with health departments to widen the scope of local resources. Also meaningful are open-door or "free" clinics staffed by volunteer dentists from the community. Most of these clinics are operated part-time, mostly in the evenings, and use either their own facility or another facility.

State Staffing Limitations

All of these activities are contingent on having qualified dental public health staff. Oral Health Section data indicate that improvements in dental health for permanent teeth have leveled off or are decreasing. Tooth decay in the preschool population is increasing. Additional staff (public health dentists, dental hygienists, health educators, and support staff) are needed to provide the preventive and educational services needed to reverse these trends. Yet, over the last 15 years, the Oral Health Section has lost almost 20% of its staff due to budget cuts. In addition, one-third of Section staff will be eligible for retirement in the next five years. The Office of State Personnel has acknowledged repeatedly since 1996 that salaries for Section dentists and dental hygienists are not competitive with private practice or local health departments, yet funding has not been identified to address these inequities. There are serious concerns about how the Oral Health Section will attract good staff to replace the retiring career dental public health practitioners as they leave the workforce.

Conclusions

Great strides have been made in reducing dental disease in the North Carolina population, particularly for our children. As described above, needed action steps include:

- Assuring adequate funding to support community water fluoridation and other dental preventive best practices.
- Increasing the proportion of young children at high risk for dental decay who receive the optimal number of IMB dental preventive services.
- Developing collaborations to educate dental practitioners about the importance of addressing the oral health needs of pregnant women to decrease the risk of low birth weight babies and to reduce the transmission of decay causing bacteria to their newborns.
- Supporting the action steps in the "2005 NC Oral Health Summit Proceedings and Proposed Action Plan," released by the North Carolina Institute of Medicine in December 2005.
- Maintaining and strengthening state public health resources and services to assure access to needed oral health services and programs for those most in need.

It is critical that adequate resources be directed toward prevention so that all North Carolinians can achieve oral health as part of their overall health. **NCMedJ**

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The Role of Free Dental Programs in Care Provision for the Underserved

Steven D. Slott, DDS

Of the approximately 4,000 licensed dentists in North Carolina, only 24% accept Medicaid reimbursement for dental services to any appreciable degree. Therefore, for the 1.5 million citizens of the state currently enrolled in the Medicaid program,[2] there are less than 1,000 dentists statewide from whom they may seek treatment. This translates into one dentist per 1,500 Medicaid recipients. Factoring in those who do not qualify for Medicaid, yet are unable to afford dental treatment, it may be noted that the number of available dentists to treat the underserved population, in private practice, is inadequate. Additionally, other factors, such as (mal)distribution of dentists, and location of clinics, add to the difficulties for the underserved, further reducing their ability to access needed dental care. Anecdotal information from dental Medicaid providers frequently includes reports of patients traveling long distances in order to find a provider who will accept Medicaid reimbursement. Given the inadequacy of the existing dental care delivery system, the value and necessity of safety net programs becomes clearly evident.

According to the Oral Health Section of the North Carolina Division of Health and Human Services, currently within North Carolina, there are more than 75 dental clinics dedicated to serving low-income patients who have limited access to dental care. These safety net clinics include public health, community health centers, and free clinics.[3] Although it is somewhat difficult to ascertain the exact number of free dental clinics or programs with a free dental component, of the 63 members of the North Carolina Association of Free Clinics, 21 list dental care as a component of their overall program.[4]

Table 1 shows the number of free dental components among 58 out of 63 members of the North Carolina Association of Free Clinics (NCAFC). Although these figures represent only those clinics who are members of NCAFC, they do offer some perspective on the amount of time, services, and equivalent dollar amounts donated toward dental needs, which comprise only 3.6% of overall visits to the free clinics.

Table 1.
Dental Component Statistics of North Carolina Free Clinics*

2004 Dollar Equivalent for Dental Services		**Percentage of Total Free Clinic Visits for Dental Care**	
$1,409,252		3.6%	
Dental Employees, Volunteers, and Hours of Service			
Number of Paid Dental Employees	Paid Dental Employee Hours	Number of Dental Volunteers	Dental Volunteer Hours
12	36,663	509	17,657
Type Dental Services Provided			
Preventive	Restorative	Emergency	Rehabilitative
31 clinics	32 clinics	38 clinics	25 clinics***

* 58 clinics participated in this survey Source: North Carolina Association of Free Clinics

Program Hurdles for Free Clinics: Funding and Personnel

Focusing on the free dental clinics, there are two main hurdles with which these programs must deal in order to be successful. As would be expected, these are funding and personnel. In addressing funding issues, it should be realized that there are many available sources for viable dental nonprofits, including,

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but not limited to, governmental organizations/grants, charitable trusts, local organizations, and private donations. Additionally, there are dental supply dealers and other organizations with programs providing free or low-cost supplies to qualified free dental clinics. The problem in funding often resides not in the lack of available resources, but in the lack of awareness of these resources by volunteers or paid personnel who are inexperienced in searching them out, inexperienced in grant writing, or lack an understanding of the various funding or resource entities' requirements. Table 2 provides examples of some sources of funding, in-kind donations, or other support. Each source has its own restrictions, but the long-term success and sustainability of the dental programs will depend to a large part on their ability to seek out these resources, match their needs to the needs and desires of the sources, and on their ability to keep expenses to a minimum while still providing necessary services for their targeted population.

Table 2.
Examples of Available Resources for Free Dental Care Programs

Source	Type of Resource
Charitable Foundations	
Kate B. Reynolds Charitable Trust	Grant/Monetary
The Duke Endowment	Grant/Monetary
Canon Foundation	Grant/Monetary
Governmental	
NC Office of Rural Health Department of Health and Human Services	Monetary
Private	
NC Dental Society	Monetary
NC Association of Free Clinics	Monetary (available to members only)
Henry Schein Cares	Supplies
World Dental Relief	Supplies (reduced cost)
3M ESPE Dental Products	Supplies
Local	
Civic Organizations	Monetary/other
Local Foundations	Monetary
Local Benefactors	Monetary
Local Businesses	Monetary/in-kind/other
Local Hospitals	Monetary/in-kind
Local Dental Societies	Monetary/in-kind/other
Churches	Monetary/in-kind/other
Local Government	Monetary/in-kind/other

The second main hurdle is that of personnel. The recruitment, retaining, and scheduling of volunteer workers is crucial to the viability of any nonprofit organization, free dental clinics being no exception. Whether or not there are paid personnel within the organization, this aspect of the program certainly requires constant oversight and effort. Additionally, as these clinics are a part of the healthcare field in which licensure, liability, competence, confidentiality, political, worker safety, and other complicated issues abound, the task of recruiting and maintaining an adequate workforce is even more challenging. Without strict strategies and policies in place with which to handle these issues, the chance of long-term success of a free clinic decreases dramatically.

Summary

Due to the shortcomings of the existing healthcare delivery system in general, and the dental field in particular, safety net programs are not simply optional; they are mandatory to help meet the overwhelming healthcare needs of the underserved. Free dental clinics are a vital part of this system, and indeed, millions of actual dollars,

"Given that most dental professionals have limited contact with the underserved, the free clinics offer the opportunity to bring in volunteer dentists, hygienists, and dental assistants who may then gain first-hand knowledge of the access crisis and work directly with North Carolina's growing population in greatest need of dental care."

The Open Door Dental Clinic of Alamance County

The Open Door Dental Clinic of Alamance County originated in October of 1998 operating one night per week in the newly opened Alamance County Health Department Dental Clinic facility. Although the focus of the health department clinic was to be on children, the Health Director and the Dental Advisory Committee desired to provide some dental services for the adult population as well. Thus, arose the idea of a free adult clinic to meet one or more nights per week. Dr. Steven Slott, a local dentist, and member of the Alamance County Board of Health, agreed to undertake the project, and the Open Door Dental Clinic was born.

Portable dental care in action—hundreds receive dental care at Burlington Missions of Mercy, October 2005

The clinic operated on Tuesday nights for extractions only. The list of volunteers included ten dentists from the local dental society, ten dental assistants, one dental hygienist, four front desk personnel, and dental assisting students from the Alamance Community College dental assisting program. Due to the overwhelming need, a second night of clinic was initiated for extractions only. In 2002, with funding from the Kate B. Reynolds Charitable Trust, in cooperation with the Alamance Regional Medical Center, a third night was initiated for restorative needs. An integral part of the restorative night was the involvement of dental students from the University of North Carolina at Chapel Hill (UNC-Chapel Hill) School of Dentistry. Through a cooperative effort between UNC-Chapel Hill, the health department, and the Open Door Dental Clinic, dental students were allowed to provide clinical services to the patients in the clinic.

In 2004, planning for a new program operating under the Open Door Dental Clinic was undertaken. A portable dental program modeled after the Virginia Dental Association's Missions of Mercy program was the desired goal, which would help the underserved not only in Alamance County, but in many different dental care shortage areas of the state as well. This program includes utilization of portable dental chairs, units, lights, and all necessary peripheral equipment to set up large portable dental clinics in which volunteer providers would render free dental treatment to hundreds of financially qualified individuals during two- or three-day weekend events. Once again, through the generous support of the Kate B. Reynolds Charitable Trust, in cooperation with the Alamance Regional Medical Center, along with funding assistance from other local and state organizations, enough portable equipment was purchased to have a 30-chair portable clinic, complete with full sterilization, x-ray, all necessary instruments and supplies, and a large truck in which to store and transport the equipment. Utilizing this equipment, as many as six or seven free clinic weekend events will be held in different areas of the state each year.

During 2005, in addition to the fixed-site clinics in Burlington, five portable clinics have been held, in the west, east, and central areas of the state. In each clinic, 250-350 needy patients received dental treatment consisting of extractions, fillings, cleanings, and other services. Volunteers for each event included ten-20 dentists; ten-30 dental students; two to eight hygienists, dental assistants, and assisting students from community college programs; and scores of general volunteers. Tentative plans for 2006 include portable clinics in Murphy, Boone, Washington (NC), Burlington, and Wilmington. Treatment for 500 or more patients per weekend event will be the targeted goal for 2006, with increases each succeeding year. For 2005, it is estimated that the dollar value of donated dental services from the Open Door Dental Clinic of Alamance County will be in excess of $350,000, with increases to be seen in each succeeding year. Patient visits for 2005 for both fixed-site and portable clinics will be estimated to be between 2,500 and 3,000. Estimated visits for 2006 will be 3,500-4,000.

Needy patients waiting for treatment in Burlington, October 2005

Funding for the Open Door clinic has come from many different sources. As previously stated, two grants have been received from the Kate B. Reynolds Charitable Trust, the first in the amount of $41,000 to fund the start up of the restorative night and, most recently, $140,000 to fund the portable initiative. In addition, funds have been received from local Alamance County foundations, the Alamance-Caswell Dental Society, civic organizations, the Alamance Regional Medical Center, and other private donors. In-kind donations of dental equipment, facilities, and supplies have also been donated by the Alamance County Health Department, the Henry Schein Cares program, and from numerous dentists in the area.

millions of dollars worth of services and thousands of hours of professional manpower are donated each year to provide free dental services for the needy. The short-term benefits of these clinics are obvious, the rendering of dental care to tens of thousands of individuals per year who would otherwise go without. The long-term advantages may be somewhat less than obvious, however. Given that most dental professionals have limited contact with the underserved, the free clinics offer the opportunity to bring in volunteer dentists, hygienists, and dental assistants who may then gain first-hand knowledge of the access crisis and work directly with North Carolina's growing population in greatest need of dental care. Additionally, the free clinics often offer the same benefit for dental students from the University of North Carolina at Chapel Hill, as well as for undergraduate pre-dental students. This is a key aspect, as for every one of these students who may eventually enter the dental profession with a willingness to provide for the underserved population, tens of thousands of individuals in need could potentially receive dental treatment over the span of a dental career.

The challenges of beginning and maintaining a free dental program over the long term are daunting. However, for those willing to invest the time and effort, the resources are available for long-term success with a resultant significant, positive impact on the dental care access crisis now in existence. As stated by Dr. Franklin M. Boyar in describing his free dental program in Florida, "Project: Dentists Care is simply an organization that brings together unmet health needs of indigent populations within our communities with the desire of individual dentists to help their fellow man, along with the responsibility of a profession to deliver needed care to the underserved."[5] Inherent in consideration of itself as a profession is the understanding by the component members of dentistry that it is indeed a responsibility, not simply an option, to deliver needed dental care to all citizens, regardless of their ability to pay. At the heart of any successful resolution of the dental care access crisis is the ability of dental providers to accept this responsibility, significantly increase Medicaid acceptance, willingly participate in access initiatives, and provide the care for which they have been granted licensure by the citizens of North Carolina. **NCMedJ**

For More Information:

To learn more about the Open Door Dental Clinic of Alamance County, visit their Web page.

www.alamanceopendoordental.net

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COMMENTARY

Improving Access to Dental Care Remains a Priority of One of North Carolina's Largest Philanthropies

John H. Frank

For more than a decade, improving access to dental care has been a priority for the Health Care Division of the Kate B. Reynolds Charitable Trust. Since 1995, the Trust has awarded more than 130 grants totaling $21.2 million in support of programs addressing multiple facets of the issue. Yet, in meetings, workshops, and consultations, front-line professionals in every corner of the state continue to list dental access as one of the top three healthcare concerns facing their communities.

With funding provided by the Kate B. Reynolds Charitable Trust and The Duke Endowment, the North Carolina Institute of Medicine Task Force on Dental Care Access began a study of the issue in 1998. Results of the study, which were released in 1999, showed that North Carolina ranked 47th in the supply of dentists to serve state residents, with only 3.8 dentists per 10,000 population—far below the national rate of 6.0 dentists per 10,000. Uneven geographical distribution of practicing dentists intensified the shortages, particularly in rural areas. At that time, four counties had no dental practice; another 36 counties had no dental practice that offered services to Medicaid patients. Although a significant number of private dentists regularly volunteer their time at free clinics and community or rural health centers, the number of Medicaid- and uninsured- or underinsured-patients exceeds the number that can be served by available providers. Following the study, the task force issued 23 recommendations intended to lay the foundation for delivering adequate preventive and curative dental care to all residents across the state.

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Even before the dental access study was undertaken, the Health Care Division of the Trust had begun funding programs to establish and expand existing dental services around the state, and that emphasis continues today. The programs funded by these grants typically rely on cooperative programming among existing organizations and generally fit one of four structural categories: hospital-based, health department-based, community or rural health center-based, and free-clinic-based.

Many of the expansion programs target children and other special needs groups, in which dental disease often remains untreated. At the time of the Task Force report, 25% of all of North Carolina's kindergarten children exhibited untreated dental disease, and a large number of those were from low-income populations living in rural areas. In an effort to extend dental care to these children, the Trust has awarded several grants for providing mobile dental services. An example is a 1996 grant to Mission St. Joseph's Hospital in Asheville for a dental van, called the ToothBus. Although it began as a stand-alone unit, a second ToothBus was soon

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The ToothBus is a 40-foot dental office on wheels that serves children who have no other access to dental care. It is a program of the Billy Graham Children's Health Center at Mission St. Joseph's Hospital in Asheville.

added, and within four years, ToothBus vans were delivering services to 46 elementary schools in ten counties. The ToothBus and numerous other mobile clinics around the state reach thousands of children each year.

Table 1.
Grantees by Region

	Grants	Amount*
Western	35	$5.5
Eastern	32	$5.2
Northern Piedmont	23	$3.6
South Piedmont	21	$3.7
North Central	12	$1.9
South Central	11	$1.3
TOTAL	134	$21.2

* Grant in millions.

Another area of emphasis for the Trust is manpower development. Grants awarded in support of manpower development are intended to increase the overall number of dental professionals in the state, with particular focus on reducing shortages in underserved areas. A majority of these education grants have been awarded to community colleges for expanded training programs for dental hygienists and dental assistants. Grants have also been made to the University of North Carolina at Chapel Hill (UNC-Chapel Hill) School of Dentistry to support student internships served in rural North Carolina counties.

As part of our commitment to improving dental access, the Trust hosted a Promising Practices Meeting in September 2003 in Winston-Salem for representatives from public and private agencies across the state. During the day-long meeting, the North Carolina Institute of Medicine presented a progress report on the implementation of its Task Force recommendations. The Trust also selected panelists from successful dental programs to discuss features of their programs with attendees. The event was intended to disseminate information while encouraging innovation and collaboration in addressing dental access at the community level.

Although significant dollars have been invested since 1995, the Trust continues to include improving dental access for the financially needy among its priorities. In reviewing grant requests, the Trust is particularly receptive to applications that address the following issues:

- A plan for ensuring adequate staffing,
- A back-up plan for dealing with "no shows,"
- Evidence of support for the program from dentists practicing in the community, and
- A financial plan that includes Medicaid reimbursement numbers adequate to sustain the program over the long term.

Please visit our Web site (www.kbr.org) to learn more about the types of programming that fall within Trust grantmaking guidelines and the procedures for submitting an application. **NCMedJ**

Table 2.
Dental Grantees

	Grants	Grantees	Amount*
Health Departments	54	37	$7.8
Rural/Community Health Centers	37	23	$6.1
Hospitals	10	7	$2.2
Community Colleges	9	8	$1.9
Gree Clinics	11	5	$1.6
Others	13	13	$1.6
TOTAL	134	93	$21.2

* Grant in millions.

COMMENTARY

Access to Primary Dental Care:

A Commentary on the Economics of Dental Practice and Thoughts on Solutions to Improve Access to Primary Dental Care

John N. Williams, DMD, MBA

Imagine a world in which there were no self-induced health problems. A world in which there were no obesity, no hypertension, no motor vehicle accidents, and no oral health problems. Realistically however, we realize that all of these conditions exist because accidents happen, individuals ignore information that contributes to healthful lifestyles, and most people are not motivated to change their unhealthful habits to healthful ones, and sometimes healthcare services are not available to provide care for those in need. In addition to accidents, knowledge, and motivation, economics play a major role in the availability of healthcare services.

A current topic of discussion in dentistry and medicine is lack of access to services to prevent and manage unhealthful conditions. It has been observed that many people living in the 100 counties of North Carolina, particularly those in counties with a lower-economic vitality, lack access to dental care. An uneven distribution of dentists practicing within the state exists in that only eight counties have a dentist-to-population ratio at or above the national average of 5.8 dentists per 10,000. These eight counties contain the large population centers in the state. Another 78 counties have fewer than the national average numbers of dentists and, thus, are designated by the federal government as dental shortage areas. Four counties of North Carolina have no dentists.[1] Much of the dental workforce literature uses a simple calculation of dentist-to-population ratio to determine shortage or surplus numbers of dentists relative to national averages without much consideration of today's dental practice economic influences on access.

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Access is a complex concept with a strong economic influence. Having adequate access, requires certain behaviors on the part of both the providers of health services and the receivers of health services. The United States healthcare system operates in a free market, capitalist economy where producers and consumers have a variety of alternatives upon which to base healthcare purchasing decisions. As with any free market, those with more financial resources have more choices. An important distinction is that *medical* care costs function differently than *dental* care costs when medical insurance is available. Most consumers with medical insurance are oblivious to the costs of services in advance of receiving them, and prior to the consumer seeing the final costs, much discounting of the full fees charged occurs through third-party contracting and negotiated prices. In contrast, dental costs, with or without insurance, are usually known in advance of receiving treatment, and the consumer can make an informed economic decision.

Another significant difference between medical and dental

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market costs is the extent to which third-party payers (insurance companies) are present. In North Carolina, fewer persons are covered by some form of third-party payment mechanism for dental care than for medical care, which has approximately 87% of the population covered by an employer, individual, or government-sponsored programs.[2] Dentistry has avoided much of the market influence of third-party payers, who can establish what they will pay through a schedule of benefit payments or determine payments based on regional usual, customary, and reasonable (UCR) fees. In economic terms, dentists, for the most part, are price makers, which gives them freedom to set fees for professional services, while our medical colleagues have become price takers—receiving whatever a third party decides to pay regardless what fee a physician may charge. This difference is significant because it has a major influence on the way dental care and, ultimately, dental care access is made available.

The supply of providers (physicians and dentists) also has an impact on the free market system. In the mid-1980s, there was a national concern over the existing number of dentists graduating from dental schools, which in some parts of the United States was perceived as an "over-supply" of dentists. Between 1983 and 2001, six private dental schools closed, and the national number of dental graduates fell from 5,756 in 1983 to 3,778 by 1993, a decline of 34%. In recent years, three new dental schools have been established, but enrollments have only increased to approximately 4,300 dental students nationally.[3] The reduction in the national supply of dental graduates by over 30% gives the dentist of today a huge market advantage when determining what fees to charge, where and when to practice, and what type of payment source (i.e., private pay, insurance, or Medicaid) to accept. Therefore, from a purely economic standpoint, dentists operating in the free market can optimize their economic benefit and avoid less financially beneficial payment arrangements. In practical terms, this explains why dentists locate in urban areas (generally more vital economic environments relative to rural areas) and avoid participation in poorly funded, third-party payment programs like Medicaid. The financial alternatives are simply too compelling.

This is not to suggest that dentists aren't concerned about access and don't participate individually or as part of various programs to reduce the access problem by providing free dental care. Many dentists do these altruistic things. From a purely economic perspective, however, this market phenomenon explains how and why dental care is delivered in the United States today, and why many states, including North Carolina, have an uneven distribution of dentists and access problems.

In contrast, enrollments in medical schools during this same 22-year time span remained unchanged despite a national call in the mid-1990s to reduce the entering medical school class size by 20-25% by 2005.[4] This reduction did not occur. While the numbers of primary care physicians in North Carolina are also a concern, relative to dentists, there are large numbers of physicians in the healthcare economic market.* This has limited physician influence over what fees to charge, where and when to practice, and what type of patients to see due to heightened competition. Third-party payers can more easily dictate the economic terms within a more competitive healthcare market.

At this point, one might ask what all this discussion of healthcare economics has to do with dental care access. I assert that our current economic climate is the basis for understanding this extremely complex topic of access and will add to one's understanding of what solutions might or might not work to improve access for the underserved populations in North Carolina.

Access to care is not only complex, but a relative concept as well. I draw on my personal knowledge of access to dental care problems in Kentucky. Kentucky is a state not very different from North Carolina in demographic and economic characteristics, but with less than half the population of North Carolina and enrolling twice as many dental students in two dental schools. Comparisons of oral health status and behavior reported by the Centers for Disease Control and Prevention (CDC) as part of the Oral Health Surveillance Program make it possible to study some dental behaviors and outcomes nationwide. Findings related to North Carolina and Kentucky indicate that, relative to the United States as a whole, Kentucky and North Carolina are doing a comparable job of providing some dental care access for the public. Compared to Kentucky, in percentage terms, in 1999 about the same percentage of people in North Carolina visited dentists annually (67.2% vs. 67.6%), and about the same percentage of the population received a tooth cleaning (68.2%), while fewer people in North Carolina had lost their natural teeth (24.4% vs. 44.3%).[5]

In 1999, these North Carolina dental health outcomes were achieved in a state with one dental school enrolling 75 doctor of dental surgery (DDS) students per year and with a statewide DDS-to-population ratio (4.3 DDS per 10,000) below the national average (6.4 DDS per 10,000).[6]

At this point, I'll summarize my commentary on today's economic market on the access question as follows: (1) access is a complex topic; (2) the free market of economics in dental care delivery has a significant influence over dentists in terms of where, when, type of practice dentists choose, and the extent of their participation in Medicaid programs; and (3) determining whether a problem with access to dental care exists is relative to the desired dental care outcomes.

With this economic context in mind, and having a major influence over the current dental delivery model, we can do better for the citizens of North Carolina. There are compelling reasons to work harder to improve the dental health outcomes of the state. As the old economies of tobacco, textiles, and

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* In 2004, there were 7,401 primary care physicians and 3,628 dentists practicing in North Carolina. That same year, the physician-to-population ratio was 8.6 per 10,000, and the dentist-population ratio was 4.2 per 10,000 population. Cecil G. Sheps Center for Health Services Research. University of North Carolina at Chapel Hill. Health Professions Database. Available at: http://www.shepscenter.unc.edu/hp/prof04.htm. Accessed November 2005.

furniture have gone away, new economic opportunities will depend even more on a healthy workforce, which includes a population with good dental health. I suggest four strategies to consider as alternatives to improve access and, ultimately, the quality of oral health for our state's population.

Expand DDS Educational Capacity at the University of North Carolina at Chapel Hill (UNC-Chapel Hill) School of Dentistry

Given the projected 52% growth in the North Carolina population (more than 12 million individuals) over the next 25 years and making some cursory assumptions about the state's current dental workforce demographics (retirements, etc.), it is prudent to increase the capacity for enrolling a larger DDS class size at UNC-Chapel Hill for a period of time.[7] University planning for this event started two years ago. We need to expand the dental education enrollment capacity by 50% (to an enrollment capacity of 120 per class) and be sensitive to ever-present market forces such that we can adjust enrollments either up or down in response to the demand for dental services. The rationale for expanding the UNC-Chapel Hill program is: (1) economy of scale, (2) availability of dental faculty, and (3) a 50-year history of graduating dentists as primary care general practitioners.

First, the American Dental Association monograph on the Economics of Dental Education reports that economies of scale are provided by expanding an existing dental school's enrollment (lower marginal cost per student) rather than incurring higher educational costs per dental student enrolled in a small (less than 50-member class) dental school.[8] Over time, adding 20-to-40 more dental students to the existing class size of 81 could be done in an incremental fashion. An upgrade in facilities would be needed to handle the maximum capacity of up to 120 dental students per class, and planning is already underway.

Second, at the national level, there is a concern about the availability of dental faculty to teach. The American Dental Education Association (ADEA) states that in 2003-2004, there were more than 240 vacant, but funded dental faculty positions existing at the 56 United States dental schools.[9] While this number has declined over the past five years, it has remained above 200, with most vacancies occurring in the clinical sciences. An established dental school with an existing faculty can more readily handle faculty shortages by reallocating faculty responsibilities in the short run.

Finally, most dental school graduates, and certainly those at UNC-Chapel Hill, enter primary care general practice. Since 1954 when the first DDS graduated from UNC, over 75% of the students have entered primary care general practice and have located throughout the state.[10]

Enhance the Integration of the Dental Care Delivery System

North Carolina is fortunate to have an existing Community College network of educational programs for educating dental hygienists and dental assistants. Better integration of the dental team during their education programs can improve productivity once in practice. There are dental care delivery systems in other states that make use of expanded-duty dental assistants and have expanded duties for dental hygienists. These arrangements can add to dental office productivity and, hence, expand access. It has been suggested that dentists should enhance their productivity through new workforce models, and North Carolina should be active in these discussions.[11,12]

Institute a Required, One-Year Post-DDS General Dental Residency Program for All Newly Licensed North Carolina Dentists

Utilizing the emerging network of dental clinics in low-access areas, the existing Federally Qualified Health Centers (FQHCs), contemporary instructional technologies and in partnership with the state Area Health Education Centers (AHEC) system, it is feasible to deploy dental graduates into a one-year general dental residency program. This could be a requirement for all graduates who attend UNC-Chapel Hill. This concept has been discussed as a realistic way to better prepare dentists for the future and can improve access.[12,13] The advantage of using dental graduates over the reliance on third- or fourth-year dental students to provide care is the graduate's better understanding and application of comprehensive care. They are more efficient and can expand their knowledge, skills, and values by serving the state in one of several selected low-access areas. In this way and through existing partners, the state could establish a network of facilities with an annual revolving dental workforce. Given the economic attractiveness of private dental practice today, it is unrealistic to expect past models of loan forgiveness to provide any long-term solution to expanding access. These facilities could establish the continuity of place, but the workforce would revolve annually. It would be hoped that some dental participants may elect to establish themselves in practice within the underserved geographic area and help to address the access issues over the longer term.

Improve Medicaid Reimbursement Rates for Dental Care

With a better understanding of the economics of today's dental practice, an immediate way to improve access to dental care for the state of North Carolina is to increase reimbursement rates paid to dentists to at least the 75th percentile of North Carolina private practice market rates in 2005. This would provide an economic incentive to dentists and increase the number of dentists accepting Medicaid patients. This was a major recommendation from the North Carolina Institute of Medicine Task Force on Dental Care Access in 1999.[14] Today, dentists operate in a free market and will respond favorably to these raised rates for treating Medicaid patients. The numerous practice opportunities available to dentists will require this type of program to create a broad enough Medicaid network across the state to meet the dental care access challenge.

Conclusion

In conclusion, I have provided a brief commentary on the economics of dental practice today, and how it influences the dental care access dilemma and current dental care delivery model in the state. There are compelling reasons to work harder to improve the dental health outcomes of the state. I suggested four strategies to consider as alternatives to improve access and, ultimately, the quality of oral health for our state's population. Working in partnership throughout the state with other educational programs, the AHEC program, the North Carolina Dental Society, state government, and others, we can and will do innovative things to engage the public and improve access to dental services for the citizens of North Carolina. It is my hope that one day we will be able to live in a world in which all citizens may enjoy optimal oral health. **NCMedJ**

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Improving Oral Health in North Carolina:
Exploring the Potential of a New School of Dentistry at East Carolina University

Michael J. Lewis, MD, PhD, D. Gregory Chadwick, DDS, MS, and F. Terri Workman, JD

Dental care is an essential component of healthcare. Inadequate attention to dental health issues can have deleterious effects on the health of our population at every age level and especially among school-age children and the adult workforce. North Carolina faces enormous challenges, as do other states, in both the recruitment and retention of dentists serving rural and low-income areas. While it is clear that dental care technologies and modes of clinical practice have made it easier, more efficient, and, often, less costly to serve larger numbers of patients' dental care needs with the same number of dental care providers, there are demographic challenges. In our rural and smaller counties, there is a serious shortage of dentists, and a number of these dentists are nearing the age of retirement. The opportunity for dentists in rural and smaller counties to implement these technological efficiencies is not likely to be in place for many more years.

Since the publication of the North Carolina Institute of Medicine Task Force Report on Access to Dental Care for Low-Income Persons,[1] there has been a growing consensus that the state faces a shortage of dentists, and that the supply is not likely to meet demand in the near-term, given current levels of productivity from the existing School of Dentistry at the University of North Carolina at Chapel Hill (UNC-Chapel Hill) or the recruitment of dentists from other states and schools of dentistry.

The Current Dental Workforce and North Carolina Demographics

In North Carolina, the dental workforce is growing older; in order to keep current ratios of dentists-to-population, we will need to replace at least one third of the 3,628 dentists in the current professional workforce in the next ten-20 years. As important, the number of dentists of African-American or other minority-group status is only 10% compared with a state population that is 34% nonwhite. There are as many as 40 North Carolina counties where no dentists provide services to persons covered by Medicaid. Four counties (in eastern North Carolina) have no dentists. There are too few pediatric dentists in North Carolina (a total of 108 as of 2004, representing 3% of the total North Carolina dental workforce), and there are many counties, particularly in the eastern part of the state, where residents would have to drive at least two hours to find an emergency care facility that would be able to treat the dental care needs of a child. It is estimated that North Carolina needs an additional 1,209 dentists to enter practice over the coming ten-20 years—without considering the impact of deaths and relocations of North Carolina dentists out-of-state—to meet the anticipated needs represented by current demand.

North Carolina was the 11th largest state as of 2000 in terms of total population (8.0 million), and it is one of the seven fastest growing states. With a population of 8.4 million in 2003, North Carolina is predicted to become the seventh largest state by 2030 (with a population of 12.2 million) and absorb the seventh largest population increase among the 50 states.[2] North Carolina has the second largest number of rural residents; only Pennsylvania has more.

Nationally, there are 5.7 dentists per 10,000 population. As of 2004, North Carolina had 4.2 dentists per 10,000, representing a slight increase since 2003. The ratio of dentists-to-population is quite different in metropolitan and rural areas of the state. Urban areas have a ratio of 4.8 dentists per 10,000 population, while rural areas have only 3.1 dentists per 10,000 population in rural areas. Despite the rapid increases in our state's population, the dentist-to-population ratios for North Carolina have remained relatively unchanged since 1987, and North Carolina's ratios are consistently low by national standards. It is significant that only eight out of 100 North Carolina counties have dentist-to-population ratios that either meet or exceed the national level of 5.7

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dentists per 10,000 population, while as many as 28 counties have only two dentists or fewer serving 10,000 or more people.

To bring the state as a whole up to the *national* level of 5.7 dentists-per-10,000 population, would require the addition of 1,251 dentists. If an effort were made to raise the ratio of dentists-to-population statewide to the *current state rate for urban areas* (i.e., 4.8 dentists per 10,000 population), an additional 480 dentists would be required. Since retirements, deaths, and relocations further increase the number of needed dentists, it is clear that current state efforts to produce more dentists cannot meet either of these goals.

The East Carolina University Response: A New School of Dentistry in Eastern North Carolina

It is against this background of need and demand for dental care in North Carolina that the Chancellor and Trustees of East Carolina University (ECU) propose to initiate the planning process leading to the development of a four-year school of dentistry in Greenville. ECU offers an appropriate location and academic venue for such a school. The University is located in and serves a geographic region of the state with a clear need for additional dental care and resources. Moreover, the professional dental community in Greenville and surrounding counties of eastern North Carolina has given strong support and encouragement to the idea of a new school of dentistry located in Greenville.

> *"...the new school of dentistry at ECU will give emphasis and exposure to the variety and excitement of practice in communities throughout North Carolina where dental care is presently in short supply."*

There is no question that the oral healthcare needs of North Carolina's underserved populations will require multiple, not single, strategies. Moreover, the persistent and urgent need for additional dentists, particularly in the largely rural areas of eastern North Carolina and the western-most counties of the state, validates the need for multiple initiatives if the oral health of North Carolina's population is to improve. But, a critical factor in all of these policy deliberations is the adequacy of professional dental workforce supply, as well as the geographic maldistribution of these professionals within the state.

Eastern North Carolina Demographics

Eastern North Carolina is a region characterized by both small and socio-economically disadvantaged populations. An examination of the data shows that a large proportion of the populations in several counties of eastern North Carolina have incomes that place them below federal poverty guidelines (FPG). Although the percentage of their populations living in poverty since 1980 has declined, 31 out of the 41 counties have as many as 20% of their children living in poverty. Further, median household income in North Carolina statewide was a modest $38,194 in 2002, but in only four of these 41 counties does median household income rise above this statewide average. Families in these lower-income areas have less disposable income and healthcare purchasing power as well as limited access to public health and other subsidized sources of dental or other healthcare.

ECU is in the fortunate position of having existing land sufficient to accommodate the footprint of any physical plant for a new school of dentistry that might be designed. Moreover, the utilities infrastructure within the Health Sciences campus is already in place and will not require significant upfitting to facilitate such construction. The implications of adding a school of dentistry to the Health Sciences Division have been carefully considered, and the faculty and administration at ECU and, in particular, at the Brody School of Medicine, are well aware of the demands of adding yet another healthcare professional school at ECU.

ECU is proposing to develop a dental school with a mission similar to the one embraced by the Brody School of Medicine at the time of its inception. With this history and the current need as guideposts, it is our intent to develop a "community-oriented" school of dentistry. By this terminology we specifically refer to our intent to develop a school of dentistry whose primary mission will be to attract into the profession individuals of high intellectual capacity who have a desire to practice dentistry in this state, and who are oriented toward a professional lifetime career of service to communities in need of high-level dental care. Moreover, the new school of dentistry at ECU will give emphasis and exposure to the variety and excitement of practice in communities throughout North Carolina where dental care is presently in short supply.

Many of the students admitted to the Brody School of Medicine are from rural and underserved counties, are identified as having a passion for primary care and are given intensive exposure to the day-to-day challenges of serving populations with either socio-economic or other barriers limiting access to care. Students are also enabled to visit and learn about constructive and effective healthcare organizations within the region that have made substantial efforts to meet the needs of these traditionally underserved populations. This same approach to be integrated with the overall plan for an ECU school of dentistry will be developed in partnership with local public health and dental professionals in private practice throughout the region.

> *“Our intent is to develop a school of dentistry whose primary mission will be to attract into the profession individuals of high intellectual capacity who have a desire to practice dentistry in this state, and who are oriented toward a professional lifetime career of service to communities in need of high-level dental care.”*

ECU embraces a global commitment to the community-based practice of dentistry, whether among those now in practice who will become involved as adjunct clinical faculty assisting our students in understanding the challenges of practice in the local settings where these practitioners now reside, or whether it is in our programs that help graduating students select a practice location where their services will be most needed and where they can satisfy both professional and personal goals.

Feasibility of a New School of Dentistry at East Carolina University

As the proposal for a new school of medicine at ECU was taking shape in the 1970’s, it was the intent that this institution would address what was widely viewed as a shortage of primary care physicians in the state, particularly those serving in rural and underserved counties. Although the goals of the new school of medicine at ECU were widely shared as highly salient policy objectives, there was anxiety over how a second publicly-supported medical school would impact the existing four-year school of medicine at the University of North Carolina at Chapel Hill. In the 24 years since the graduation of its first four-year class, the Brody School of Medicine has clearly delivered on its mission. The school has (1) improved access to care; (2) graduated classes of physicians with a high proportion choosing to practice in North Carolina after finishing their clinical residencies, one of the highest percentages of in-state practice locations among United States medical schools; and, (3) graduated one of the nation’s highest percentage of graduates who have chosen to practice in primary care fields. In addition, the Brody School of Medicine often has one of the highest percentages of minority population graduates of all the United States medical schools. In fact, last year, the school was number one in the United States (with the exception of the three historically African American schools of medicine). Given the low percentage of minority dentists (10%) in North Carolina contrasted with the growing need for minority providers, this would be a great advantage.

Moreover, the claims or the fears that the existence of a medical school at ECU would threaten the programs and strengths of the medical school at UNC-Chapel Hill have not been borne out. While the two institutions are different in so many ways, having different overall philosophies and programs, each serves the state in distinctive ways. The schools enjoy a collaborative relationship in both educational and research ventures. A new school of dentistry would continue with this same level of collaboration to benefit of the people of North Carolina.

Conclusion

This proposal is offered by *East Carolina University* for it is now clear, and has been clearly demonstrated through our very successful Brody School of Medicine, that we know how to do this, and have done it successfully. This proposal is offered because *the people of North Carolina deserve no less.* **NCMedJ**

REFERENCES

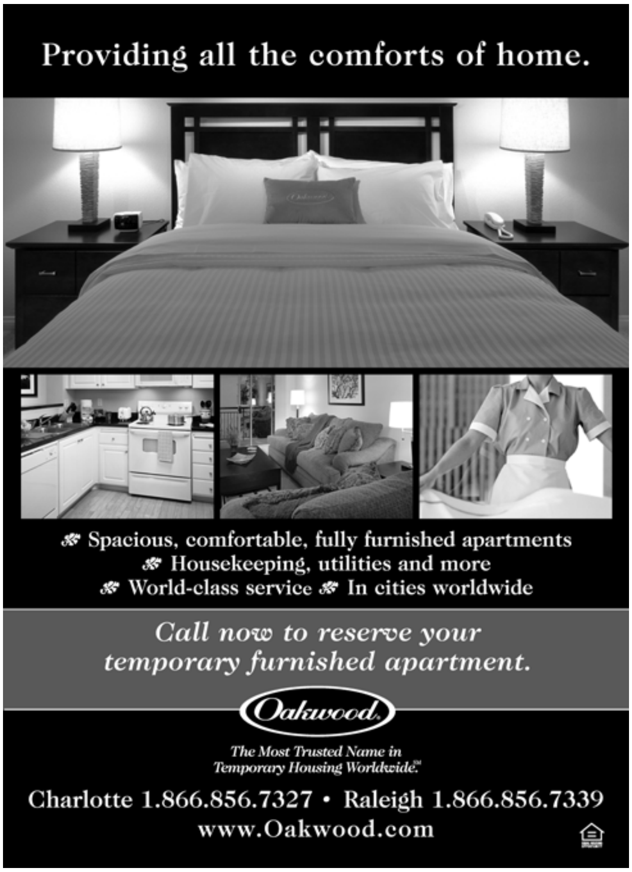
1 NC Institute of Medicine (NC IOM). North Carolina Institute of Medicine Task Force on Dental Care Access. Report to the North Carolina General Assembly and the Secretary of the NC Department of Health and Human Services. NC IOM: Durham, NC: 1999. Available at: http://www.nciom.org. Accessed October 2005.

2 US Census Bureau, Population Division, Interim State Population Projections, 2005 (Release date: April 21, 2005).

Coming in the January/February 2006 issue of the

North Carolina Medical Journal

a look at Rural Health



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- Please include the writer's full name, address, and daytime phone number. Letters may be edited for clarity or space.

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North Carolina MEDICAL JOURNAL

NC Health Professions Profiles—2004

The Cecil G. Sheps Center for Health Services Research
The University of North Carolina at Chapel Hill
Published: September 2005

NORTH CAROLINA
HPDS
HEALTH PROFESSIONS DATA SYSTEM

DENTISTS 2004

TRENDS IN PROFESSIONAL SUPPLY

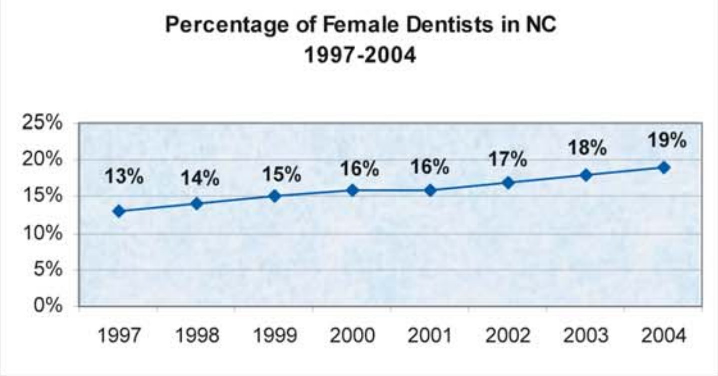
Did you know ...

In 2004 there was a 15% increase in the number of dentists indicating that their primary specialty was dental public health.

STATE TOTAL

There were 3,628 licensed, active, in-state dentists in North Carolina in 2004.

- Between 2003 and 2004, North Carolina experienced a 4.8% (+167) increase in its supply of dentists.
- Twelve counties lost dentists between 2003 and 2004, thirty-seven counties had no change in supply and fifty-one counties had an increase in the number of dentists.
- Gates, Graham and Northampton each have only one dentist and Camden, Hyde, Jones and Tyrell have not had a dentist indicating a primary practice location in those counties since 1995.


Percentage of Female Dentists in NC
1997-2004

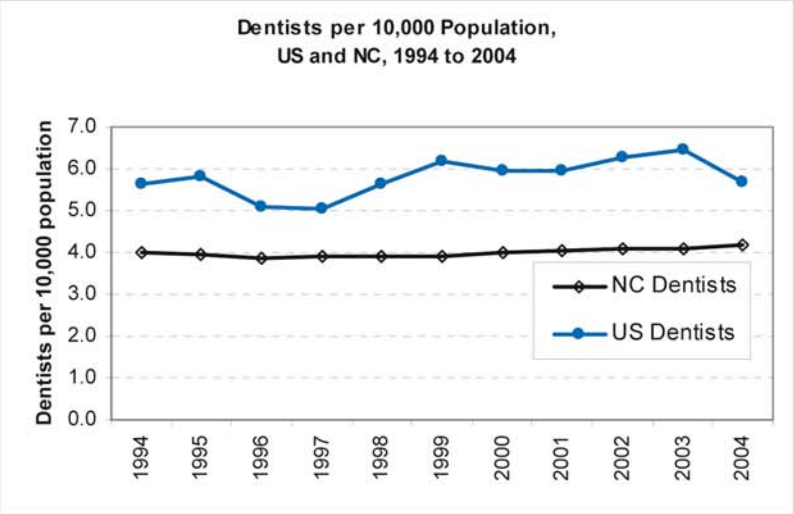
AGE

<31	8.7%
31-40	25.2%
41-50	26.3%
51-60	26.4%
61-70	9.5%
>70	3.8%

RACE

White	87.9%
Black	7.0%
Asian	2.3%
American Indian	0.5%
Hispanic	0.4%
Other	1.8%

DENTISTS PER 10,000 POPULATION

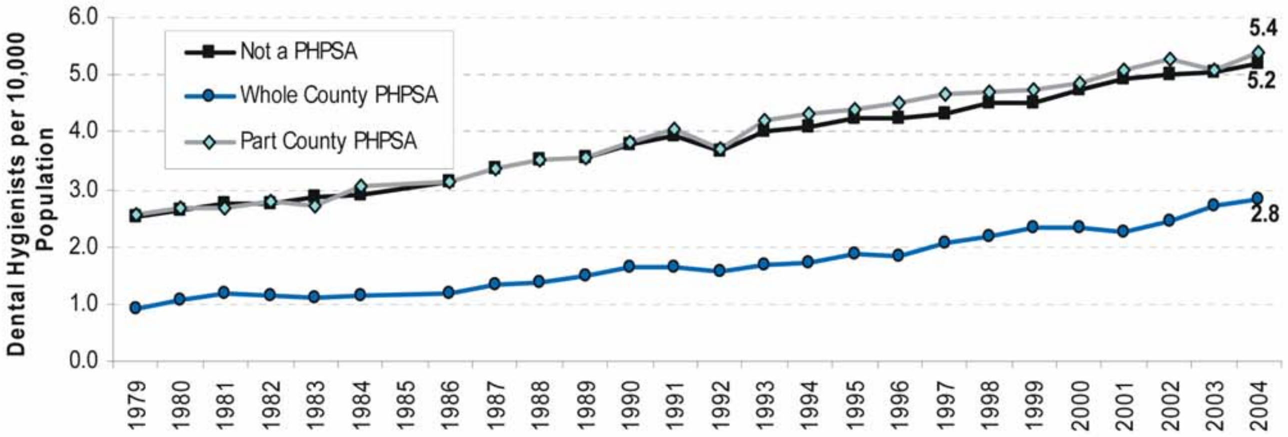

Dentists per 10,000 Population, US and NC, 1994 to 2004

North Carolina had 4.2 dentists per 10,000 population in 2004—a very slight increase from 2003. There were 4.8 dentists per 10,000 population in metropolitan areas and 3.1 dentists per 10,000 population in non-metropolitan areas.

Nationally, the ratio was 5.7 dentists per 10,000 population in 2004.

Sources: North Carolina Health Professions Data System and the Southeast Regional Center for Health Workforce Studies, 1979 to 2004; HRSA, Bureau of Health Professions; US Bureau of the Census; North Carolina Office of Management and Budget. Figures include all licensed active dentists. Population data are smoothed figures based on 1980, 1990 and 2000 Censuses.

PERSISTENT HEALTH PROFESSIONAL SHORTAGE AREAS, 1979-2004



Persistent HPSAs are those designated as HPSAs by HRSA from 1993 through 1997, or in 6 of the last 7 releases of HPSA definitions.
Source: Area Resource File, HRSA, Department of Health and Human Services, 1998.

FORM OF EMPLOYMENT

Individual Practice	64%
Partnership or Group	22%
Local/County/State/Federal Gov.	6%
Unknown	6%
Other	2%

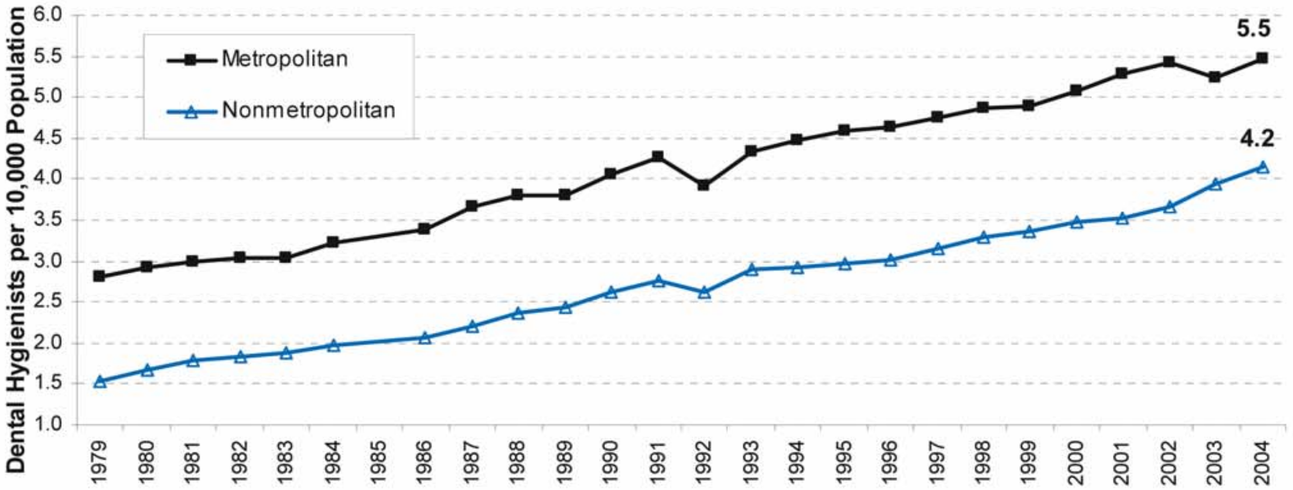
EMPLOYMENT SETTING

Non-federal Practice Office	84.1%
School/Educational Institution	2.4%
V.A./ Public Health/Indian Health	1.6%
Unknown	6.3%

Less than 1% each:

- Federal Health—Military
- Clinic—Non-Federal
- Group Health
- Hospitals
- Nursing Homes
- Other

DENTAL HYGIENISTS PER 10,000 POPULATION BY METROPOLITAN AND NON-METROPOLITAN COUNTIES, 1979-2004



Sources: North Carolina Health Professions Data System, 1979 to 2004. North Carolina Office of State Planning (Office of State Management and Budget). Figures include all licensed active in-state dental hygienists.

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NC Health Professions Profiles 2004

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Regional Center for Health Workforce Studies 2005
The Cecil G. Sheps Center for Health Services Research
The University of North Carolina at Chapel Hill
Published: October 2005

NORTH CAROLINA
HPDS
HEALTH PROFESSIONS DATA SYSTEM

DENTAL HYGIENISTS 2004

STATE TOTAL

In 2004 there were 4,324 licensed, active, in-state dental hygienists in North Carolina and 99% (4,291) were female.

DID YOU KNOW ...

In 19 states, dental hygienists can initiate treatment and provide dental hygiene services without the specific authorization of a dentist.

Source: ADHA, May 2005

TRENDS IN PROFESSIONAL SUPPLY

- In 2004, there was a 5.6% (+229) rise in the number of dental hygienists registered with the Board of Dental Examiners. This is a return to moderate growth rates seen in 2002 (4.9%, +192) and 2001 (5.4%, +197) after the drop in growth seen in 2003 (0.9%, +37).
- Sixty counties showed growth in 2004 while 19 counties decreased their supply of hygienists. There were twenty-one counties that had no change in their number of hygienists.
- Three counties had only one hygienist with a primary practice location (Currituck, Jones, Northampton) and 4 counties did not possess any (Bertie, Gates, Hyde and Tyrrell).

DENTAL HYGIENISTS PER 10,000 POPULATION

State of North Carolina: North Carolina has 5.1 dental hygienists per 10,000 population—slightly more than the 4.8 per 10,000 population ratio in 2003.

Metropolitan and non-metropolitan counties: In 2004 there were 5.5 dental hygienists per 10,000 population in metropolitan counties, and 4.2 dental hygienists per 10,000 population in non-metropolitan counties.

National ratios: National statistics show a ratio of 4.4 dental hygienists per 10,000 population in 2004, a slight increase from 4.3 per 10,000 population the previous year.

AGE

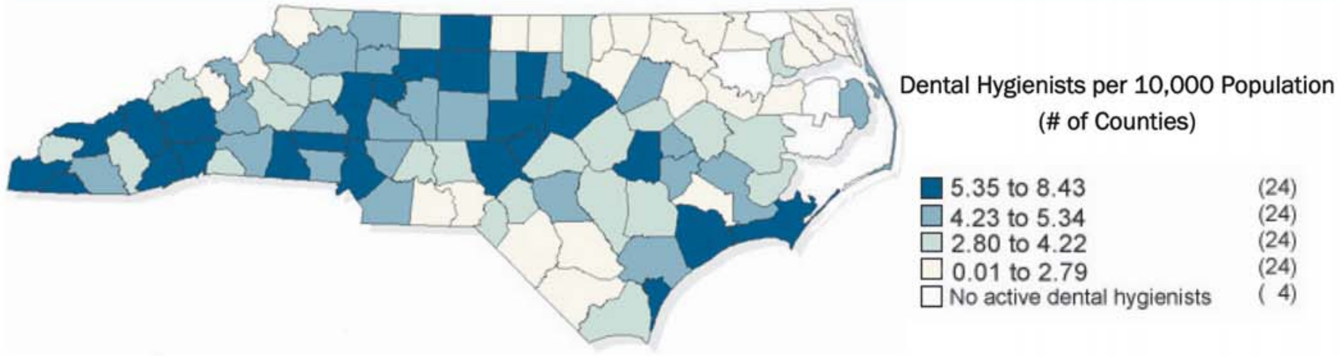
< 31	24%
31-40	33%
41-50	32%
51-60	10%
>60	1%

RACE

White	95%
Black	3%
Hispanic	<1%
Asian	<1%
Native American	<1%

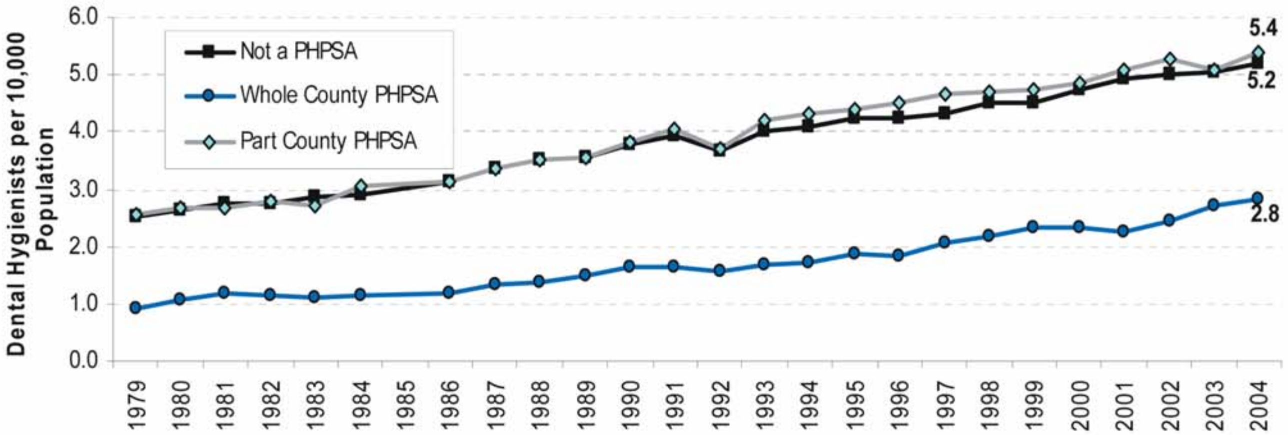
The dental hygienist workforce profile by race in North Carolina differs slightly from the workforce profile for the United States as a whole, which is 92% White, 4% Hispanic, 3% Black and 1% Asian.

DENTAL HYGIENISTS PER 10,000 POPULATION BY COUNTY, 2004



Sources: Bureau of Labor Statistics; "Employed persons by detailed occupation, sex, race, and Hispanic or Latino ethnicity,' ftp://ftp.bls.gov/pub/special.requests/lf/aa2004/aat11.txt National resident total population estimates: "Table NST-EST2004-01—National Population Estimates: April 1, 2000 to July 1, 2004" http://www.census.gov/popest/states/tables/NST-EST2004-01.pdf

PERSISTENT HEALTH PROFESSIONAL SHORTAGE AREAS, 1979-2004



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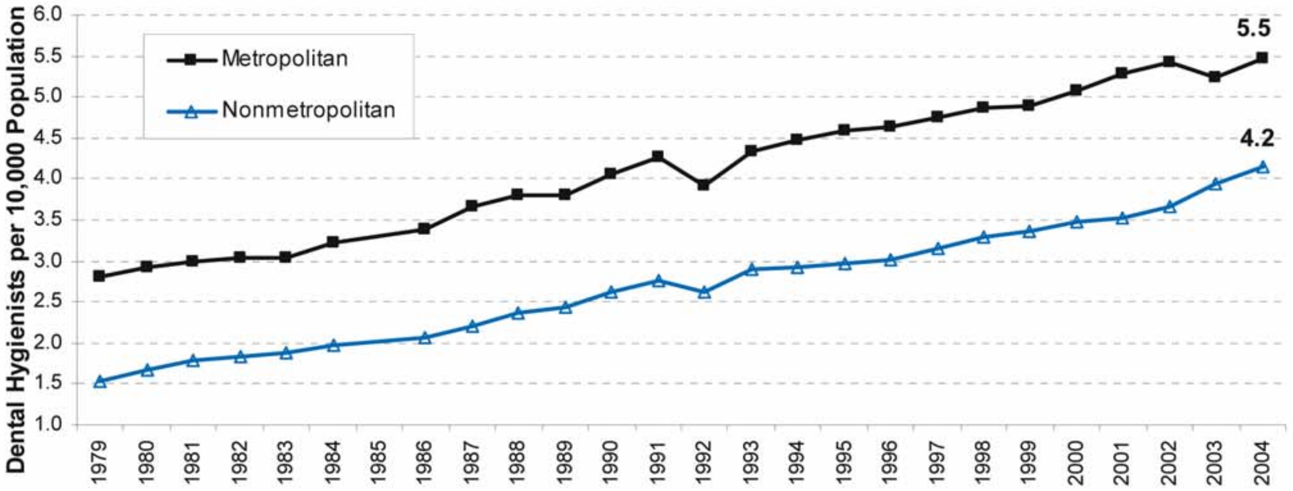

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Readers' Forum

To the Editor:

I read the issue of the *North Carolina Medical Journal*, "Preventing Child Abuse and Neglect," with interest. I note, however, that even scientists do not face up to the real issues when faced with the tenets of religion, no matter how illogical those beliefs may be.

To discuss child abuse without even mentioning that at least half of all children are unwanted and born into dysfunctional families who cannot care for them, reveals the fear and reluctance of society to disagree with religious teachings. It is well known that crime and child abuse decrease as the number of unwanted children decreases.

There is a big difference if a functional family unit has an unplanned pregnancy as compared to a single woman without family support who is forced to continue her pregnancy on the basis that a god doesn't like contraceptives or abortions.

Until we face the necessity of family planning, we are "spitting in the ocean" and will just be throwing money at another welfare program. Until we can rationally discuss the necessity of family planning, contraceptives, day-after pills—yes, even abortions—we are only fooling ourselves about the prevention of child abuse.

John A. Henderson, MD
Asheville, NC

Editorial note: The full report of the North Carolina Institute of Medicine Task Force on Child Abuse Prevention includes a recommendation to expand the Medicaid family planning waiver to provide family planning services to more people more quickly. For complete details on the report, please visit the North Carolina Institute of Medicine's Web site at http://www.nciom.org/projects/childabuse/childabusereport.html.

The North Carolina Institute of Medicine

Since January 2002, Publisher of The *North Carolina Medical Journal*

In 1983 the North Carolina General Assembly chartered the North Carolina Institute of Medicine as an independent, nonprofit organization to serve as a nonpolitical source of analysis and advice on issues of relevance to the health of North Carolina's population. The Institute is a convenor of persons and organizations with health-relevant expertise, a provider of carefully conducted studies of complex and often controversial health and healthcare issues, and a source of advice regarding available options for problem solution. The principal mode of addressing such issues is through the convening of task forces consisting of some of the state's leading professionals, policy makers and interest group representatives to undertake detailed analyses of the various dimensions of such issues and to identify a range of possible options for addressing them.

Members of the North Carolina Institute of Medicine are appointed for five-year terms by the Governor, and each task force convened by the Institute typically includes at least one-third of its membership from among the appointed members. Topics to be addressed through task force efforts are chosen following requests from the Governor, the General Assembly or agencies of state government. In some cases, topics are selected on the basis of requests from a number of stakeholder organizations across the state where this type of analytical process is considered to have potential value.

The North Carolina Institute of Medicine assumed the role of publisher of the *North Carolina Medical Journal* in January 2002 through an agreement with the North Carolina Medical Society, which founded the Journal in 1845. The Institute views the *North Carolina Medical Journal* as an extension of its mission. The Journal provides a forum for stakeholders, healthcare professionals, and policy makers and shapers to study and discuss the most salient health policy issues facing our state. Like many states, North Carolina is grappling with issues such as an increasing number of uninsured, the unmet health needs of the growing Latino population, a critical shortage of nursing personnel, the health risks of tobacco and obesity, rising prescription drugs costs, mental health system reform, the increasing societal burden of chronic illness care, the threat of bioterrorism and the necessity of assuring adequate public health preparedness—all in the midst of an economic downturn. Each of these issues presents unique challenges to healthcare providers and state policy makers. Yet, a fully implemented task force to consider each of these sets of issues is not feasible. The Journal makes it possible to present an organized and balanced overview of some of these issues, six times per year, and allows interested persons the opportunity to engage in the ongoing discussion of these issues throughout the year. The Institute hopes that our readers of the *Journal* will, in this way, become involved in the continuing debate about the most promising avenues for assuring the highest standards of health and healthcare for all North Carolinians.

health policy

North Carolina Institute of Medicine

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MEDICAL JOURNAL

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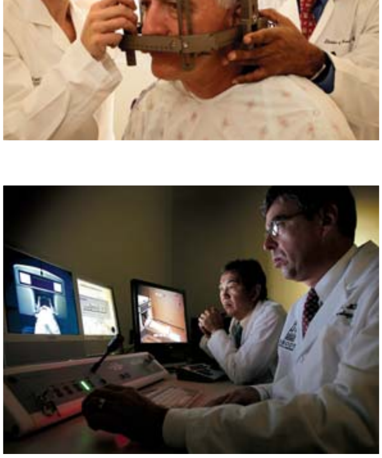

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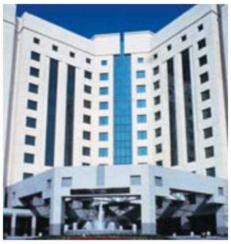

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a journal of health policy analysis and debate

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January/February 2006, 67:1

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- 5 Star – Outpatient (CMC Outpatient Cardiac Cath Lab)

(continued)
- Top Performer (Overall Quality of Doctor Care) – Outpatient
- 5 Star – Cardiology-Telemetry

Carolinas Medical Center-Mercy
- 5 Star – Outpatient
- 5 Star – Emergency Department
- 5 Star – Medical/Surgery

Carolinas Medical Center-Pineville
- 5 Star – Outpatient
- 5 Star – Inpatient

Carolinas Medical Center-University
- 4 Star – Outpatient
- 4 Star – Inpatient

Union Regional Medical Center
- 5 Star – Medical

Cleveland Regional Medical Center
- 4 Star – Outpatient
- 4 Star – Inpatient

Kings Mountain Hospital
- 5 Star – Outpatient

Lincoln Medical Center
- Top Performer(Doctor's Explanation of Treatments and Tests) – Outpatient
- 5 Star – Outpatient
- 4 Star – Inpatient

Valdese Hospital
- 4 Star – Outpatient
- 4 Star – Emergency Department
- 5 Star – Inpatient
- 5 Star – Medical/Surgical
- 5 Star – Medical/Surgical

Grace Hospital
- 4 Star – Outpatient
- 4 Star – Emergency Department

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North Carolina
MEDICAL JOURNAL

Founded by the North Carolina Medical Society in 1849
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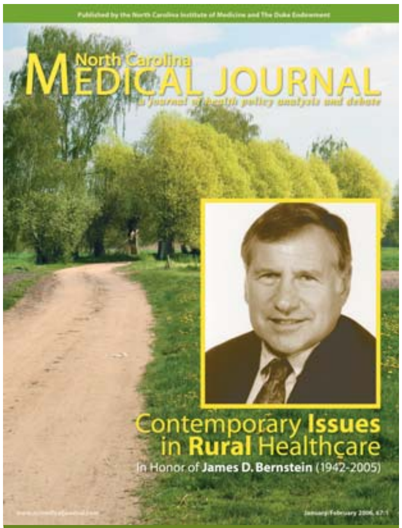

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Co-Publisher of the *North Carolina Medical Journal*

In 1983 the North Carolina General Assembly chartered the North Carolina Institute of Medicine as an independent, nonprofit organization to serve as a nonpolitical source of analysis and advice on issues of relevance to the health of North Carolina's population. The Institute is a convenor of persons and organizations with health-relevant expertise, a provider of carefully conducted studies of complex and often controversial health and healthcare issues, and a source of advice regarding available options for problem solution. The principal mode of addressing such issues is through the convening of task forces consisting of some of the state's leading professionals, policy makers and interest group representatives to undertake detailed analyses of the various dimensions of such issues and to identify a range of possible options for addressing them.

Members of the North Carolina Institute of Medicine are appointed for five-year terms by the Governor, and each task force convened by the Institute typically includes at least one-third of its membership from among the appointed members. Topics to be addressed through task force efforts are chosen following requests from the Governor, the General Assembly or agencies of state government. In some cases, topics are selected on the basis of requests from a number of stakeholder organizations across the state where this type of analytical process is considered to have potential value.

The North Carolina Institute of Medicine assumed the role of publisher of the *North Carolina Medical Journal* in January 2002 through an agreement with the North Carolina Medical Society, which founded the Journal in 1845. The Institute views the *North Carolina Medical Journal* as an extension of its mission. The Journal provides a forum for stakeholders, healthcare professionals, and policy makers and shapers to study and discuss the most salient health policy issues facing our state. Like many states, North Carolina is grappling with issues such as an increasing number of uninsured, the unmet health needs of the growing Latino population, a critical shortage of nursing personnel, the health risks of tobacco and obesity, rising prescription drugs costs, mental health system reform, the increasing societal burden of chronic illness care, the threat of bioterrorism and the necessity of assuring adequate public health preparedness—all in the midst of an economic downturn. Each of these issues presents unique challenges to healthcare providers and state policy makers. Yet, a fully implemented task force to consider each of these sets of issues is not feasible. The Journal makes it possible to present an organized and balanced overview of some of these issues, six times per year, and allows interested persons the opportunity to engage in the ongoing discussion of these issues throughout the year. The Institute hopes that our readers of the *Journal* will, in this way, become involved in the continuing debate about the most promising avenues for assuring the highest standards of health and healthcare for all North Carolinians.

health policy

North Carolina Institute of Medicine

The Duke Endowment

Russell M. Robinson, II
Chairman

In 1940, the North Carolina Medical Society began re-publishing the *North Carolina Medical Journal*, which was founded by the Society in 1849. In its 20th century reincarnation, the Journal intended to promote communications among physicians. It was a noble cause then and remains so today. In 2002, the North Carolina Institute of Medicine assumed responsibility for publishing the Journal, expanding both its scope and its readership to include all the healthcare professions.

The Duke Endowment recognized the importance of the Journal, not only to the physicians of North Carolina, but also to the medical and health communities in general, and so an association was formed between The Endowment and the Institute of Medicine to financially support the Journal. That relationship was solidified further in 2005 when The Endowment became co-publishers with the Institute of Medicine to produce the Journal on a bi-monthly basis.

The Endowment recognizes the historical significance of the Journal and hopes to build on that base by expanding its audience and contents. Today, each Journal features a particular healthcare theme, and includes articles featuring ideas and programs addressing those issues. The topics are designed to be relevant to physicians, physician assistants, nurses, dentists, pharmacists, public health officials, hospital administrators, healthcare decision makers, policy makers, and philanthropists.

The Endowment's goal in this partnership is to improve and provide a literary journal that will aid communications among the healthcare providers and to assist them in understanding health and policy issues as well as learning of successful programs being funded by this and other foundations. We invite others to join us in this venture through subscriptions to and/or advertisements in the *North Carolina Medical Journal*.

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James D. Bernstein
October 21, 1942 - June 12, 2005

The Jim Bernstein Health Leadership Fund
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CAPRELA (Cancer Prevention for Latinas):
Findings of a Pilot Study in Winston-Salem, Forsyth County

Alejandra E. Koval, MA, MPH, Alicia Alemán Riganti, MD, and Kristie Long Foley, PhD

Abstract

Objective: *To evaluate knowledge and attitudes that affect cervical and breast cancer screening among uninsured Hispanic women.*

Study Design: *Cross-sectional, descriptive study of uninsured Latino women in Forsyth County, North Carolina.*

Data Sources/Study Setting: *A convenience sample of Hispanic women who immigrated to the United States within the last ten years, primarily from Mexico (N = 70).*

Data Collection Methods: *Two trained lay health advisors (promotoras) administered in-person, structured surveys to 70 women in the community. All interviews were conducted in Spanish. Additionally, two focus groups were conducted in Spanish to elucidate cultural beliefs and barriers to cancer screening not otherwise captured in the standardized surveys. Quantitative data were analyzed using logistic regression analysis. Qualitative data were transcribed and analyzed using a multi-step framework approach to identify and validate themes.*

Principal Findings: *Of 70 women, 42 (60%) reported a Pap smear within the last year; 26 (37%) reported two exams within the past three years. Among women aged 40 and older, 10 of 18 (56%) reported ever having a mammogram. Being married (OR=4.05, CI 1.07-15.25) and having the same healthcare provider (OR 5.64, CI 1.04-30.56) predicted better Pap smear screening in multivariate analyses. Limited knowledge about breast cancer and needing an interpreter to communicate reduced the likelihood that women received a mammogram. Qualitative results indicated that women had poor prior experiences with Pap smears, held several misconceptions about cancer etiology and risk factors, and expressed distinct gender roles for Latina women and men that may affect healthcare utilization.*

Conclusions: *Screening rates for cervical and breast cancer are low among uninsured Latina women. Therefore, community and clinic-based interventions are needed to improve underutilization of and satisfaction with cancer screening practices among uninsured Latina women.*

Introduction

Cancer is the leading cause of death for women between 40 and 79 years of age and the second leading cause of mortality in American women of all ages. Even with reduced incidence rates, there remain significant disparities in the incidence and mortality rates of cervical cancer among women of color, when compared to rates among white women. The incidence of cervical cancer among Hispanic women is 16 cases per 100,000, compared with nine cases among white women.[1,2] Breast cancer incidence is low among Hispanic women compared with non-Hispanic white women, but a greater proportion of Hispanic breast cancer patients experience a longer duration of symptoms and are more likely to die from the disease.[3,4] Having both a longer duration of symptoms and excess mortality point to the lack of adequate care received for breast cancer in this population. It may be expected that breast cancer incidence rates among the Hispanic population will increase due to changing exposures associated with increased acculturation.[5]

Disparities in breast and cervical cancer screening are at least partially to blame for the excess morbidity and mortality experienced by Hispanic women. Only 67% of Hispanic females

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(over age 40) report having had a mammogram within the past two years, which is 4.7 percentage points lower than non-Hispanic whites. Differences in screening rates appear to be declining. There is a 9.7 percentage-point decrease in today's rates from those ten years ago.[6] Low income, lower levels of formal education, race, ethnicity, culture, insurance status, and age all contribute to underutilization of breast cancer screening.[7] Similarly, although Pap smear screening rates are rising for ethnic minorities, Hispanic women consistently report lower rates of cervical cancer screening than non-Hispanic women or African American women. Twenty-five percent of Hispanic women have never had a Pap smear, compared with 9% of non-Hispanic women. Fifty-one percent of Hispanic women 40 years and older and 43% of Hispanic women between 18 and 40 years of age reported not having a Pap smear during the previous year.[8]

While Hispanics are generally treated as a homogenous group, there is great variability in screening patterns among various Hispanic/Latino subgroups. In a comparison of three cancer screening practices (Pap smear, mammogram, and clinical breast exam) among five subgroups of Hispanic women, Zambrana et al[9] determined that Mexican women were the least likely to be screened with any procedure. Additionally, using data from 1990-1992 National Health Interview Survey (NHIS), Peek[6] reported mammography rates of 35% among Mexicans, 43% among Puerto Ricans, 41% among Cubans, and 47% among other Hispanics. Further, regional variations exist: 45% of Mexican Americans in Texas had been screened for breast cancer compared to 60% of Mexican Americans in California.[6]

This study evaluates breast and cervical cancer screening patterns among uninsured Hispanic/Latino women living in North Carolina, primarily of Mexican origin. Our goal was to evaluate screening practices and barriers to early detection among women who had recently immigrated to the United States and who had limited financial resources, yet had access to free mammography and Pap smear services through a local free clinic.

Methods

Setting

This study was conducted in Forsyth County, North Carolina. This county was home to 19,577 Latinos as of 2000. New arrivals are mainly from the rural areas of Mexico, such as the states of Guerrero and Oaxaca, where access to healthcare services is limited. The average level of education among Hispanics/Latinos who immigrate to the United States is fifth grade, a lower attainment level than for Hispanics at the national level. More than one quarter of North Carolina Latinos live in poverty (27.4%).[10,11] The study targeted an apartment complex with 260 occupied units, where 90% of the residents are of Hispanic origin.

Data Collection

Upon Institutional Review Board (IRB) approval, the study team identified, contacted, and established a rapport with two *promotoras* (lay health advisors). The selected *promotoras* were of Mexican origin to reflect the majority of Latina immigrants in the Forsyth community. They act as a bridge between researchers and the target population and are able to develop a sense of trust in the participants of a community program. They are often the best recruiters, not only of participants, but also of other community health workers.[12,13,14]

The *promotoras* were paid to attend two training sessions, which entailed how to: inform the women about the purpose of the study and the target populations and instruct them about confidentiality issues and consent procedures. Training also familiarized *promotoras* with the questionnaire and provided a mock interview session. In addition, *promotoras* received an operations manual. Because the survey included the use of color-coded cue cards, we taught *promotoras* how to manipulate the cards as they were reading the questions.

Promotoras recruited women who met the following criteria: (a) an adult (at least 18 years of age); (b) uninsured; and (c) a resident of the United States for less than ten years. *Promotoras* maintained a roster where they indicated the number of attempts they made until they were able to reach the participant, as well as contact information for them and intent to participate in a focus group. The average number of attempts was 1.34 (± 0.90), range 1-5.

Sample

The *promotoras* conducted 70 in-person, structured, Spanish interviews within eight weeks during the Spring 2004. The average time to complete the survey was 30 minutes. Surveys were conducted either in homes (95%) or at the workplace (5%). Participants received a gift card to a grocery store when they completed the survey.

The principal investigator (PI) and a co-PI also facilitated two focus groups with seven and eight women, respectively. For the first focus group, women between 20 and 40 years of age were recruited. The goal of the second focus group was to include women 40 years old and older, but the research team experienced difficulty locating and recruiting older women to participate. Only two women over age 40 participated in the focus group.

We used a model apartment that was made available by the management of the property. Food and childcare in a nearby location were provided. Although the initial goal was to stratify the women by age group, we were not able to recruit enough women age 40 and over for the second session, so we invited women who were younger in order to meet the minimum necessary for a fruitful focus group experience.

Focus group questions addressed knowledge, beliefs, myths, barriers to screening practices, *familismo*[a] and *machismo*,[b] and probed into the women's interest in participating in an educational intervention. The goal of the focus groups was to provide greater insight into the cultural impact of cancer knowledge and screening behavior. The discussions were taped, transcribed, and then translated into English. Women received a gift card to a grocery store for their participation in the discussion.

Measures

We selected the survey constructs based on a review of the literature and previously established surveys[15,16] used among low-income women. We also modified them to be culturally relevant to Hispanic women, based on input from our two Hispanic study team members, the co-PI, and a nurse practitioner who works in the Hispanic community.

Cancer Screening Practices. The dependent measures in this study included Pap smear screening behavior and mammography screening behavior. Pap smear screening behavior was divided into the following categories: ever had a Pap smear, having had a Pap smear within the last year (since 2003), and whether they had received at least two Pap smears within the last three years (since 2001). This latter measure was calculated to establish whether the women had adopted regular Pap smear screening behavior.

Mammography screening behavior was measured among women 40 years old and older and included: ever had a mammogram, having had a mammogram within the last year (since 2003), and whether they had received at least two mammograms within the last three years (since 2001). Similar to Pap smear screening, our goal was to establish whether regular screening behavior occurred.

Demographics included age (less than 24 years, 25-32 years, 33-39 years, and greater than or equal to 40 years), place of origin, and length of residence in the United States (less than or equal to three years, three and one half to six years, greater than or equal to seven years). For marital status, we categorized all responses into: married/living together, and residing without a partner (single, divorced/separated, widowed, and never married). We also determined the total number of children in the home, but dichotomized the variable into (any children vs. no children.). We stratified educational attainment as sixth grade or less, seventh through 11th grade, and high school graduate or more. We measured employment status as follows: housewife, volunteer (no job), part-time job, full-time job, unemployed (job hunting), unemployed (not seeking job), retired, can't work (disabled), and other. We computed the total number of people in the household (continuous measure). Women were asked if they typically see the same provider when they go for healthcare (yes/no). We asked women to determine how well they spoke English (very little and need interpreter, enough to manage without an interpreter, and fluently). Because no one responded that they spoke English fluently, the item was dichotomized.

Knowledge of cervical cancer was a summary measure of six items. For each correct response, respondents received a score of 1. A total score of 6 was possible on the cervical cancer knowledge scale. They were asked whether they agree or disagree with the following statements: (1) "Cervical cancer runs in the family;" (2) "Hispanic women have a higher cervical cancer risk than other women;" (3) "Young women are at higher risk of developing cancer than older ones;" (4) "Women smokers are at higher risk of developing cancer;" (5) "Having sex without a condom increases the risk of cervical cancer;" and (6) "If the Pap test is positive, they will have to remove my uterus." A maximum score achieved among the women was 5 out of 6. We totaled and divided the scores into low knowledge (0-1), moderate knowledge, (2-3) and high knowledge (4-5) for analytical purposes."

Knowledge regarding Pap smear screening was a summary measure of seven items, with each correct item scored as 1. A higher score on the total scale indicated greater knowledge. The women were asked (1) "Do you know whether there is a test for cervical cancer?" Women who said yes and could either name or describe the procedure were coded as 1. We also asked (2) "How often do you think a healthy woman should have a Pap test?" Women who responded that they should have a Pap smear at least once per year were considered correct and assigned a value of 1. Women were also asked to indicate whether they agreed or disagreed with the following statements: (3) "I feel ok; I don't need a Pap;" (4) "If a woman no longer has menstrual periods, she doesn't need to have a Pap any more;" (5) "After a few negative Paps you don't need a Pap any more;" (6) "Women who have had their uterus removed don't need a Pap;" and (7) "Only women who have had several sex partners need a Pap." Women who correctly responded to these questions were scored a 1. Again, we totaled and categorized the scores into low knowledge (less than or equal to 3), moderate knowledge (4-5), and high knowledge (6-7).

Barriers to Pap smear participation included three items: (1) "Getting a Pap can hurt;" (2) "No cure for cancer, so why bother getting a Pap;" and (3) "I don't have time to get a Pap." The scores were then dichotomized into having at least one or more barriers (1,0).

Knowledge of breast cancer was a summary measure of five yes/no items. Women were asked whether they agreed or disagreed with the following: (1) "Hispanic women are at greater risk for breast cancer than others," (2) "Older women are at higher risk for breast cancer than younger women," (3) "The only treatment for breast cancer is surgery that removes the breast,"(4) "Women

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[a] The concept of *familismo* (familism) is used to describe a high degree of interpersonal bonding within the Latino family, resulting in greater identification with the group and dependence on the family.

[b] *Machismo* (as opposed to Marianismo, which defines the role of the ideal woman modeled after the Virgin Mary, as based on chastity, abnegation, and sacredness, while reinforcing obedience and virginity) characterizes the male gender role in Latino society. It stresses virility, independence, physical strength, and sexual prowess. *Machismo* is socially constructed, and promotes and reinforces a particular set of behaviors. The influence of *machismo* and *marianismo* on sexuality and gender roles leads to the exaltation of penetrative sexual behavior and to women's ignorance about their bodies and about sexuality.

who have never had children are at lower risk for breast cancer," and (5) "Breast cancer runs in the family." The possible range of scores was 0 to 5. Scores were categorized into low knowledge (0-1), moderate knowledge (2-3), and high knowledge (4-5).

Knowledge about mammography screening was a summary measure of five items, with each correct item scored a 1, and a maximum possible score of 5. A higher score on the total scale indicated greater knowledge. The women were asked, (1) "Do you know whether there is a test for breast cancer?" and (2) "How often do you think a woman your age should have a mammogram?" They were also asked whether they agreed or disagreed with the following statements: (3) "A woman over 40 who feels well does not need a mammogram;" (4) "mammography radiation can cause cancer;" (5) "After a few mammograms that show everything is ok, you don't need to continue having them." We categorized scores into low knowledge (0-1), moderate knowledge (2-3), and high knowledge (4-5).

In order to explore *barriers to mammography screening*, we asked women whether they agreed or disagreed with the following statements: (1) "It's difficult for me to get an appointment for a mammogram," (2) "The technician does not treat me with respect," (3) "It is too complicated to go somewhere else for a mammogram," (4) "I have no money for a mammogram," (5) "I don't know where to go for a mammogram," (6) "I'm embarrassed to have a mammogram done," and "(7) It hurts to get a mammogram." Scores assigned were yes = 1 and no = 0. We ranked barriers into low (0-3), moderate (4-5), and high (6-7).

Data Analysis

Quantitative. We computed descriptive statistics for all variables in the study. Measures of central tendency (e.g., mean, standard deviation) were obtained for continuous variables and frequencies for nominal and ordinal data. We conducted bivariate analyses using chi-square tests to evaluate the correlations between all independent and dependent variables (screening behavior). Multivariate analyses using logistic regression were conducted to evaluate the effect of knowledge of cervical cancer and barriers to Pap smear on Pap smear screening behavior within the last year. Due to a limited sample size of women age 40 and older, mammography screening behavior could not be evaluated using logistic regression techniques. All quantitative analyses were conducted using Stata 7.0.[17]

Qualitative. Transcripts of focus groups were analyzed using a multi-step framework approach.[18] The first step involved familiarization and immersion in the raw data. Two investigators who were present during the focus groups independently read the transcribed interviews and extracted key comments associated with how individuals ascribed meaning to the cancer experience. The second step was identification of a thematic framework. The investigators met to discuss the abstracted information and identified themes that emerged. This process was also reviewed by a third and independent reviewer. Third, the thematic framework, including all themes, was applied to all data.[18]

Results

Descriptive Statistics

Seventy-eight women were approached, 70 (90%) completed the survey. Table 1 describes the demographic characteristics of the survey. Women were, on average, 32 years of age (± 9.2; range 19-52). They had eight years of formal education (ranging zero to 15), which is slightly higher than the average for new immigrants into the state,[11] yet lower than the national average of high school attainment.[10] Most women were married or living together (72%) and less than half were employed outside the home (46%). The mean number of years of residence in the United States was 5.2 (range 0.5 to 9.5). The sample was predominately of Mexican origin (97%) and Catholic (79%), with limited knowledge of English. Almost everyone (93%) responded that they need an interpreter during a medical visit. Most of the women typically received healthcare at a local free clinic (62%) or a local university-owned community clinic

Table 1.
Characteristics of the Study Population

Demographics (N=70)	**%** *(unless otherwise noted)*
Age [mean, (standard deviation), range]	32.2 (9.2) 19-52
Years in the United States [mean, (standard deviation), range]	5.2 (2.8) 0.5-9.5
Years of formal education [mean, (standard deviation), range]	8 (3.1) 0-15
Country of Origin	
Mexico	97.0
Guatemala	1.5
Venezuela	1.5
Marital Status	
Married	48.6
Living together	22.9
Divorced/Separated	11.4
Widowed	2.9
Never married	14.3
Work Status	
Homemaker	47.1
Employed part-time	24.3
Employed full-time	21.4
Unemployed	5.7
Disabled	1.4
Religious Affiliation	
Catholic	78.6
Pentecostal	5.7
Christian (not otherwise stated)	14.3
Children	
No Children	16.2
Any Children	83.8
Continuity of Care	25.7

Table 2.
Knowledge and Screening Practices for Cervical and Breast Cancer

	Pap Smear (N=70) %	Mammogram[a] (N=18)
Ever screened	90	56
Screened within the last year	60	33
Screened regularly	37	11
Knowledge regarding screening[b,c]		
Low	14.9	0
Moderate	35.8	25.0
High	49.2	71.4
Average	5.01 (1.58) Range 0-7 71% accurate	4.33 (1.02) Range 0-5 87% accurate
Knowledge regarding cancer	Cervical (n = 65)	Breast (n = 18)
Low (score: 0-1)	16.4	39
Moderate (score: 2-3)	65.7	50
High (score: 4+)	17.9	11
Average Cervical Cancer Knowledge Score	2.49 (1.06) Range 0-5 42% accurate	2.0 (1.23) Range 0-5 40% accurate

a Only includes women who were at least 41 at the time of the interview to ensure that they had at least one year since their 40th birthday.

b At least two within last three years and not in same year. For mammography, the women had to be at least 43 years of age to be included in the calculation.

c Pap smear scores were categorized as follows: low (0-3), moderate (4-5), and high (6-7). Mammogram scores were categorized as follows: low (0-1), moderate (2-3), and high (4-5).

(17%). Approximately one-in-four women (25.7%) reported that they typically see the same healthcare provider for care.

The majority of the sample reported that they had at least one Pap smear, but only 60% were examined within the last year (see Table 2). Only 37% had regular screenings (at least two consecutive Pap smears within the last three years and not in the same year). Among the 18 women age 40 and older, ten (56%) had a mammogram once, six (33%) had a mammogram within the past year, and only two (11%) reported at least two mammograms during a three-year time frame.

Respondents answered an average of two and one half (± 1.1) out of five questions correctly on the cervical cancer knowledge scale and five (± 1.6) out of seven questions correctly on the Pap smear knowledge scale. Approximately one half of the sample (49.5%) experienced at least one barrier to Pap smear screening. The most commonly cited barrier to Pap smear was pain associated with the screening test (38%). An additional 19% indicated that they don't have the time to get screened. Of the possible three barriers, the average number of barriers reported was 0.6 (± 0.8).

Women were able to correctly answer an average of two (± 1.2) out of five questions related to breast cancer knowledge and four (± 1.0) out of five questions related to mammography knowledge. On average, women reported 1.9 (± 1.5) barriers to mammography. The most common barriers were: no money for a mammogram (61%), too complicated to go to a different place (28%), and too embarrassed to have a mammogram (22%).

Bivariate analyses revealed significant associations between greater Pap smear knowledge (p = 0.03), having children (p = 0.02), being married (p = 0.007), and being seen by the same provider (p = 0.02) with Pap smear screening behavior. Using these variables, we conducted a multivariate analysis. We utilized this simplified model due to the limited sample size and reduced statistical power to include many covariates. Greater knowledge about Pap smear (OR 4.3, 95% CI 0.8-22.9) and having any children (OR 5.0, 95% CI 0.9-27.9) showed a non-statistically significant association with recent Pap smear completion when controlling for marital status and having the same healthcare provider. Married women (OR 4.05, 95%CI 1.07-15.25) and those who had typically seen by the same healthcare provider (OR 5.64, 95% CI 1.04-30.56) were more likely to have had a Pap exam within the past year (see Table 3).

Bivariate analyses also demonstrated that women who stated that were able to communicate with a healthcare provider without an interpreter were significantly more likely to have received a mammogram within the past year (X2 4.57, p = 0.05). Higher knowledge scores were also marginally associated with having a recent mammogram (X2 24.57, p = 0.10). No multivariate analyses were conducted regarding mammography due to small sample size.

Table 3.
Adjusted Odds of Having Had a Pap Smear within the Last Year

Indicator	OR	95% CI
Pap Knowledge		
Low	—	
Moderate	0.83	0.15-4.56
High	4.33	0.82-22.87
Married	4.05	1.07-15.25
Any Children	5.04	0.91-27.87
Same provider	5.64	1.04-30.56

Note: Odds ratios from the multivariate logistic regression equation, adjusting for Pap knowledge, marital status, children, and receiving care from the same provider.

Focus Group Results

Several themes emerged from the transcribed focus groups. These include themes specifically related to the Pap smear experience, knowledge about cervical and breast cancer etiology and risk, and the importance of gender roles on healthcare utilization.

Focus groups revealed that the primary reason women sought a Pap smear was for contraception or pregnancy-related planning or care. This provides some explanation as to the higher rates of Pap smear among married women and women with children in this sample. Some women reported that they found the providers who performed the Pap smear to be impersonal and uninformative. Women reporting impersonal or uninformative providers had very little understanding as to the purpose of having the Pap smear; they were simply complying with the provider's request. One study participant said:

> She didn't tell me anything. That is, she only told me that … they had to see … to see that each month the cells got better … or worse…. I tell her [her friend] "maybe the doctor is waiting until I get the illness pretty bad…. I don't know. Because I … I mean, she didn't give me any medication or anything. She didn't tell me this … nothing, nothing, nothing … that's why … I don't know what causes cancer, nor anything of that sort. And they haven't … told me anything….

Some women complained that they never receive results of the Pap test, which led them to worry unnecessarily and to avoid going for Pap smears in the future. "*Si estás bien … olvídate. Ni una llamada ni nada. Si te hablamos es que tú estás mal. Pero como nunca hablan….*" (If you're ok … forget about it; not even a call, nothing. If we call you, it means you're unwell. But since they never call….")

Women had very little knowledge about breast cancer etiology and risk factors. Some misconceptions revealed during the focus groups were that milk clots may form during breast feeding, which can lead to breast cancer. Some women also thought that eating nuts or seeds and using antiperspirant deodorant could lead to breast cancer. In regard to cervical cancer, some of the women said that certain birth control methods can produce cysts which, in turn, can become cancerous. Although they identified a few accurate risk factors and behaviors, women never identified age as a risk factor. There was no understanding that uterine, vaginal, and cervical cancers are different. Some of the barriers to seeking a Pap smear or mammogram included procrastination, lack of information or recommendation from the healthcare provider, lack of time, cost, and language/communication barriers with their healthcare provider. Fatalism was also described as a barrier to cancer screening. "*…de todos modos, cuando Dios dice: 'Te toca' … es porque te toca.*" ("When God says, 'It's your turn,' it means it is your turn)" and "*Para mí el cáncer es la muerte….*" (For me … cancer is death.").

We also inquired about gender roles and *machismo* as a barrier for cancer screening. Some women stated that many husbands do not want their wives to be examined by a male doctor, which could be a major barrier to screening, especially when women have little control over who provides their healthcare. Other participants stated that their husbands care about the health of their family, but do not play an active role in it. Being screened or taking the children to the doctor is the wife's duty; "À la Mexican," they commented.

Discussion

This study provides preliminary evidence that uninsured women of Hispanic origin have low rates of regular cancer screening and healthcare utilization. This has serious public health implications for Hispanics, the fastest growing population in the United States, as well as the healthcare system that serves this population.

The structured survey and focus group data suggest that barriers to both breast and cervical cancer screening reported in this study are consistent with results observed in previous research among Hispanic women.[1,10,19,20] These women are likely to receive an initial Pap smear to obtain birth control. They are not likely to have regular Pap smears, however, which may be due to their considerable dissatisfaction with the Pap smear experience and the lack of follow-up regarding their results. This may be one explanation for the very low rates of maintenance Pap smear behavior.

Women who regularly see the same healthcare provider were 5.5 times more likely to have repeat Pap smear exams. Together, these results suggest that seeing the same provider may help build rapport and trust and improve communication surrounding the Pap smear experience. Free clinics could greatly improve the care that they deliver to the uninsured population by identifying a core group of healthcare providers who regularly conduct Pap smears for their patients. Focus group data also suggest that female healthcare providers may be more desirable among this population.

Focus group data also reinforce previous literature, which has demonstrated that Latinos hold negative conceptions of cancer as being a death sentence, something to avoid talking about, and a form of punishment from God, and they believe that there is little one can do to prevent it.[21] Because of their fatalistic view and fear associated with the disease, many Hispanics are reluctant to find out information about cancer or to get screened for the disease. In this regard, Burgess Wells et al. observed that there is a high correlation between purpose-in-life and breast health behavior. Purpose-in-life is significantly related to self-efficacy (having the knowledge and ability to care for oneself),[22] which may explain why Latinas delay seeking healthcare. This has significant implications for intervention development and should be incorporated into strategies to promote Pap and breast cancer screening among Latina women.

Although this study had a very limited sample of women ages 40 and older (18), the results suggest very low breast cancer screening rates for uninsured Hispanic women. This may be due to limited knowledge about breast cancer and poor communication with the healthcare provider. Women who did require an interpreter were significantly less likely to receive a mammogram. Myths about breast cancer also pervade (e.g., eating nuts may cause breast cancer), which also need to be debunked in order for women to have adequate breast health and screening behavior.

The results of this study should be interpreted with caution, as they were derived from a small, convenience sample of uninsured Hispanic women. *Promotoras* were able to recruit only 18 women ages 40 and older, thus limiting the interpretation of data regarding mammography utilization. Older women were also difficult to recruit for the focus groups, which limits the generalizability of the findings to a younger population of recent Latina immigrants. Additionally, the presence of an academic institution and a free medical clinic in the community from which these women were recruited may have influenced access to cancer screening services. Although the results could be safely generalized to low-income, Hispanic women in Forsyth County who have recently immigrated to the United States, they may not be generalizable to other counties in North Carolina.

Conclusion

Despite these limitations, this study is an important preliminary evaluation of breast and cervical cancer screening patterns among uninsured Hispanic women and the factors that contribute to poor regular screening behavior in this population. Interventions should be targeted not only to educating women about cancer and early detection, but also to the healthcare providers likely to provide care to these women. Cultural beliefs that underlie their screening behavior (e.g., lack of 'prevention' concept, machismo) need special attention when designing Hispanic-friendly interventions. Additional research is necessary to replicate these findings in larger populations of uninsured, Hispanic women, with more attention given to the healthcare delivery system and its contribution to poor screening behavior. **NCMedJ**

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ARTICLE

Racial Disparities in Birth Outcomes Increase with Maternal Age: Recent Data from North Carolina

Paul A. Buescher, PhD, and Manjoo Mittal, PhD

Abstract

Background: *Racial disparities in birth outcomes persist in North Carolina and the United States. We examined patterns of birth outcomes and women's health measures in North Carolina by race and age to portray the largest disparities. We wanted to see if our data were consistent with the "weathering hypothesis," which holds that the health of African American women may begin to deteriorate in early adulthood, with negative effects on birth outcomes.*

Methods: *We conducted a descriptive analysis of 1999-2003 North Carolina live birth and infant death records and 2001-2003 Behavioral Risk Factor Surveillance System survey data. Birth outcome measures examined were low birth weight, very low birth weight, infant mortality, neonatal mortality, and postneonatal mortality. Women's health measures examined were obesity, self-reported health status, high blood pressure, high cholesterol, current smoking, and smoking during pregnancy. Rates for whites and African Americans were compared for each of three age groups.*

Results: *Racial disparities in birth outcomes increase with increasing maternal age. African American teens often experience better birth outcomes than older African American women. Racial disparities in measures of women's health also increase with increasing age.*

Conclusions: *Health problems among older African American women of reproductive age may contribute substantially to racial disparities in birth outcomes. Improving the health of older African American women may be an effective strategy to reduce the overall racial disparities in birth outcomes.*

Introduction

There are longstanding disparities in birth outcomes between whites and African Americans in North Carolina and the United States. For infant mortality and low birth weight, African Americans have rates at least two times those for whites, and the gap has been increasing over time. Arline Geronimus has proposed a "weathering hypothesis" to help explain this pattern.[1,2] The weathering hypothesis proposes that the health of African American women may begin to deteriorate in early adulthood as a physical consequence of cumulative socioeconomic disadvantage. As a result, the racial differential in infant mortality, for example, is larger at older maternal ages than at younger ages. A conclusion from this is that improvements in health among adult African American women would help reduce their infant mortality rate. This report examines recent North Carolina data to see if these data are consistent with this hypothesis.

Many studies suggest that women's preconceptional health is an important determinant of birth outcomes. Chronic health conditions, substance abuse, and other health problems cannot all be fixed after a woman becomes pregnant. In this study, we look at patterns of women's health measures and birth outcome measures by maternal race and age. Since we present only parallel, descriptive data, this study cannot demonstrate that women's health problems cause poor birth outcomes. However, a number of previous studies suggest that this is the case. For example, other researchers have found that maternal chronic hypertension,[3,4] obesity,[5,6,7] smoking,[8,9,10] and high cholesterol[11] are associated with subsequent adverse birth outcomes. One study suggests that the excess incidence of maternal chronic hypertension among African American women, including hypertension preceding pregnancy, contributes to the racial disparity in pregnancy outcomes.[3] Since smoking cessation interventions during pregnancy have had limited success,[9] efforts should be made to reduce smoking among all women of reproductive age as a

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strategy for improving birth outcomes. Postpartum maternal smoking strongly increases the risk of Sudden Infant Death Syndrome (SIDS) and is associated with other infant health problems.[12]

Methods

We examine several 1999-2003 birth outcome measures for non-Hispanic African Americans and whites for the maternal age groups 15-19, 20-34, and 35 years and older: percentage low birth weight (less than 2,500 grams), percentage very low birth weight (less than 1,500 grams), infant deaths (first year of life) per 1,000 live births, neonatal deaths (first 27 days) per 1,000 live births, and postneonatal deaths (28-364 days of age) per 1,000 live births. These measures pertain to the entire five years of birth and infant death data combined, 1999 through 2003 inclusive. The percentage low birth weight and the infant mortality rate are standard overall measures of birth outcome, though the causes of low-weight births and infant deaths are heterogeneous. The vast majority of very low-birth-weight births and neonatal deaths are preterm deliveries, while more than half of postneonatal deaths result from SIDS, birth defects, and injuries/accidents.

We also present selected 2001-2003 health indicators from the North Carolina Behavioral Risk Factor Surveillance System (BRFSS) for non-Hispanic African American and white women for ages 18-24, 25-34, and 35-44: obesity, self-reported health status, high blood pressure (2001, 2003 only), high cholesterol (2001, 2003 only), and smoking. These measures pertain to the entire three years of BRFSS data combined, except those for blood pressure and cholesterol, which are for two years of data combined (these two questions were not asked on the 2002 BRFSS survey). Previous studies have shown these measures to be associated with adverse birth outcomes. The BRFSS is an ongoing random telephone health survey of adults in North Carolina.

The 15-19 year-old age group was used for the birth and infant death data because this is an age category commonly used for analysis of teen birth statistics; there are very few births to girls under age 15. The BRFSS survey interviews only persons ages 18 and older, and so the 18-24 year-old age group was used to define young adult females.

Several years of vital records and BRFSS data were aggregated to yield large enough numbers for meaningful analyses by race and age. All numerators of the race-age specific birth outcome measures are greater than 30, and most are much larger than 100. All numerators of the race-age specific BRFSS measures for females except one (African American women ages 18-24 with high cholesterol) are 20 or greater. African American/white ratios of the birth outcome and women's health measures were computed for each of the three age groups. Statistical significance of the racial differences was assessed using the chi square test. For the BRFSS measures, statistical significance was calculated using the SUDAAN software, which accounts for the complex sample design of the BRFSS when computing the errors of the estimates. A p value of less than 0.05 indicates a statistically significant difference at the 95% confidence level.

Birth weight is reported very accurately on birth certificates in North Carolina, and maternal smoking during pregnancy is reported fairly accurately.[13] An infant death was ascertained by an infant death certificate that matched to the live birth certificate. These matched records are needed because maternal race and age are recorded only on the birth certificate. Less than 1% of the 1999-2003 birth records were missing information on maternal race, age, or smoking or on birth weight.

The BRFSS data are self-reported by the respondents over the telephone and, thus, are subject to some bias. However, if the degree of bias does not differ much by race and age, the basic results here will not be affected. Overall in North Carolina, approximately 5% of households do not have a telephone. A higher percentage of African Americans than whites live in poverty; therefore, it is likely that a higher percentage of African Americans do not have a telephone. A result of this would be that health problems among African American women, as measured here, are more understated than for white women, since the poorest women (without telephones) have the most health problems. Therefore the racial differentials in the BRFSS measures in this study may be somewhat understated. Less than 1% of the 2001-2003 BRFSS records for females ages 18-44 were missing information on age, race, health status, blood pressure, or cholesterol. Approximately 10% were missing information on Body Mass Index (BMI), which was used to measure obesity.

On the birth certificate, mother's race and ethnicity are self-reported by the mother around the time of delivery, usually while in the hospital. In the BRFSS, race and ethnicity are self-reported over the telephone by the adult survey respondent. Self-report is the preferred method of collecting data on race and ethnicity.[14] The race reported by the mother on the birth certificate is sometimes reclassified to a standard category according the coding rules of the National Center for Health Statistics.[14] However, this will have little impact on the results of the present study since the data here are limited to non-Hispanic whites and African Americans.

Results

Table 1 shows the distribution of live births in North Carolina during the period 1999-2003 for non-Hispanic African Americans and whites, by maternal age. Twenty-eight percent of all live births shown in Table 1 were to African Americans, while 44% of the teen births (ages 15-19) were to African Americans. Table 1 reveals that teens comprised 18.7% of African American births, compared to 9.2% of white births.

Table 2 shows differences in selected birth outcomes by maternal race and age. The general pattern is that the percentages and rates of adverse birth outcomes for African Americans increase with increasing maternal age, and the racial disparities increase with increasing maternal age. Most of the racial differences shown in Table 2 are statistically significant at $p < 0.0001$. The two measures that are most associated with preterm delivery, the percentage very low birth weight and the neonatal death rate, have the largest racial disparities at the older ages. The teen postneonatal death rates are the same for African Americans and whites (3.8), but for mothers ages 20 and older, the rates for African Americans are more than two times the rates for whites.

Table 3 shows differences in selected women's health indicators by maternal race and age. We include several chronic disease indicators and two measures of smoking, a behavioral risk. The general pattern here is similar to that for the birth outcomes: the measures for African American women increase with increasing age, and the racial disparities in these indicators increase with increasing age. All of the racial differences at age 35-44 except one are statistically significant at $p < 0.05$. For four of the measures—percent with fair or poor health, percent with high cholesterol, percent who currently smoke, and percent of mothers who smoked during pregnancy—African American 18-24 year-olds have lower rates than white 18-24 year-olds (two of these are statistically significant). But the African American rates increase substantially with age, so that by ages 35-44 African American women have higher rates than white women for all but one of these four measures.

Table 1.
North Carolina Resident Live Births by Maternal Race and Age, 1999-2003

	African American		White	
Age Group	Number	Column %	Number	Column %
15-19	26,065	18.7	32,659	9.2
20-34	101,249	72.8	276,536	77.6
35+	11,783	8.5	47,259	13.2

Table 2.
Selected Birth Outcome Measures by Maternal Race and Age for North Carolina Residents, 1999-2003

	Age 15-19	Age 20-34	Age 35+
Percent low birth weight (<2,500 grams)			
African American	14.4	13.5	16.7
White	9.5	7.1	8.3
Ratio: A.A./White	1.52	1.90	2.01
p value for racial difference	< 0.0001	< 0.0001	< 0.0001
Percent very low birth weight (< 1,500 grams)			
African American	3.2	3.5	4.4
White	1.8	1.3	1.6
Ratio: A.A./White	1.78	2.69	2.75
p value for racial difference	< 0.0001	< 0.0001	< 0.0001
Infant deaths per 1,000 births			
African American	14.3	15.0	15.3
White	10.7	5.8	5.5
Ratio: A.A./White	1.34	2.59	2.78
p value for racial difference	< 0.0001	< 0.0001	< 0.0001
Neonatal deaths per 1,000 births			
African American	10.5	10.7	12.1
White	7.0	4.1	4.0
Ratio: A.A./White	1.50	2.61	3.03
p value for racial difference	< 0.0001	< 0.0001	< 0.0001
Postneonatal deaths per 1,000 births			
African American	3.8	4.2	3.1
White	3.8	1.7	1.5
Ratio: A.A./White	1.00	2.47	2.07
p value for racial difference	.708	<.0001	<.0001

Discussion

A much higher percentage of births occur to teens among African Americans than among whites (19% vs. 9%). Also, African American teens often experience better birth outcomes than older African American women. Though perhaps controversial, Geronimus raises the question of whether African American communities adjust their fertility-timing norms and expectations to emphasize childbearing at the ages when women are the healthiest or may have the greatest social support available.[1]

The BRFSS data presented here show that selected health indicators for African American women worsen substantially with age, and racial disparities in measures of women's health increase with age. Geronimus found sharp increases with age in the African American/white ratios of hypertension and high blood lead level prevalence among women.[1] These results suggest the

Table 3.
Selected Women's Health Indicators by Race and Age for North Carolina Female Adults, 2001-2003 Behavioral Risk Factor Surveillance System (BRFSS) Data

	Age 18-24	Age 25-34	Age 35-44
Percent obese (body mass index 30)			
African American	24.2	32.2	43.9
White	12.4	18.7	19.1
Ratio: A.A./White	1.95	1.72	2.30
p value for racial difference	0.014	0.0001	< 0.0001
Percent who report their health as fair or poor			
African American	4.5	7.7	21.1
White	7.1	6.7	12.2
Ratio: A.A./White	0.63	1.15	1.73
p value for racial difference	0.212	0.617	0.0039
Percent with high blood pressure (2001, 2003)			
African American	11.9	16.5	32.0
White	6.1	5.5	12.7
Ratio: A.A./White	1.95	3.00	2.52
p value for racial difference	0.137	0.0002	< 0.0001
Percent with high cholesterol (2001, 2003)			
African American	5.2	17.0	25.3
White	13.6	17.4	22.9
Ratio: A.A./White	0.38	0.98	1.10
p value for racial difference	0.071	0.929	0.580
Percent who currently smoke			
African American	16.8	15.8	23.1
White	34.1	25.8	32.5
Ratio: A.A./White	0.49	0.61	0.71
p value for racial difference	0.0001	0.0003	0.006
Percent who smoked during pregnancy*			
African American	8.3	11.4	14.5
White	31.1	16.5	11.0
Ratio: A.A./White	0.27	0.69	1.32
p value for racial difference	< 0.0001	< 0.0001	< 0.0001

*This measure is based on 1999-2003 birth certificate data; age groups are 15-19, 20-34, and 35+.

importance of targeting health interventions to African American women in their 20s and 30s as a means of reducing the overall racial disparity in low birth weight and infant mortality. This is consistent with the overarching Healthy People 2010 goal of reducing health disparities.

A limitation of this study is that it presents only descriptive statistics, without other control variables. Therefore the differences that are attributed here to race and age could be due substantially to other factors (such as education, income, social support, or medical conditions) that are associated with race and age. Also, the similarity in the race/age patterns in the data on women's health and birth outcomes does not prove that women's health problems cause adverse birth outcomes.

The observation that racial disparities in neonatal mortality widen with maternal age is consistent with the view of aging as a "weathering" process, which may involve life circumstances that undermine women's health in ways that can affect reproduction.[1] Racism, poverty, crime, and environmental problems disproportionately take their toll on the health of African American women,[15] leading to increasing health disparities as age increases. A recent North Carolina study suggests that unequal treatment based on race has negative effects on adult health, and African Americans are much more likely than whites to experience unequal treatment based on their race.[16] Eighteen percent of African American adults reported having emotional upset and/or physical symptoms due to treatment based on race, compared to 4% of white adults; 7% of African Americans reported experiences worse than other races when seeking healthcare, compared to one percent of whites.[16] There is evidence that prolonged, active coping with social injustice may exact a physical price.[1] High levels of stress may have negative effects on health, and stress can affect maternal behaviors such as smoking, nutrition, and substance use.[17] Strategies to improve the health of older women of reproductive age should include measures to provide protective resources for women at earlier ages to prevent health problems when they become older.

As Geronimus states: "While most Americans take for granted their good health during their young and middle adulthood—indeed these ages are referred to as the 'prime' of life and the 20s as the 'prime childbearing ages'—our findings suggest that among African American women in poverty, health deterioration may begin on an accelerated course in the mid-20s, and reproductive disadvantage may intensify."[1]

In conclusion, an effective strategy to prevent infant deaths and reduce racial disparities in birth outcomes must include measures to improve women's health before they become mothers and to sustain their health throughout the reproductive years.[18] Future research on racial disparities in birth outcomes should examine differential exposures to risk and protective factors not only during pregnancy, but over the life course of women.[19] **NCMedJ**

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POLICY FORUM

Contemporary Issues in Rural Healthcare, In Honor of James D. Bernstein (1942-2005)

> *"State government could not merely issue edicts or dangle money; it had to engage in meaningful partnerships, be prepared to make long-term investments in communities and nurture the leadership needed to deliver the desired improvements."*
> *— Jim Bernstein*

COMMENTARIES

INTRODUCTION

Policy Forum:
Contemporary Issues in Rural Healthcare
In Honor of James D. Bernstein (1942-2005)

To a state like North Carolina, there are few topics as central to the concerns of those responsible for the development of health and healthcare policies as rural health. But even in North Carolina, where a number of innovative approaches to the delivery of personal healthcare services and the education of healthcare professionals have been developed, special arrangements have been necessary to ensure rural residents could access care and that adequate numbers of professional healthcare providers were available.

Most of the nation sees North Carolina as a state that has embraced the challenges of rural healthcare and made substantial progress in addressing the most pressing problems in rendering services to the state's rural populations. Many other states have looked admiringly at the accomplishments of North Carolina's four medical schools in training a generation of physicians who have chosen careers in primary care and to practice in North Carolina. Many of our state's graduates locate in smaller, non-metropolitan communities. Likewise, the state's Area Health Education Centers Program has become the national model for how to organize regional systems to: provide continuing education for healthcare professionals, bring the benefits of specialty consultation to smaller communities, and educate students from multiple disciplines in community-based settings to help attract newly educated healthcare practitioners to become permanent community members and participants in local healthcare delivery systems. But, perhaps the single reason North Carolina is so highly respected for its accomplishments in the arena of rural health and healthcare derives from the efforts led by James D. Bernstein (1942-2005) and the program he began in the early 1970s, then known as the Governor's Rural Health Program (and the North Carolina Office of Rural Health).

In contemplating a special issue of the *North Carolina Medical Journal* in which we would take stock of lessons learned over the past three decades or more about the problems of assuring access to quality healthcare for rural communities, and reflecting on current issues and problems in relation to rural health still needing attention, the Editors of the Journal decided to dedicate this installment of the Journal in honor of Jim Bernstein, our beloved colleague, friend, mentor, and national leader. Jim set the pace and defined the direction of much of what we would consider the nation's rural health agenda for the 21st Century. Jim's untimely death this past year brought to Chapel Hill hundreds of individuals who wanted to visit with Jim one last time, to share his wisdom and good humor, to share stories of battles won (and lost), and efforts made in behalf of rural communities in North Carolina and elsewhere. Several hundred of his friends and admirers attended the memorial service in his honor. For all of this, Jim would have been (and was) very grateful. But, he would be most pleased to know that we took this opportunity to reflect on what has been learned from our years of concentrated effort, to analyze current issues still needing attention, and to re-dedicate our individual and collective efforts to keeping these issues in the forefront of national, state, and local health policy deliberations for the decades ahead. It is our hope that this issue of the Journal will be an additional step in that direction.

A Personal Reflection on Jim Bernstein

I hope that our readers will allow me this brief opportunity to print a few words about a close friend and colleague, who has been a constant source of inspiration and intellectual stimulation throughout my 35 years in North Carolina.

When Jim arrived in North Carolina near the beginning of the 1970s, there was no way that he could have known what a tremendous influence he would have in this state, in the nation, and among his colleagues at the University of North Carolina at Chapel Hill (UNC-Chapel Hill). Although he knew he wanted to work on the special problems in rural healthcare, he could not have known what serendipitous events would give him the opportunity to launch *the single most extensive and effective program in rural health anywhere*. Nor could he have known what great personal influence he would have on the people served by the program he spawned or among the colleagues he assembled to make these things happen.

Jim did not begin the program in rural health in North Carolina by writing on a "blank slate." There was a rich history of efforts to develop the resources and capacities of several communities and prominent healthcare facilities in this state, which he and his colleagues were able to bring into closer working relationships with one another. Moreover, there were a number of outstanding health professionals with whom Jim established personal relationships, and together, they forged an effective alliance that worked well for many years. Thomas Ricketts, himself a national figure in rural health research at the Cecil G. Sheps Center for Health Services Research at UNC-Chapel Hill, offers a detailed overview[1] of this history and the pillars of personality and professional esteem on whose shoulders Jim was able to stand in building the program for which he is so well known.

Jim Bernstein managed to make the task we were all engaged in, and the process of getting the job done, both stimulating and fun. There are few people like Jim Bernstein we will meet in this life, and we are fortunate to have been some of the many who have known him well. He will always be a part of our lives and careers, despite how much we will miss him every day, and for that, we must be very thankful.

Jim was always an unselfish person—willing to share (or *give*) the credit for almost everything he did to some other member of his colleague group. Even as he "retired" from some of the roles he previously played in North Carolina state government, he had a hard time taking credit for many of the things he caused to happen. He only wanted to talk about his colleagues and the pride he had in assembling such an effective team.

Jim was one of the two or three people I met and got to know well when I arrived in North Carolina in 1971. A year or so after my arrival here, Jim "decided" (and then *gently* told me) that now that I had a PhD *degree*, what I needed was a "real education" because I knew "next-to-nothing about contemporary healthcare policy and program development." He proceeded to help me acquire the understanding clearly missing from my previous degree program and my brief professional experience in medical sociology. He set up a series of luncheon discussions for the two of us with Glenn Wilson, then the Associate Dean of the UNC School of Medicine. The *quid pro quo* in all of this was that Jim and I would get a chance to ask questions of one of the most knowledgeable people in American healthcare, and Glenn would get lunch prepared by the two of us. It was a wonderful education for us, but Jim was ahead of me in that he had come to know Glenn in Cleveland when Glenn was Vice President of Kaiser, and he had experienced a couple of years of service with the Indian Health Service before coming to Chapel Hill. He had far more information and background than did I, so I learned from the *two of them* … something I have continued to this day. In a very real sense (and this is something I said to him, but to few others until now), were it not for Jim Bernstein, I think I would have spent my career very differently. One can never repay that level of influence.

Over the years, as I have tried to make my way in the field of health services research, Jim and I teamed up on many levels to obtain grant funding, to lend technical assistance to various organizations, to address policy issues at the state and county levels, or just to share our interest in several areas of our work.

I only regret that I did not help get him appointed to more boards and committees where I had a role. Few people could enrich a discussion, a meeting, or a complex organizational task like Jim Bernstein.

INTRODUCTION—continued on page 24

As Editor of this Journal, I am very grateful to Jim's good friend and colleague, Donald Madison, for writing in this issue an overview[2] of Jim's remarkable career and a description of how North Carolina's rural health program took shape and continues to have great influence in the field of rural health at a national level.

Contemporary Issues in Rural Healthcare

In our attempt to identify and clarify some of the more complex and demanding issues in rural health and healthcare with this issue of the Journal, we hope to honor Jim Bernstein in a way he would consider useful. It is our hope that publications like this one can help keep the initiatives he and others started in forward motion and help raise their visibility as public policy issues of our time.

Those who have examined the differential health indicators for both rural and urban communities in the United States have come to the conclusion that, when the effects of age, gender, and other covariates are "controlled" through statistical adjustments, the once clear disadvantage of rural areas in terms of both mortality and morbidity is no longer apparent.[3] Disease and mortality differences between metropolitan and non-metropolitan areas in this country are more likely associated with racial and ethnic or socio-economic characteristics of populations than with the size or remote location of place. Yet, the accessibility of healthcare services for those with virtually any disease or disability is far less certain in rural areas of the United States. Moreover, rural residents consistently are more likely to describe their health as "poor" or "fair" than are residents of more urban areas.[3] These observations, coupled with the urbanization of the population as a whole and the "aging" of United States rural populations in general, will make the task of assuring the availability and accessibility of quality healthcare services for rural populations an even greater challenge for future healthcare policy and program development.

Despite these seemingly paradoxical findings of non-differential urban-rural differences in critical health indicators (when other factors are taken into account) and the lack of access to basic healthcare services in rural areas, wide variations in health status indicators of the nation's rural areas exist. Geographic areas characterized by low socio-economic status or minority racial, and ethnic group concentrations are likely to have far worse health status indicators, as well as more restricted access to healthcare services.

These wide variations and the implications of limited access to basic healthcare services have caused most states to give special attention to these issues. In North Carolina, since the early 1970s, this effort has revolved around the work of the Office of Rural Health, or what is now known as the Office of Research, Demonstrations, and Rural Health Development, within the North Carolina Department of Health and Human Services. In this issue of the Journal, it is our intent to give special focus to a number of the key issues confronting this state and others in the first decade of the 21st century. For some of these issues, it will seem as though little or no progress has been made. For others, considerable forward movement has taken place.

One observation worth noting is that rural health policy, after several decades, is now a matter of significance in national health policy. Jeanne Lambrew, one of President Clinton's chief health policy advisors, describes the current political landscape and illustrates evidence of the how rural health constituencies have been influential in recent national policy development.[4]

In a broad brush examination of contemporary rural health issues, there are several issues that still seem to be the defining issues of the field. The first of these relates to the healthcare professional workforce and its distribution. Concerns regarding an adequate supply of healthcare professionals are perhaps as important now as they were three decades ago, especially with regard to certain professions (e.g., dentistry), and yet, these issues have become intertwined with others, such as reimbursement (payment) policies, practice act limitations on non-physician providers, and practice organization arrangements. There are still significant issues related to how we recruit and retain healthcare professionals in small and remote communities. Examples include considerations of how newly trained physicians, dentists, nurses, pharmacists, and others are incentivized to consider practice locations in rural communities through educational loan repayment programs, scholarships, and other financial inducements. Donald Pathman[5] offers a detailed discussion of ways in which these programs have had an impact and how lessons learned from past decades of experimentation with financial and obligated service placements can be used to further refine programs. Robert Seligson and Pam Highsmith[6] of the North Carolina Medical Society Foundation provide a description of the Community Practitioner Program, which was developed under the Foundation with support from the Kate B. Reynolds Charitable Trust and the Society's own membership. The Program's purpose is to help rural communities acquire the medical personnel needed to sustain primary care services when recruitment and retention have proven to be a problem. This is an initiative that has worked "hand-in-glove" with the activities of the state Office of Rural Health and helps to explain why so many North Carolina communities, formerly without primary care services, have achieved success in starting and maintaining such programs in recent years.

A second major dimension of efforts to address the nation's rural health problems involves a complex set of factors that determine which rural communities will be able to address these issues most successfully. The North Carolina Office of Rural Health, under Jim Bernstein's leadership, put the majority of its emphasis on facilitating communities who had the leadership capacity to organize viable local efforts in response to these problems. As a result of decades of intense collaboration with local communities across North Carolina, there is now a body of knowledge and experience that has proven to be useful in assuring the success of local health services planning efforts. Torlen Wade and his colleagues[7] provide an overview of the basic approach to the establishment of local community and state governmental partnerships in rural health program development that has characterized the modus operandi of the Office of Rural Health since its inception. Rita Salain,[8] a person who has worked both in North Carolina and now in Georgia, adds to this discussion by illustrating in greater detail the various components of community development that have been shown to be essential and effective in making organized approaches to rural health issues possible.

In the discussion of the program development aspects of rural healthcare, practicing physicians play a critical role, both as direct providers of care and as leaders through the restructuring or development of local healthcare services to ensure greater effectiveness and long-term organizational and financial viability. Steve Crane[9] provids a useful discussion of the potential role physicians may play as these discussions take place, building on the experience in three of the western-most counties of our state. Leadership of rural community development efforts and the skills involved in identifying appropriate and effective leaders for such efforts were among the most important aspects that many have identified as a central feature of the way Jim Bernstein and the Office of Rural Health were able to facilitate the development of so many separate rural health programs across our state. In this issue of the Journal, we are pleased that one of Jim's many colleagues, Tim Size[10] from Wisconsin, offers a perspective on the importance of leadership and its development based on his many years of developing rural community-hospital networks in southern Wisconsin.

In every effort to bring greater coherence and organizational effectiveness to rural health services, a vital function is associated with local or regional hospitals. Jeff Spade, Executive Director of the North Carolina Hospital Association's Rural Health Center, and Serge Dihoff, Assistant Director for the North Carolina Office of Research, Demonstrations and Rural Health,[11] provide an overview of the way in which North Carolina hospitals have become closely involved with small rural communities in the effort to facilitate these developments.

A discussion of rural healthcare programs and priorities would not be complete without consideration of the difficulties these communities face in meeting the challenges of mental health and substance abuse services. Given the enormous impact of efforts to restructure mental health services in our state, there are many opportunities for persons with serious and persistent mental health problems to fall through the cracks and to have their needs go unmet. In this issue of the Journal, John Gale and David

Lambert[12] of the University of Southern Maine provide a discussion of the problems associated with assuring access to such services in rural communities. In addition, a sidebar illustration of a successful program offering mental health and substance abuse services in North Carolina has been contributed by Denise Levis.[13] Levis describes how mental health and substance abuse services have been integrated with the Community Care of North Carolina (CCNC) Program, a set of networks across the state through which the care of Medicaid enrollees is managed in an effort to achieve both quality of care and cost-containment objectives.

The area of major concern to all who have focused their work in the rural health arena that is absent in any detail from these pages is the matter of financing rural healthcare services and programs. However, these issues are raised parenthetically throughout these discussions. It is clear that the patchwork of federal and state programs to cover the cost of particular rural health programs and needs does not reflect a comprehensive approach to meeting these national health challenges. It has, more often than not, been possible to address rural health needs through public financing only when specific rural-urban comparisons are made visible and raised to a level of importance that justifies specific targeting of new funds. Today, more funds are available to meet the broad spectrum of rural healthcare needs than were three decades ago. However, much work remains to be done to help rural residents benefit equally from the modern healthcare capacities that residents of more urban areas have.

We hope that these papers will be of interest and encouragement to those who have worked long and hard to address the fundamental problems of rural health. We also hope that our readers will find stimulation among these papers for further efforts toward the goals embraced by these authors and enunciated on so many occasions by Jim Bernstein, to whose memory this issue of the Journal is respectfully dedicated.

Gordon H. DeFriese, PhD
Editor-in-Chief

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The Work of James D. Bernstein of North Carolina

Donald L. Madison, MD

It is fairly common that someone's extraordinary service to the state be commemorated with a named building—commonly a dormitory on a state university campus—a park, a street, a stretch of interstate, even sometimes with a new, man-made lake. But such commemoratives are reserved ordinarily for governors, senators, or other long serving elected politicians. Their service to the state is doubtless deserving of such recognition; but so, often, is that of certain bureaucrats who over an extended period managed to change the face of North Carolina in some significant way—not by votes collected or bills signed, but simply by their vision, creativity, and long, hard work.

That North Carolina has led the nation in production of bright-leaf tobacco for many years is widely known. And the names of some of those responsible for the manufacture of tobacco products—Hill, Duke, Reynolds, Gray—are also well-known, if not by the nation as a whole, then at least by North Carolinians. The same can be said for textiles and furniture and banking, where this state has also been in the lead or threatens to place or show. But rural healthcare, which is neither a product, a highly marketed service, nor even a recognized "field" of labor or keen academic interest, is yet vitally important to the well being of this still predominantly rural state. And it is also linked to North Carolina in the minds of all those who know of it. For North Carolina leads the nation in rural healthcare and has for a good while—at least since the late 1970s.

There are several reasons, but the indisputable main one is the work of the late James D. Bernstein (1942-2005) and that of the superb staff he assembled. For his labors on behalf of the people of North Carolina, Jim Bernstein deserves to have a dam or a bridge named after him, at least a byway that branches off from some blue highway and leads to one of the approximately 85 rural community health centers for which his North Carolina Office of Rural Health is responsible for helping groups of local citizens establish. In addition, that Office collaborated with or followed some other agency—federal, state or philanthropic—or one of the universities in the state, in building, repairing, or helping stabilize several other community health programs. We should also recognize Jim Bernstein's work on the national level, for leading change in both the Medicaid and Medicare legislation to permit more equitable reimbursement for rural health centers and hospitals, and his leadership of national organizations devoted to the interests of rural health. Finally, and as important, historically, is the example that the North Carolina Office of Rural Health set for other states, that example activated by a national grants program of the Robert Wood Johnson Foundation with Bernstein at its helm. These efforts and more are his legacy to the state of North Carolina and the nation, and all were done from a home base in state government in Raleigh.

He was not a native North Carolinian. In fact, Jim Bernstein came to Chapel Hill temporarily; that, at least, was the plan. He had been an officer in the United States Public Health Service in Santa Fe, New Mexico, where he served as administrator of the Santa Fe Indian Hospital and Director of the Indian Health Service for Northern New Mexico.

Jim grew up in Westchester County, just outside New York City. His paternal grandfather was treasurer of Loews, the nation's oldest theater chain, which for a time, before the Justice Department intervened, also owned the lion's share of Metro-Goldwyn-Mayer (the pun is acknowledged and accurate). Jim's father manufactured advertising clocks, including those with the image of a certain grocery chain store pig with the "Piggly Wiggly" legend on the face. His mother, Jacqueline, was the family intellectual as well as the main attraction for most visitors to the Bernstein household—visitors who often included celebrities, especially artists and actors. Once people visited the Bernstein home, says Sue Bernstein, they were glad to return. And that was mainly because of Jackie Bernstein, who during the week regularly drove her Chevy Nova, alone, into northern Manhattan to work with needy children. As a youth, Jim was an athlete: swimmer, football player, hockey player—and later a hockey coach—first a playing "head coach" for the Johns Hopkins club team—"Fightin' Jim Bernstein," the college newspaper called him. Later in North Carolina, not a traditional hotbed of hockey, he served as a coach to youngsters.

After graduating from John Hopkins with a degree in political economy—and where he volunteered some of his time as a teacher of prison inmates—Jim applied for and was accepted

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into the third class of Peace Corps volunteers. The core training for his assignment, at Princeton University, was followed by a brief French language immersion in Quebec. A group of volunteers then headed for their two-year terms in Morocco, where Jim would become an English teacher, and also as it turned out, the physical education instructor for boys at the Lycee Ben Barra, a high school in Taza. Not his top choice, Taza was only about 280 miles from Tangier and the Mediterranean coast. Jim preferred going to the far south of Morocco, to the desert. But the need was in Taza. Lycee Ben Barra was a state-run boarding high school for young people who lived in the sparsely populated countryside, in places that were too rural to have a local high school. Several Peace Corps volunteers were assigned to Taza, but only one other—Susan Dill, a native of the San Francisco Bay Area—was a teacher; and like Jim, she taught English and physical education (for girls) at the Lycee Ben Barra. As the two Americans at the school, Jim and Susan became friends; and when Jim ignored the Peace Corps' warning to avoid Moroccan French pastry and came down with a severe bout of gastrointestinal inflammation, Sue prepared soup and other light fare until his digestive tract had healed. Upon recuperating from his illness, Jim built up an appetite so voracious that, says Sue, he soon "looked like a butterball."

Those bacteria-induced events led to an even closer friendship between the English teachers Bernstein and Dill, and during the latter half of their term in Taza, they were married. As it does virtually everywhere, marriage in Morocco involves certain articles of written certification, but in Taza, Jim was taken aback to learn while filling out the requisite form that he would be permitted to take up to three additional wives. He was, however, obliged to certify with his witnessed signature that he would not exceed this limit.

After Morocco, Jim applied to graduate programs in hospital administration and attended the School of Public Health at Ann Arbor. From there he went to Cleveland for a yearlong administrative residency at Mt. Sinai Hospital. After that he entered the Public Health Service, requesting an Indian Health Service assignment. His two preferences were Anchorage, Alaska, and Santa Fe, New Mexico. When she learned that Jim had marked Alaska first on his preference list, Sue responded, "We need to talk." He learned the next day that it was still not too late to change his first choice to New Mexico, and soon the Bernsteins were on the road to Santa Fe.

In 1969, along with nearly two-dozen other young PHS officers with ambitions to be leaders in the broad field of public health, Jim was awarded a fellowship in "Global Community Health." The Public Health Service described what it had in mind for these Fellows:

> *The Global Community Health Fellows are bridging the gaps of our time by respecting tradition but refusing to be bound by it. These men and women from all parts of the United States have been making special contributions to federal, state, local agencies, and private organizations in the United States and developing nations. Each brings to his or her fellowship assignment a sensitivity and commitment to*

(Above) The burka-clad Susan Dill. (Below) Newlyweds posing by the wedding cake, a traditional French croquembouche, which consists mainly of a decorative "tree" made of creampuffs held together by caramel syrup.

alleviate the health problems of the community. During their concentrated exposure to the mosaic of health, its interlacing problems on all levels, and academic pursuits, the Fellows gain invaluable practical knowledge for the transmutation of the health system.

Looking past the rococo metaphors, this is in fact an accurate representation of what Jim did during his three fellowship years and the work he continued beyond that time.

The fellowship allowed these young PHS officers to follow their muses wherever they might lead. They could arrange to study some aspect of community health virtually anywhere in the world. The fellowship usually included an advanced degree program in something, perhaps one of the fields of public health or public policy or administration. Slightly more than half of the fellows in Jim's group were physicians; the others were administrators, environmental engineers, dentists, and nurses. Administrator Bernstein, who had already spent two years in Morocco, and who had a master's degree in hospital administration, wished to pursue an advanced degree in public health and study the problems of rural health in America.

From looking at some basic statistics from the census, Bernstein learned that Texas, Pennsylvania, and North Carolina had the most rural towns (those with 2,500 population or less) of any of the states. And so he considered these three first. Texas, he said, interested him; but although it had many, many small towns, it also had several large cities. Pennsylvania had Philadelphia and Pittsburgh. North Carolina, on the other hand, had no large city. (In the early 1970s Charlotte was not yet considered large, not at least by the rest of the nation.)

The doctorate Jim was seeking would perhaps be in administration or possibly in epidemiology. According to Glenn Wilson, whose friendship with Bernstein began in Cleveland while Jim was doing his hospital administrative residency there (and where Glenn was Vice President of the Kaiser Health Plan, in charge of the Ohio region), Jim called Glenn from Santa Fe to tell him that he was thinking of enrolling in a doctoral program in epidemiology at the University of Texas School of Public Health in Houston.

Glenn says that he told Jim: "Well, It's alright for you to go to Houston, but Sue and the baby can't go with you." (The first of Jim's three children, Lori, was born in Santa Fe; Eric, two years younger, and Donna, six years younger than Eric, were both Tar Heels born.)

I asked Glenn why he would say that about Houston?

"Have you been there?"

I had; but I'd also lived in the Los Angeles basin in the 1950s, and so my impression of the air pollution in Houston was considerably less graphic than Wilson's. Jim, however, apparently took Glenn's point.

"You need to come to Chapel Hill and talk to Cecil Sheps," Wilson told him.

At the time Glenn was still in Cleveland but was completing negotiations to relocate to Chapel Hill to become Associate Dean of the School of Medicine for Community Affairs, where he would later launch the North Carolina Area Health Education Centers (AHEC) program.

Bernstein in his summer USPHS uniform, Santa Fe, New Mexico.

Bernstein had first entered the Public Health Service, as had many of his generation of healthcare professionals, because of the Vietnam War. He went to Santa Fe in 1966, which was the year when the draft accompanying the Vietnam buildup accelerated sharply, the year when virtually every medical graduate of the class of 1965 (my class), having just completed internship, would be drafted (unless they were deferred for residency training). Wilson says, "The only good thing I can say about the Vietnam War is that it diverted Jim. He was going to be a hospital administrator … in civilian life … somewhere. But the specter of the draft stood in the way. And with some assistance from me, but more from Congressman Charles Vanik [of Cleveland], he ended up in the Indian Health Service."

While Jim was in Santa Fe, he had become interested in an idea that Professor Bob Oseasohn, an epidemiologist and chair of Family and Community Medicine at the University of New Mexico in Albuquerque, had launched as an experiment and for which he asked Jim to serve on the planning committee. The experiment called for a nurse to deliver primary care for a small town—Estancia—backed up on the telephone, mainly, by physicians in Albuquerque, 62 miles to the northwest. Oseasohn later left New Mexico to become Associate Dean of the University of Texas School of Public Health in Houston. And when Jim became a Global Community Health Fellow, Dr. Oseasohn tried to recruit him as a doctoral student, thus, Jim's interest in Houston.

Why, I asked Wilson, did he want to get a PhD?

"All I remember was what he told me as he was getting out of the PHS. He had finished his two-year term, and this opportunity (the fellowship) had come along, and he had decided he wanted to get a PhD and become a teacher. I think that the experience in the Indian Health Service persuaded him that he didn't want to be a hospital director, nor, as best as I recall, a line bureaucrat in the federal government. He wanted something different than that. So that may have been part of the motivation to do something else. It was not very well defined."

But, pollution aside, why did you bad-mouth Houston to him?

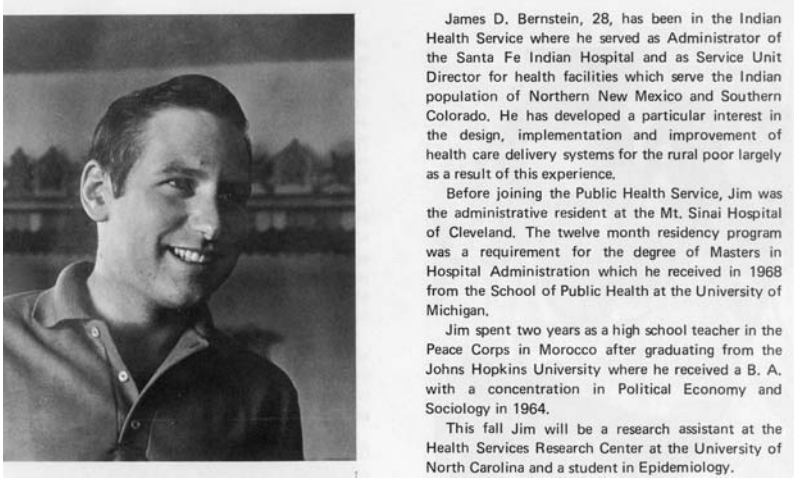
"Well," Glenn said, "I have the highest respect for Bob

Oseasohn. As you know, I tried to recruit him here later. But I really doubted that Jim would be happy in Houston, and I wanted him to talk to Cecil, which he did. Now why he wanted to do the PhD, I still don't know."

Jim's own version of his visit to Chapel Hill is worth quoting. This is from the remarks he made at the memorial service for Cecil Sheps in May of 2004.*

> "[Taking Glenn Wilson's advice], I called Cecil Sheps, and he said, "You need to come to Chapel Hill to see me." Don Madison picked me up at the airport and took me to Cecil's office, which was in the South Building. After a brief introduction, Cecil handed me an agenda, which included interviews with Don, Conrad Seipp (Deputy Director of the Health Services Research Center), a professor in Health Policy and Administration, and John Cassell (Chair of Epidemiology). He said that after I was through with all that we would meet at his house. My plan was to combine academic coursework with a rural practicum at the Health Services Research Center. My first interview at Health Policy and Administration was not encouraging. The professor I spoke with only wanted to tell me that my grades would probably not meet the high admissions standards of the program.… Next I went to see John Cassell in Epidemiology. It was graduation day and Cassell was putting on his cap and gown to go to the ceremony. Cecil had obviously put in a good word for me. Dr. Cassell asked me to walk with him to the graduation ceremonies so we could talk. By the time we reached Memorial Hall he said that he wanted me in his department if I wanted to come. Later that afternoon, I met Cecil at his house, where he said, 'Let's take a swim in the pool.' Within 20 minutes, he had laid out my next three years as a part-time student in epidemiology and a Research Associate at the Health Services Research Center."

I recall that Jim seemed to enjoy his coursework and classmates and appeared to be a well-motivated, serious public health student.


James D. Bernstein, 28, has been in the Indian Health Service where he served as Administrator of the Santa Fe Indian Hospital and as Service Unit Director for health facilities which serve the Indian population of Northern New Mexico and Southern Colorado. He has developed a particular interest in the design, implementation and improvement of health care delivery systems for the rural poor largely as a result of this experience.

Before joining the Public Health Service, Jim was the administrative resident at the Mt. Sinai Hospital of Cleveland. The twelve month residency program was a requirement for the degree of Masters in Hospital Administration which he received in 1968 from the School of Public Health at the University of Michigan.

Jim spent two years as a high school teacher in the Peace Corps in Morocco after graduating from the Johns Hopkins University where he received a B. A. with a concentration in Political Economy and Sociology in 1964.

This fall Jim will be a research assistant at the Health Services Research Center at the University of North Carolina and a student in Epidemiology.

The Public Health Sevice published a booklet introducing its class of Global Community Health Fellows, devoting half a page to each. This is the entry for Jim Bernstein.

Glenn Wilson remembers, however, that he "…didn't want to settle down and write a dissertation. He never did write very much, as a matter of fact…. He and I and Gordon [DeFriese, then an Assistant Professor of Sociology and a Research Associate in the Health Services Research Center] used to have lunch about once a week when my office was in MacNider. That dissertation project fell apart to some extent. I'm not sure he would ever have finished it anyway, because he wanted to do something practical and they wanted some theoretical paper. That's how it was described to me. And as the weeks went by I could see it unraveling. And then when Cecil came by and said: 'Walstonburg,' away Jim went."

That is probably an accurate reading of Jim's motivation, although it is incorrect chronologically, because according to Jim, the Walstonburg project began almost immediately upon his arrival in North Carolina: "When I arrived in Chapel Hill, in July, I went to see Cecil, and he informed me that I was to be in Wilson, NC, the next day to meet Dr. Edgar Beddingfield, and that night to be in Greene County to meet with a group of citizens who wanted to build a health center."

Walstonburg, a small town without a doctor, was representative of hundreds of others in North Carolina, and perhaps thousands throughout the south and midwest by the late 1960s and early 1970s. But it had something special going for it: It was less than 20 miles from Wilson, where Dr. Edgar Beddingfield was affiliated with the Wilson Clinic. Beddingfield was a past-president of the North Carolina Medical Society, but his influence in the state went well beyond medical society office-holding and even medical affairs. He was widely respected as a statesman. Early in his career he had gone to Stantonsburg, a small town between Wilson and Walstonburg, had entered general practice, and was still practicing there, albeit on a part-time basis (the rest of the time he was doing occupational health work through the Wilson Clinic).

Beddingfield had long been interested in the problems of the small town without a doctor, and he was intrigued by the possibility of relief offered by the physician assistant (which had more or less been invented by Dr. Eugene Stead, the legendary chair of medicine at Duke) or the family nurse practitioner, which was just then being advanced by the nursing school at Chapel Hill and its Dean, Lucy Conant, with the strong backing of Dr. Sheps, Director of the University of North Carolina at Chapel Hill (UNC-Chapel Hill) Health Services Research Center, or some other type of trained "intermediate level" practitioner supervised by a physician, such as the Medex program, at the University of Washington and Dartmouth, where ex-military corpsmen, Vietnam veterans, were trained to perform essentially the same duties.

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* The remarks at the Sheps memorial are published in James D. Bernstein, "Cecil Sheps Was My Mentor," in Donald L. Madison (editor), *Cecil G. Sheps Memorial Volume*. Chapel Hill: Cecil G. Sheps Center for Health Services Research, The University of North Carolina at Chapel Hill, 2005. All other quotes by Bernstein that appear in this article are taken from a long interview recorded by Nan Rideout in 2004 and transcribed by the author.

All of these “intermediate’ level practitioners required some defined clinical protocols, plus telephone and occasional personal clinical support and backup by a reasonably nearby physician, and, of course, intensive training. And in the case of Walstonburg, Beddingfield, who believed strongly in the concept, but who himself had no personal experience with it, was interested in providing the necessary medical backup. He also knew something about small rural communities and how to approach them. Bernstein credited Beddingfield as the “real father” of the North Carolina Office of Rural Health largely because of his support and critical political interventions. But Jim already knew, or at least had the instincts that told him, much of what he would have to do.

Walstonburg became Jim’s “field work,” supervised by Cecil Sheps. I told Wilson my take on this experience, as I remembered it, and then asked him to respond: If you look up Greene County in the Atlas of North Carolina, the 1967 version published by the UNC Press, you would find, I told him, that it was not the poorest county in the state, although it did rank toward the lower end and it was one of eight counties in the state with a majority African American population. Jim was going down there all the time, probably not every other day, but it seemed like it. He had this plan of educating the population, and so he goes over to North Carolina State to the School of Design to find students who could create a sort of cartoon book that would explain the health center and what a nurse practitioner would do. He was just a bundle of energy and ideas (some of which I thought were just short of wacky). But how, I asked Wilson, do you explain all that?

“Well,” he replied, “I think it was several things: One, Walstonburg was a clean slate; there’s nothing there. So there’s a chance to do something, and he got caught up in that. And then there was another kind of challenge, and that was to show the doubters—there were a couple of them in that general area, who quietly scoffed at this Jew from New York and what he was attempting to do; and he took that as a challenge. And so he started. And he was accepted. This was the beginning of his rare talent of sitting down with people, all kinds of people, and listening to them, and putting factions together. Now, not in the sense that he would always do what they wanted. He would bring in others to lead them away from some stupid mistake they were about to make. But Walstonburg is where he learned that. And he came back every week just full of himself, at what they, the community, could do. I told him it was crazy to take these design students to Walstonburg, but he didn’t always listen to me. And then we had a long conversation about what could be done for those people, and I reminded him of my friend Henry Daniels’ statement [Daniels was a career labor union executive with the health program of the United Mineworkers of America] that when you try and do something for people, you usually end up doing it *to* people. You’ve got to do it *with* them. And they’ve got to buy into it, and they’ve got to put up some money. So we had a long discussion about getting them to put up some money. I think I learned that with the Mineworkers clinics, in Canada [with the Steelworkers], and in Cleveland [in organizing the Community Health Foundation]. And Jim became an evangelist of that notion. And most importantly—this is another important trait of his—he never took the credit. And that’s one reason that the Office of Rural Health under his leadership worked so well.”

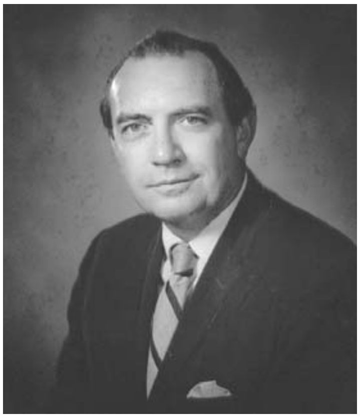
Did you go out to Walstonburg?

“Yes, a few times. And as you said, there wasn’t anything there, except a few poor people, mostly black, who had a magical relationship with a guy named Bernstein. Remember, this was 1971 or 1972. It wasn’t that far removed from the days of segregation.”

I asked Glenn what he could tell me of the relationship between the blacks and whites on the board that had to be formed—or I guess it had already been formed when Jim got there?

“You know, I think that was the first Bernstein magic. Because at that time, there was Klan activity, at least there were Klan signs up and down that road, to my certain knowledge, because I was traveling through that area, including Greene County, frequently—I didn’t have any business in Greene County, but I traveled through there to visit hospitals in the east, to learn the state (we were beginning the AHEC effort then), and I was mostly wandering around on my own, usually taking the long way to Wilmington. But the Walstonburg board members got along with great civility. I must have gone to maybe half a dozen meetings in that community.

“This was the same time,” Wilson continued, “that a community hospital in the east and another in the piedmont wanted to see pictures of the medical students we were going to send them—for obvious reasons. And we refused. So it wasn’t yet the era of enlightenment across the state. We finally told them that we weren’t going to do business with them on those terms. We would send them qualified students, who might be female or black. But those meetings in Walstonburg were far more congenial than anything I saw in my work with the community hospitals. And I never asked Jim how he put it together. So I don’t know. But that same pattern ensued in all of the rural health centers. Remember, though, you had not only black and white, but also rich and poor, who often don’t speak to each other—in civil terms. How did he do it? I don’t know, but he did. And as far as I’m concerned that’s the reason the Office of Rural Health was such a smashing success.”



Dr. Edgar Beddingfield

So Jim had Greene County, which was essentially a medical vacuum. He had a community board. He had Dr. Beddingfield to back up the nurse practitioner. But he didn't have a nurse. As Bernstein explained: "The idea for the program was that we would ask the boards in these communities to locate a nurse that they thought highly of. The kind of person they'd go to at night when people were sick. And then we would send that person to school, pay for them to go back to Chapel Hill or, later, to Greenville or Asheville. And they would then come back to the community where they lived and their family lived, and they then would stay there. They wouldn't leave. That was a really good concept. But in Walstonburg, it didn't turn out that way. So we had to search for somebody from the outside. And we finally found a nurse practitioner in Colorado. And she came here. Donna Shafer was her name. She did a really nice job. Donna was just a good one to be there—she was very unassuming, not aggressive. Which was what we needed at the time. So they just couldn't get mad at Donna. It worked very well."

Entrace to Walstonburg, NC

In fact, Donna, who later married an Englishman and moved to the United Kingdom, became a close personal friend of the Bernsteins, who named their youngest daughter after her.

I asked Torlen (Tork) Wade, who now directs the Office of Rural Health, how, in fact, the staff found the nurses who would be trained as practitioners in the early days.

"It was a combination," said Tork. "Some were hospital nurses, but most were nurses in doctors' offices. That made it a lot easier to sell the model because they would be backed up by that same doctor. Those were the ones who really worked well —taking a nurse out of the practice, sending her to Chapel Hill, and having her come back to work with that doctor. It was a very good model. But, it's funny; today it doesn't work nearly as well. You know, the level of education is much higher now. Most of them have master's degrees. But it's much harder to get them out into the community. And there isn't that confidence on the part of the doctors, because they haven't worked with them over a long time already. They're just hired. Maybe they're better trained, but having a local person be the provider was critical in the early days. Betty Queen in Black River was the first nurse practitioner there. Everybody knew her in the whole county. They loved her. They didn't really care if she was a nurse practitioner or even what that was; what they knew was that she could help them."

I knew that Glenn Wilson would remember how the Office of Rural Health came about.

"Well, it was Cecil. The committee of the legislature came to me, because we were preparing to reapply to the federal government for renewal of the AHEC support, and I said, 'How about making this statewide?' And they agreed to that (with state money). Meanwhile, Cecil had gone to Governor Holshouser and put this rural program in as part of the AHEC program. Chris [Fordham, then Dean of the UNC School of Medicine] and I went over there to see the Governor and told him, 'You really can't do that.' (Because medical schools don't do these kinds of things very well anyway, and we'll be seen as being in competition with the local doctors, and it will all blow up.) 'You need to set up something separate for this.' Holshouser said, 'But there isn't time.' And so at about 11:00 that night, it landed in the Governor's Office. And then the question, who would run it? It was very clear—that fellow from Walstonburg. It was settled that night, in my presence. And the Governor called Bernstein."

Jim's own account is not inconsistent with Wilson's, but it leaves out the organizational questions and the University's concern about combining it with AHEC.

"James Holshouser had just been elected Governor of North Carolina…. Cecil, in his unique fashion, calls up the Governor-elect to tell him that he has this terrific health program that is going to help solve the health access problems of rural North Carolina. He then asks the Governor-elect when he should come see him. Later, Cecil describes to the Governor his concept of a rural heath program built around community-operated health centers staffed by family nurse practitioners and physician assistants. When the Governor asks how he is supposed to make this happen, Cecil tells him that will be no problem—just leave it to him. Cecil then calls me into his office to tell me that he has figured out what I need to do next with my career. I am going to Raleigh to set up this new health program."

The program was announced publicly by the Governor and the Secretary of Human Resources, David Flaherty, who introduced the 30-year-old Bernstein at a news conference on Monday, June 19, 1973. Earlier the Legislature had appropriated $456,000 for the program—for the first five clinics. But the Governor's announced goal was to have 15 new clinics established within 26 months. Obviously, this goal anticipated further appropriations.

Soon after the announcement, Jim went to see Flaherty to negotiate his job. The conversation went well, although, as Jim said: "We didn't come to any resolution in his office, but it looked like we would come to some kind of understanding. And then he surprises me, and says, 'Oh, by the way, before you leave I want you to talk to this group.' Well, what he had done, when the notice had gone out from the Governor about the program, and it was in all the newspapers and on television, he had gotten all these letters of protest, most of them from physicians. And so they had invited all the people who had questions or who were mad to meet in this auditorium in one of the state buildings in Raleigh. I've forgotten which one. So he marches me on the stage, and there must have been 150 or 200 people in that room—lots of Board of Medical Examiners people and all these types. And he gets up there and says: 'Now I've invited all you people here who have criticisms or questions about our program, and here's the guy who can answer all your questions, he's the new director of the program.' So I took question by question by question. And you know something? When you're younger, in a lot of ways it's easy. You think you know more than you know. And it was such a new kind of thing, they didn't know if I was wrong or right. So when I said there is evidence around that the doctor can be in a different spot than the nurse or nurse practitioner, seeing patients with protocols, and it's worked in other places—I'd seen it in New Mexico and other places, but they'd never had any experience with it. So it was difficult for them to tear it down. I went through question by question by question for about an hour and a half until everybody wore down and went home."

That opposition was one obstacle. A second one was getting a law passed that would permit nurse practitioners and physician assistants to practice in these clinics at the level for which they were trained to practice. Bernstein explained: "Dr. Beddingfield was doing this in Walstonburg without a law to back him up. So we had to get a law through, and that was the next big fight. And I was sort of the floor manager, since I was the only one there who knew much about it. So I was hooked up with key legislators that Senator Royal and some of the others had put together. And we had our battle. And if it weren't for people like Dr. Beddingfield we wouldn't have won that battle. He was key to the whole thing. Anyway, at the end, when the bill was going through, and I was watching from the top, looking down, some legislator, I won't say where he was from, made a motion to fire Jim Bernstein. And the Speaker of the House said he was out of order. Because the legislature doesn't have the authority to fire a named person. They have the authority to get rid of a job, but not a named person. So I survived."

Having escaped that episode of parliamentary chicanery, Bernstein had to organize a statewide program. It was one thing to work, as he had done day and night, on the Walstonburg project. But now he was committed to be a wholesaler.

In this story, there are three Jims—Bernstein, Holshouser, and, later, Hunt. The young Bernstein, just beginning his work in Raleigh, once told me about a phone call he'd received at home the night before. It came from Atlanta, as best I remember, but it could have been from someplace else where a national governors' conference was then being held. The conversation left Bernstein in mild shock, which lasted at least until the next day when he told me about it. From this phone call, he learned that he had made the big time. The dialogue began like this: "Hello." "Jim?" "Yes." "This is Jim." (silence—then): "Jim who?" "Jim Holshouser."

Glenn Wilson notes one crisis Jim's Office was about to face: "I should remind you that the office was up and running and Jim was scrambling around the state. I know that while Jim was scrambling around the state, it wasn't that long before we had a change in administration. And he and I had concluded that Jim Hunt would not continue that program on which his Republican opponent had campaigned. And Sarah Morrow, who was Secretary of Human Resources under new Governor Hunt, thought this was something the local health departments should be doing. And so Jim Bernstein went to see Jim Hunt. He was accompanied by Mrs. Warren of Prospect Hill, who was a friend of Jim Hunt's—I think Glenn Pickard may have called her. Anyway, she called Jim Hunt and got him to come up there and see the Prospect Hill Clinic. I think Jim Bernstein went with him. And he had some support in some communities, not a lot at that point because it was still getting off the ground, but some, enough so the Democratic Administration was persuaded that it was a good idea. What Governor Hunt saw at Walstonburg and Prospect Hill and Snow Camp and one or two other places was some real community support and, potentially, a powerful political force, and he wasn't about to put it in the health departments or do anything to Jim Bernstein."

Along with Governor Hunt, Dr. Morrow would also become one of the program's most ardent supporters.

But, Glenn added, "…as for the overall operation. At the beginning, I wouldn't have given you a nickel for the chances of that succeeding. High visibility programs like that, programs that are cooked up by administrations usually don't survive when there's a change, I don't think. But here was an exception to that rule."

Bernstein needed a staff. First to join was Terry Alford, an architect recently graduated from North Carolina State University. Terry was a North Carolina native who had helped on Walstonburg as a student. He stayed on Jim's staff for a couple of years before going out on his own, although he continued working on rural health clinics in North Carolina and all over the nation. The Office of Rural Health helped build new buildings, but renovations were generally less expensive, and Jim's principle that the local community be required to come up with part of the money (a small part—the state put up the majority share on a five-to-one match) suggested a need for economy. So most of the earliest buildings were renovations, and, as Tork Wade remembers, "Terry Alford would put those blue awnings on some otherwise ugly building and make it look spectacular." In fact, Terry quickly became famous among those of us who knew his work because of those blue awnings. They became his motif.

But Jim also needed field staff, people who would do essentially the same job he himself had done in Walstonburg—attend board meetings, decide what technical assistance was needed and find it, help procure a nurse to be trained as a practitioner, arrange for physician back-up, and any number of other tasks that went into organizing a community health center. These people had to be self-starters with a talent for community organization, but also have a practical working knowledge of primary healthcare—not the clinical skills, but a knowledge of the things clinicians needed to perform their craft and a feel for how the relations among clinicians and the other staff and between the staff and the board and the community of patients should work.

First, Bernstein found Fred Hege, who had been director of the local Office of Economic Opportunity (OEO) Community

Action Agency (the basic local building block for President Johnson's War on Poverty) for Vance, Warren, and Franklin Counties. The Community Action Agencies were then being slowly dismantled (along with most of the other parts of the War on Poverty) by the Nixon Administration, under the leadership of OEO Director Donald Rumsfeld and his special assistant Dick Cheney. From this job, Fred had acquired the requisite community organizing experience, but he was also a former Moravian minister—a "missionary" in a sense, who by nature was an organizer of people and their efforts. Fred also had experience in state government. Soon afterward, Jim found Tork Wade and Burnie Patterson. Like Jim, Tork had been a Peace Corps volunteer (in Malaysia and on the Island of Borneo). He was just completing his master's degree in public health at Chapel Hill and for his fieldwork, had assisted Jim with the Walstonburg Clinic. Burnie was a social worker from Dare County, who met Jim while he was organizing a clinic on Nags Head. Burnie had earned his master's degree in social work at UNC-Chapel Hill. At about this time (1973-1974), I was teaching, through the School of Public Health, a reading seminar on rural health services, which I continued for about five years. It met once a week for two hours, and the assignments were formidable, since I included nearly all of both the recent and historical literature on rural healthcare in America. Jim sent Terry, Tork, and Burnie to take the course.

Other members of Jim's staff, who joined a year or two later, included the third ex-Peace Corps member, Roger Hagler, who had been an original volunteer—one of the group that had been sent off by President Kennedy with a ceremony in the Rose Garden. Roger, in fact, had been Tork's supervisor in Malaysia. There was also a second "missionary"—Gail Kelly, an ex-Maryknoll nun in Bolivia and Ecuador, where she had been a "do everything" healthcare provider—the general practitioner for an entire community; and Nan Rideout, who came from the western part of North Carolina and whose background was in teaching and hotel management (with a master's degree in the former, a bachelor's in the latter, and work experience in both).

Fred Hege was considerably older than Jim and provided a complimentary set of skills and experience. Nan Rideout had this to say about them: "The synergy that worked with Fred and Jim was amazing. I remember saying to them, 'I wish I could think the way you guys do.' And Fred said, 'you forget, there's two of us working at it, not just one.' There were so many things to deal with in terms of politics in local communities, politics in the General Assembly, as well as moving ahead with our goals for developing health services, and then the medical society also. Fred, I remember as being invaluable in that way, while Jim was completely involved in moving these projects ahead. Fred was also very instrumental in training those of us who came in later. I think Fred's background as a pastor and his ability to deal with people, understand people, was also invaluable. He used it well, because none of us ever saw him as a preacher, but he had those skills, which he used very adroitly. With many of the early office staff, it was a push-pull relationship, because Fred was very demanding, but he was very instrumental in shaping the office and those of us who came in."

Other early staff members, included Joan Peacock, who stayed on as Jim's assistant until she retired, and Judy Howell, who remains on the staff.

"You know," Nan continued, "I think that one of the most significant things about Jim was his ability to hire people. Regardless of their backgrounds or anything else, he hired really good people, and he wasn't afraid to take a risk if he thought someone, at a gut level, was right for the Office. He, in fact, eschewed those people with a background that would seem to fit because he wanted to take a new approach. He didn't want people to come in with preconceived ideas."

So people with degrees in health services administration?

"That was a definite negative. You'd have to prove to him that you could think outside the box."

Although later on, he did take people with those backgrounds, from the UNC School of Public Health and a few from the policy school at Duke. Tork says that the Office had a steady stream from there for a time and that they still have a couple, but that "the bread and butter came out of the School of Public Health."

"In addition to Jim's hiring good people," Nan says, "he was able to instill in us a sense of mission. We were focused on what we were doing. We didn't think of ourselves as part of state government. Jim was wonderful in isolating the office and letting it develop and percolate on its own. He was a wonderful buffer. And I have examples of times he really stood up for us. You could count on him when the chips were really down. And he also kept us stimulated and gave us enough independence in those early days. All of the original core field staff stayed with him at least 20 years, until we retired. There was virtually no turnover. I think that he hired people who were devoted to the mission and not to achieving status. And while we may have had some desires for the responsibility of running an Office, the greater desire was to see if we could accomplish something and achieve change. And that's why those of us in the early days never thought about leaving. It was a little frustrating to him because of that, maybe."

You mean he wanted you to go?

"Well, we all had other opportunities, and when we'd talk to him about them, he'd say, 'Go.' But nowhere else could one envision having the combination of responsibility for achieving a product like a health center and seeing the effect on a community, and

I think we were much more motivated by that than by the status of running a program. Jim was self-confident, but I didn't feel that he had any vanity or arrogance at all. He respected people for what they offered. And once I looked around the office, and I said to myself, 'My God, do you see how many tall women Jim has here?' (And tall men, too.) But it's unusual to find a person of short stature who's entirely comfortable surrounding himself with people who are quite tall. But I don't think he thought about that for a minute. It never occurred to him."

Well, he married a tall wife.

"I guess that was a good sign."

But there were those who didn't stay. Jim set down a set of principles. And many of them concerned the work of the field staff:

He started by saying: "We weren't going to run anything.… They, the community, would be primarily responsible, and we would provide the pieces that they couldn't put together themselves, as well as the know-how to make it work. Nor were we going to push ourselves or come out from Raleigh saying, 'We've got this new idea for your community and this is what you should do: You should have a health center; you should have a nurse practitioner; it should be run by the community.…' We acted only where we had a request. We might get a call saying, 'We haven't had a doctor in a long time and we're interested in just talking to you.' Then we'd send a staff person out. So that was another principle: Don't tell the community what they need. If they don't want what we have, that's fine. The next thing was to be able to put together all the pieces that were needed to do the job. So if a community wanted to do it, we had the ability to make it happen. And the most important part of that was our field staff … the people who interfaced with community folks. Our philosophy was, we go to them. So our field people were on the road all the time, meeting at whatever hour the community group could get together, whether it was Sunday afternoon or Monday night. And most of those meetings were at night. So we were going to be an agency that went to the community; very rarely did a community person ever have to come to Raleigh. And the staff person had to be able to deliver the goods. So if the community group wanted to explore this idea and then develop it, the staff person had to put together all the pieces. If a building was needed the staff person had to have access to an architect, which is why we had our own architect—and our own media person to back up our staff people. It was important that the community didn't see the staff person as someone who had—we didn't have much—a little bit of money to sprinkle around, but rather as someone who could actually help them get healthcare in that community. So the field staff had to learn about erecting buildings, they had to learn about medical records, and most important, they had to learn to work with communities and had to have community organizational skills, which are something, I've come to conclude, that you can't teach very easily. They are somethings you either have or you don't have."

Bernstein continued: "People—potential staff—who came by mistake to this office (versus another office), who were looking for a cookie cutter kind of job, something they could do every day, didn't make it in our Office. It just didn't work. And in the beginning, it was really hard on those people who would say, 'What's my job? What do I do?' Well, you've got to get on your feet out there. But there's a lot of support from the staff back home; you know, myself and the other staff people would kick around with you about how you're going to deal with your problems in that particular community—because always there were problems. None of it was easy. But if you were looking for someone who used a workbook and went out to a community and said, 'This is how we're going to do step one,' just like that, it wasn't going to work. You had to be a person who could think on your feet and make decisions and move forward on your own. Most of the people who could adapt to that kind of style, who liked it, stayed for years. Others, who didn't fit, didn't last long. They just left. Because they were uncomfortable in that kind of a role."

During the first year, Tork Wade remembers, the field staff identified five communities to work on: East End, Bakersville, Bladenboro, Newton Grove, and Westfield. Tork described, in general terms, the method that the field staff followed: "We'd kind of have these steps we'd follow. It might start with a call that said our doctor is retiring. They didn't want a nurse practitioner, per se, they just wanted a doc. But we'd go out and meet with them—and we didn't really have a physician recruitment program yet at that point—so we'd tell them what we had, what the requirements were, and they might not be interested. So it was, 'Thank you, and who else can we call?' There were a number of those. But once there was interest, where they would say your program does look like it might fit our needs, then we would do a market study and compile all kinds of preliminary statistics—you know, to decide whether there would be enough demand to make it work. And once we went through that and decided there would be demand and that the market was OK, it generally went through. It might have taken a while, but I just can't think of any that failed after it went that far. There might be delays, for example, to get the physician support. I remember places where the docs would object to the program simply because it was from government. You know, that was usually the biggest barrier—getting the back-up physician lined up. But they would usually come around in time. You might have to move on to another doctor. But they would come around, finally. And there would often be pressure from the community for them to respond."

"We might say, 'Well, Dr. Pickard would be glad to come in and talk with you.' Physician-to-physician, you know, and that would often turn them. Glenn Pickard [internal medicine at Chapel Hill] was the primary one who did that. Terry Kane [family medicine at Duke] went out some. And Zell Hoole [internal medicine at Chapel Hill], I think, once or twice. And Rob Sullivan [internal medicine at Chapel Hill and then at Duke]. And Larry Cutchin [internal medicine and pediatrics at the Tarboro Clinic] did some, too. But the major share of it was Pickard. He would go anywhere we needed him to go. He connected so well with the docs, and he was from North Carolina. Plus, he was the pioneer on all of that—along with Betty Compton [family nurse practitioner at Prospect Hill]. And then on the legal issues, Dave Warren [Duke Law] would go to assure them they weren't taking on a huge liability. We had wonderful support out of Chapel Hill. And then Jim had that connection with Beddingfield on Walstonburg. And that was huge. Because he was a big shot who all the docs respected. He was from the country, and a former president of the state medical society. And he was not an academic. But he carried a tremendous amount of weight. He didn't go around and speak, but he would pick up the telephone and talk at association meetings. But those were contributions without which the program wouldn't have gotten off the ground. A lot of that Jim pulled together. But some of those people came on their own initiative, because they believed in it. But Jim never had any problem asking, either. He knew it was important."

Over the 30-odd years of its existence under Jim Bernstein's direction, the Office of Rural Health established more than 80 health centers. But there were some additional programs where the Office did not take the lead, at least not initially (another agency—a foundation, the federal government, or perhaps another state agency—began the program or provided the initial funding and technical assistance), but the North Carolina Office of Rural Health usually either worked alongside or followed up later when there were problems. A good example is the Hot Springs Health Program in Madison County, started by Linda Mashburn (nee Ocker), a nurse with experience throughout Appalachia and in India; and Jerry Plemmons, former head of the local rural electric cooperative, who did the initial community organizing; and with assistance from the Health Services Research Center at Chapel Hill and major funding from the Appalachian Regional Commission (ARC). After a modest beginning, some early success; several crises; three decades of growth and change; assistance along the way from the UNC School of Medicine, the Mountain AHEC, the Office of Rural Health, several foundations, and an influential local politician, the Hot Springs Health Program is now a countywide primary care program (in a county with no hospital) that has more than filled the gaps left when the aging private physicians in the county could not replace themselves as they retired or died. It may be unique in the nation in this respect or at least one of a very few.

The Bernstein Family: Donna, Eric, Lori, Sue, and Jim

In its early days, the program got off to a good start, but then got into trouble—political, administrative, clinical, and fiscal. Jerry Plemmons is now chair of the board. I asked him what Jim Bernstein's role in all this was.

"He was the fixer."

And, indeed, when the Hot Springs Health Program seemed on the verge of "going down the toilet" (Linda Mashburn's description), Jim sent Gail Kelly from the Office of Rural Health staff, who practically lived in Madison County for the better part of four months. Linda, who by this time was no longer the executive director, but was still employed by the program as a home health nurse, says that she talked with "all the board—over the phone and in person, behind the scenes, and then I called Jim and said, 'Help, help, help!' And Gail Kelly, when she came up to do her work, stayed at our house. She came on the heels of this airlift of medical personnel [from Chapel Hill, because the program was, by then, without a doctor], and it was obvious that we could not survive long doing that. The airlift was a short-term thing, and we needed a long-term plan, and so Gail was there to work that out."

Jerry Plemmons added, "She made many of the decisions that an executive director would have made. She served in that role without being in that role. She put together … a plan to include an expansion to Marshall and the development of a Marshall clinic.… A part of that, as I recall it, was that the five-year ARC funding cycle was due to expire. And the program could not sustain itself without some outside support."

Linda explained why: "Because it had too small a service area, and it was operating in the poorest area of the county. Also, the major thing that had changed by the time Gail was there was that one of the two elderly physicians in Marshall had completely retired, and the other one was only half time and was looking to retire within the year. When I started the program in Hot Springs, Marshall did have medical services, but by this time those services were gone or going."

"What happened," Jerry said, "was that the board and the community supported expansion of the program into the Marshall area, which was Gail's recommendation. There was already a clinic in Walnut, which is maybe eight miles from Marshall, and that clinic was to be moved in the direction of Marshall. It ended up being about half way between the two communities, which then expanded the program's service area to include Marshall. And then, of course, the docs in Mars Hill were still active and were still opposed to…."

"But they were coming around a little bit," added Linda. "Because during the time I ran the home health agency for Hot Springs, and it was a county-wide home health agency, so I had many of the patients of the physicians in Mars Hill that I visited and had to deal with them for orders and such, and at least they saw some value in all of that. They were less hostile, let me put it that way."

Plemmons said, "That did do a lot to at least cool them down a little bit, but it certainly didn't change their attitude toward socialized medicine, which the Hot Springs Health Program was in their minds."

Did they use that term? I asked.

"Oh, my yes! Very definitely."

"Within a period of four months," Jerry said, "we were having an organizing meeting in Marshall—of community people. And it was at that kind of meeting that you [Linda] and I got elected to the board. When they changed the bylaws to include Marshall, then you and I went onto the board together; and we were on the fund-raising, planning committee for the new Marshall facility. The Office of Rural Health provided architectural services. Taylor Barnhill from Jim's staff—that was his entry into Madison County, and he did the architectural work. We had done a business plan, believe it or not, which said we could pay for the building in seven years. This would have been Gail's doing. None of us would have paid any attention to something like that."

"The next thing," added Linda, "was that I organized a door-to-door volunteer fund-raising campaign and got the volunteers to do it so that every single resident in the whole Marshall area was visited by a volunteer and told about the new facility and asked to pledge or donate to it. We raised about $25,000 that way, maybe a third or almost of the total cost."

Jerry remembers that the total renovation of the building, "…so that we could start the down payment of it and so on, was around $80,000. But what we learned early on from that fund-raising was … and we did that in order to have some match for some foundation monies. But we learned that by giving the community an opportunity to donate, they felt a greater sense of ownership and were more likely to use it if they felt it was theirs…. We maintained that philosophy throughout the years.

"But then Liston got us a state grant." Liston Ramsey was from Marshall and represented Madison County in the state legislature. He was, at the time, Chairman of the House Appropriations Committee and, later, for six years, Speaker of the House. He is a political legend, not only in his former district, but statewide.

I would be interested, I told Jerry (who is the consummate storyteller) in hearing how that happened.

"Well, one morning one of the fund-raising committee members ran into Liston down on the street in Marshall. And Liston said, 'I see where you fellas are trying to raise some money for a new clinic.' And he said 'yeah.' And Liston said, 'Well, do you'uns need a little state help?' And he said 'Well, yeah, I guess we could use a little state help, if the state has any money to give us.' And it just so happened that we were having a meeting of that committee that night—at my house. So he invited him to come, and he did come. We talked for maybe 45 minutes or an hour, just general conversation. And he thanked us. And we said, 'Well, do you need a proposal from us?' And he said, 'No, but them people in Raleigh, they like to see them articles of incorporation and bylaws. If you'll send that to me, that should be enough.' And we said, 'What do you think we might get from the state?' And he said, 'I really don't have any idea,' he said, 'Normally, them fellas don't cut me any more than half of my request.' He said, 'If I ask for 40, I might get 20.' So we were operating on the assumption that the state was going to kick in about $20,000. And the articles of incorporation and bylaws were sent to Raleigh. Didn't hear another word from Liston. Didn't see nothing in the paper about the Hot Springs Heath Program getting any money. The legislative session was over. Still nothing. And Liston's pattern then was that every Monday morning, he'd go by the post office at Marshall, pick up his mail, and go to Raleigh. Even when the Legislature wasn't in session, he would be in Raleigh most of the week. And one Monday morning one of the committee members ran into Liston, and he said, 'Well, I guess you fellas heard that we was able to get you fellas a little money.' He said, 'No, hadn't heard that.' Liston said, 'Well, we'll get you a check in a while.' He said, 'It takes the state a little while to write them things, but we'll get 'em to ye.' And so, the next Monday morning, I was in the post office at nine o'clock, when Liston came in for his mail. Liston said, 'Did you hear?' And I said, 'Yeah, Liston, I heard that you'd been successful, but didn't hear how much.' He said, 'Oh, I was pretty fortunate this time.' He said, 'I asked for $80,000 and got all of it.' And so with that our building was completely paid for. We had gotten so excited about that. And we had found out that when we switched from ARC funding to Public Health Service 330 monies, that we were then eligible for bricks and mortar from ARC, and we said, 'That's great. Let's see how we can use some of that money.' So, the original facility at Laurel was a 100-year-old farmhouse that had no insulation in the walls, and we had to put a radio in every exam room so the doctor could turn the radio up while he was interviewing his patient so that the confidential information didn't flow around and feed into the grapevine. And we decided that it was time to replace that facility. So we went to ARC and went to the community, and we got…. We opened the new Laurel facility and the new Hot Springs facility both in 1984. And not only did we get ARC money, but Liston, who by this time was Speaker of the House, helped too. He'd say, 'Well, a lot of people call it pork, and they's welcome to do that, but Madison County don't have any large state university or no large state employers or any state buildings, and if I can bring some state money back to help my people help themselves, then I'm proud to do it.' That was his line, and it was a good one. Because ours was a poor county, the poorest or second poorest in the western part of the state. And for many years it was the poorest in the Appalachian Regional Commission area."

"The new Hot Springs facility, which included a dental program, opened in '84, and then in '86 in Mars Hill, there was the community clinic staffed by three private physicians. There was also a solo practitioner across town. And by '86, one of the physicians in the clinic had moved to Florida to practice, another had died, and the third wanted to retire. And what ended up happening was—he wouldn't sell his facility directly to the Hot Springs Health Program…, so in '86 the Program bought the Mars Hill Medical Center through a convoluted deal with Mars Hill College. He'd given the facility to the College with the understanding that the College would sell it to us. And one of the significant things that happened was that MAHEC (Mountain Area Health Education Center) began graduating family physicians in '79, and we got a person out of their first graduating class—Chipper Jones."

That's before he went off to play baseball?

"Yeah. He only does that in the summer.* But recruiting physicians became easier. We can recruit physicians a hell of a lot easier than we can recruit dentists, that's for sure. And about as easy as we can recruit nurses. When we opened up the Mars Hill facility, that meant that we were the only primary care provider in the county. There were no private practice doctors. And that's still the case. I will say that the first two years we were in the Mars Hill facility, we did rent space to Dr. Whitson, who wasn't fully ready to retire. But that helped, because he retired gracefully, and he was not anti-Hot Springs Health Program."

Linda remembers the first time Jim Bernstein came to Hot Springs. "In the very early days, even before we got the grant from the Appalachian Regional Commission, this would have been in 1972, probably. You brought a whole planeload of folks out from Chapel Hill to Hot Springs, including Cecil Sheps, and I think Jim was on that trip. I know there was someone from Public Health Nursing along, too. This would have been in the first six or seven months I was there."

I remember that trip, I told her. The money from the ARC looked certain by then, and I wanted to see what kind of help might be available from Chapel Hill, which I had more or less assured the people at the ARC would be forthcoming. Jim would no doubt have been along because he was our "fellow" in rural health. So I took him with me everywhere I went—Wise and Clinton, Virginia; Harlan, Kentucky; Logan, Man, and Buffalo Creek, West Virginia, I remember. And to a conference in Davis, California, on rural health that I had helped organize for The Robert Wood Johnson Foundation. (Linda was at that conference, too.) And when I started the Rural Practice Project for The Robert Johnson Foundation—by this time Jim had begun the Office of Rural Health—I insisted that he be on the board. The Foundation officers objected because none of them had heard of him, but they gave in. I told them I needed someone local whom I could rely on for advice and feedback, and I trusted both Jim's experience and candor.

Jerry added to Linda's comment about Jim earliest visit to Hot Springs, speaking about that program's later years: "Every groundbreaking, every dedication, anything of that significance, Jim Bernstein was always there. You didn't have to beg Jim to come. He wanted to be there. He wanted to take part. And he was very generous in his comments at those events. I don't have a lot of stories about Jim that I could tell, other than to say that. But in later years I became amazed thinking back over those times.... I became chair of the Hot Springs Health Program, I think in '79. In those early years, I had gotten to know Jim, but not too well. But I felt comfortable in calling him anytime there was a question or an issue. No matter how elementary or simple it was. Jim would take all the time in the world to talk me through it and give me advice, and if someone else should be involved, he made sure that they were involved too, and were well informed. And I must admit, before I got involved in some other things, that I thought Jim had a really plush job, that all he did was sit down there in Raleigh and wait for me to call him. Because if I called, and he was on the other line or out of town or in a meeting, it didn't matter what, within 30 minutes to an hour, I could expect Jim to return the call. And later on I realized, of course, that he had a fantastic ability to keep a lot of balls in the air at one time. I'm glad I didn't know all of the things Jim was involved in because I wouldn't have called him. And I would have been the lesser for it. But he never made me think that I was taking his time or that he had other things to do. I'm sure that many times he had to rearrange his schedule to come up for our groundbreakings and dedications and things of that nature. But I never knew that. He never indicated that."

Another example, perhaps the best one, of joint programming was with the North Carolina Medical Society Foundation and its first Director, Harvey Estes, who took that position upon his retirement from the Duke University medical faculty in 1989. As Harvey remembers, "I was sitting there with four and a half million bucks in the bank from Kate B. Reynolds and with a mandate to do precisely what Jim had been mandated to do all along. And as I sat around thinking of my task, it became plain as the nose on your face that it made no sense to compete with a program that is already out there and successful. Well, we began to have weekly meetings at the Office of Rural Health, which became, I think, the most productive piece of my program and maybe of Jim's as well, because we began to sit around and think of what we could do together, me with my pot of money, he with his pot of money, to jointly tackle problems that neither of us could solve by ourselves."

Because of the limitations of the two pots?

"Yes, but mainly his. Ours had few limitations. We could spend it for most anything we wished. So we put together an advisory committee, which was a widely divergent group of practitioners and policy makers. It was a good group. And Jim, of course, already had lots of advisors, with the state and the University and the Sheps Center [previously referred to as the UNC Health Services Research Center], that he called on regularly. So we began to work together—not just occasionally, but every day, there would be something that the two of us talked about, a circumstance, some problem, something. And in our working relationship, we quickly became integral to each other.

"But I will say that I have never seen an office of any type that ran with more noses to the grindstone that they're supposed to be getting polished with than Jim's. Everybody on that staff was attuned to what they were doing, not to who's in charge, or the money. The money was important, but that was Jim's job. Their job was to go to Jim and say, 'Jim, I've got to have so many more thousand dollars because we've got to have it to do this thing that needs doing.' And then Jim would scratch his head

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* For the uninitiated and those who will find this reference confusing, Dr. Chipper Jones, who must have heard and responded to this joking reference hundreds of times (and for which I apologize for my inability to resist repeating it yet again) does not play baseball for the Atlanta Braves.

and worry about where that money was going to come from, whether it came out of this pot or that pot. He knew his sources and he knew—he had this Foundation by then, and he could operate that mechanism. But he played all those things like a well-tuned orchestra. And our piece of money became another major instrument in the orchestra. And that was fine, because what we were really doing was for Bertie County or Hoke County and not for Jim or his Foundation or ours or anybody else. And never once was I under the impression that we were being courted for being a funding source.

"Jim was the most unselfish program leader I have ever worked with. There was nothing that interfered with his interest in the result at the other end. And he believed, vehemently, and he taught me, that you'd never get it to work unless those people are involved in what happens to their own community. And that gets to the fund raising. The amount may be inconsequential in terms of the total that is required, but it is very consequential in terms of getting the loyalty and involvement of people. They have to be involved. And he knew people. This was the thing that was most impressive to me. Here is this guy who sits in Raleigh, and you talk about some county—X County—and he would say, 'Let's go talk to (this guy) because he knows everybody in that county; and he can tell us what the political structure is and who you've got to get involved in order to make it fly.' And we would go to the strangest places. I remember once we flew down to Hatteras Island and landed on the island to talk to one of his old buddies…."

Not the lighthouse keeper?

"No, but it was an amazing experience. And we would go to Troy to meet with one of his old buddies. And we'd talk about his problem over dinner or after dinner. We'd have a cup of coffee, and then we'd drive back to Chapel Hill. Or I would go out with one of his seasoned crew. These were people who lived in the Raleigh area and had as their responsibility a covey of community boards. And they were responsible for the relationship between the Office of Rural Health and that community board. And they would go to the community board meetings, that were always at night. They would travel huge distances and spend the night and go to a board meeting, and meet with the staff, and then they would come home. And we would go with them on these trips, and we would do our business, jointly. Jim would go with us to these meetings. He knew all of these people, and he would meet others. When we came back, Jim's architect would draw up the preliminary drawings. It was a very wonderful and productive relationship, and a happy one. I just had all the admiration in the world for him and his crew and what they were doing. There was not a mean bone in his body, not a bit of selfishness. He just gave all of his effort and time. How his family put up with it I don't know."

So you had a first hand look at the problems of rural medical practice, rural hospitals, that whole scene, I told Harvey. I call it a "first hand look" to contrast it with the kind of look you'd had as an academic leader at Duke—just as important, surely, but different. Plus, you chaired a panel of the National Institute of Medicine on the topic of primary care. But counting all those academic activities, as well as your work with the Foundation and with Jim's Office, you've spent a long time looking at this whole body of problems, enough so that I can ask you as a real expert this question: How have those problems changed? Which ones have been solved or have disappeared?

"I don't think we have solved any of them."

But some have become less important, perhaps?

"Well, they've changed their order of magnitude, but they are still there. We have shifted from one set of problems to another. Manpower is still a major problem, but different than it used to be. Let me refer back to Ed Beddingfield, who quickly immersed himself in a very busy practice in Stantonsburg, doing a lot of OB (obstetrics), doing a lot a primary care, and living upstairs over his clinic. Well, the demand quickly ran away with him. And back then when the practice would overrun a doctor, that doctor would look for a partner, and they would split the work 50/50. I'm on call; you're on call. But that only works if your expectation is that I will work every day, and I will work every other night. Today's crowd is quite different from that. Half of those who aspire to go into primary care are women, or men with young kids, and to them that's not the way it is. You really aspire to work eight hours and to be off 18, or at least 12. Well, primary care does not lend itself to that kind of day for its practitioners. So today it's not the same as it was when Ed Beddingfield was in Stantonsburg, but in some ways it is the same, and we are having difficulty recruiting young men and women into it, because of the demands of the practice and the fact that the practice has to be thought about 24 hours a day. Somebody's got to worry about it. Because people call on the practice 24 hours a day. But the young doctor doesn't want to do that, so you've got to set up some administrative mechanism, some organizational entity, that will take that load, and then you've got to get the clinical load divvied up in eight-hour shifts. So in a way the problem is more complex now, because the demands on the practitioner—or on the practice—are more complex. The practitioner now doesn't have anything to do with business. That's somebody else's job. If the practitioner was handling it all, it would be intolerably complex now. Because he would worry about the business, the schedules, the new partners, who's working where, what the equipment is in that place. If the practitioner were to embrace all that into his activity, he couldn't do it. So we must learn how to do that. Our large medical centers are failing miserably. Because they don't know how to do it.

President Clinton hears about the problems confronting rural hospitals. To Bernstein's left is Montgomery County Hospital Administrator Kerry Hensley.

"Now Jim knew that. His passing is a tremendous loss because people trusted Jim, that he knew what he was talking about. Jim understood the problems I'm relating. But very few others do. Deans think they know. They may think they've got a good primary care service, because it takes care of the poor in their community. But does it take care of the well-to-do in the community? Let's ask that question. Because it doesn't take care of them either; it doesn't answer their basic question, which is 'Who am I going to go to at 12 o'clock at night?' And that's their basic responsibility if they take over primary care.

"Jim did not necessarily come across as a person with great strength. Meeting him the first time, you wouldn't figure that Jim had fiber that was not visible. His staff knew it. And his staff knew that you didn't rile Jim. You got Jim mad and you caught hell. He would lay in to people, read them the riot act. They all understood that it was not a pleasant experience. I never saw it, but they told me. See, I would get in the car with one of his senior staff people, and we would go to some community for two days, drive there and back in the car, and during that time, a lot of things would come up. Or you're there eating dinner and having a beer after dinner, so things come up."

You were one of his senior staff in a sense.

"Exactly."

Going out and doing the legwork?

"Not that Jim was unwilling to go, and he did go if he was needed."

Besides directing the Office of Rural Health, Jim became President of the Foundation for Alternative Health Programs in 1982. It was a non-profit, non-governmental body that could accept grants from private foundations, and its first task was to bring health maintenance organizations and other managed care schemes to North Carolina. In the late 1970s and early 1980s, the overriding concern in North Carolina and around the country was control of healthcare costs, and HMOs were seen as an effective solution. The Foundation was successful in bringing in the Kaiser Health Plan, although after 15 years Kaiser folded it's North Carolina tent and left the state. Later on, the Foundation changed its name to the Foundation for Advanced Health Programs. "Alternative" had, in the interim, taken on an entirely different meaning in terms of healthcare; but the program of the Foundation had also morphed over the years from a focus on managed care programs toward more general issues in medical care. Two of the Foundation's board members are Jerry Plemmons and Don Patterson. I asked Jerry, who has been on the board since sometime in the late 1980s, what the business at hand was when he became a member.

"Access, I think, and Medicaid. But the interesting thing about those meetings was seeing how Jim's mind got around whatever issue came up and thinking about it differently. It was always interesting for me to watch and listen to him, because he was not one to be put off by barriers. He would always see them as a challenge and an opportunity to figure out a different way."

Well, then, I asked him, what was the nature of the interaction between Jim and the board in those meetings? Was he using the board to learn or was he trying to convince the board.

"I think it was an equal kind of thing. It was an open brainstorming time, when an issue would be thrown out and anybody who had any thoughts or ideas or had seen anything similar or had run into anything that might be a problem with it, they would share that, and Jim would absorb it, of course, and then come back at the next meeting and say, 'Now here's what I've done.'

"I remember another thing that Jim got me into in 1993. The Clinton Administration was having a national conference in Little Rock on the Clinton health plan. And the Jackson Hole Group was there. And each state had two representatives. This was focused on rural healthcare. Dr. [Tom] Ricketts from Chapel Hill was there, too."

Jerry, you and Linda seem to agree from your own observations of the Hot Springs Health Program and its history that five years is about the time for a program administrator before burn-out sets in. But I want to remind you that Jim Bernstein was in that position for 30 years. And you, Jerry, made the point about how often he returned your phone calls in 30 or 45 minutes and was at every groundbreaking and so on. I guess my question for you is how do you explain that he didn't burn-out in five or even 15 years?

"I think he was a missionary," said Plemmons. "I think he realized that this was his calling. That's the only way I can explain it. Also, he had developed a heck of a support network. I mean, he knew people everywhere doing everything. And he wasn't at all shy about calling on them. Also, I think that Jim's survival under so many administrations speaks to his professionalism."

Don Patterson, a retired IBM executive and another member of the Foundation board, met Jim after IBM "loaned" him for a year to work for Governor Hunt. During this time he managed personnel administration, which included benefits, and other matters. It was also during Don's year in state government that the legislature started the Foundation, which at the beginning had a board that was appointed by various office-holders, including the Governor. And Governor Hunt appointed Don Patterson to the Foundation board in 1983. Patterson was also a neighbor of the Bernsteins in Chapel Hill, so their relationship became social and personal as well as professional.

"You know," said Patterson, "Jim didn't say a whole lot in those meetings, but when he said something, it was kind of like that old ad you'd see on TV for that stockbroker: When so-and-so spoke, everybody listened. E.F. Hutton, wasn't it? And that's the way Jim was. When he spoke, you knew that what he was saying was the way it would come out; that's what would happen. He didn't want to take a lot of chances. He wanted to make sure that everything was honestly done, and that's why I say he was one of the most ethical persons I ever knew. He did not want to have to report back to one of the foundations that we blew some of their money. It's just marvelous what he's done for this state when you stop and think about it. And not only this state. You go around the country to some of the rural areas … and see how they've patterned themselves after what Jim started here. We'd go to meetings. I remember one time we were down in Boca Raton … the meeting was about rural health, and they knew I was from North Carolina, and I bet you that nearly everybody said, 'Well, do you know Jim Bernstein?' 'Yes, he's here with us, at this meeting.' 'Oh, I've got to meet him,' they'd say. 'I've never seen so much that he's had a part in starting up.' And I'd say, 'Well come on, I'll introduce you.' You'd think they were meeting the President of the United States or something. That's just the kind of guy he was. He wanted to do everything right. He was willing to take chances, but he wasn't the kind of person who would take risks. He wanted to be sure it was right. It was, 'I don't know if this is going to work, and if it doesn't work we've wasted a lot of money that really isn't ours.' You know, we're up to almost $5 million in our budget now. That's what we distribute out through the state programs now, working with Tork Wade and the Office of Rural Health.

"When I think about Jim, the more I worked with him and saw what he was doing, he just had a knack for picking good people. Really good people. He wasn't a very formal guy. You know, he didn't know a lot about their resume or anything, but he could work with them for a little bit and know that they were going to be a good person and a good worker. He has surrounded himself with a lot of good people. Tork Wade is a good example, and Burnie Patterson. A bunch of those folks, are just good people. And another thing: Jim had no ego. As much as he'd done for this state, he could probably have developed an ego, but he just didn't. He'd say, 'It's part of the job. This is what they hired me to do.' And you never heard him brag about anything. But when you looked carefully at what had been done, you saw that he was the leader, he was the catalyst. But it was never an ego thing. That's what I admired about him."

Tork Wade also reflected on the Bernstein style: "As we got bigger Jim became more Raleigh-based, and it changed the amount that he was engaged with the rest of us on a day-to-day basis. And he delegated to either Burnie or myself a lot of the key operations. He'd do his own thing. He'd take a special interest in hospitals or something like that. And while he was doing hospitals, we were doing health centers. I had a special relationship with Jim, personal, too; it wasn't just work; and Burnie did, as well. So during all that time, we'd have a regular interaction every day during the day. And even at the end, after Jim left here to become Assistant Secretary, he and I talked several times every day. And we got together every day. I think that just the way we had worked for 30 years continued. It was fun. He was so engaging, and full of ideas, and enthusiasm, and laughter. It got so that I knew what he was going to say even before he said it. And the same with me. I didn't have to ask Jim how should we start, because I knew what he would say."

Nan Rideout says, "Jim was the one person we always thought would be there. Part of the esprit in the staff was the feeling of family that he was responsible for. We could always count on him being there for our personal problems and our family problems. And as a result, we thought he always would be there. He was always sensitive to his friends and needs of people in his sphere, but he was equally sensitive in terms of values to the disadvantaged. That was his primary focus, and that communicated a lot.

"Jim would talk with all of us on the staff, but in different ways. Once he told me, 'Burnie is the only one I can tell what I really think.' I think he also valued Tork a lot, because he was always steady, calm. And the women, Gail and I, were the ones who argued with him. He didn't like it, but we knew him and loved him and trusted him enough so that we could get away with it. It was successful so we kept doing it. But we always felt tremendous loyalty to him."

What about office intrigue? I asked Tork. As the staff grew, there must have been some tension.

"You know, we were so busy we didn't have time for any office intrigue, worrying about who was getting ahead of the next person. There were a few people who didn't fit in well. If you were someone who needed a lot of direction, you were up the creek. If you were young and you tagged along with someone that would be fine. But if you came in and were expected to carry your own weight and yet expected to get a lot of feedback … Jim wasn't a person who gave feedback very readily. You'd know if he was mad. But if you were doing a great job you'd hear that from someone else. It would be rare for Jim to say anything. And if he did, it was usually because he had another motive. The people that needed a pat on the back would be unhappy."

I asked Glenn Wilson why he thought Jim took the job as Assistant Secretary.

"Well, he thought for several weeks that he wanted to be Secretary. And we talked about that. I called Bill Friday to intervene on his behalf. The interview, according to Jim, went poorly. He answered all the questions directly. He came back and said, 'I blew it.' And he quickly realized that he didn't want the job."

Well, I don't see Jim as a politician, and when you get that high, you're a politician.

"No, and that's what he understood from the interview."

Why do you think he wanted to be Secretary?

"He wanted to fix things. Now Jim's naiveté was part of his charm."

He did, however, become Assistant Secretary.

"The reason Jim took that job, I think," said Tork Wade "is that Carmen [Hooker Odom] is very, very persuasive, and Jim liked Carmen. She convinced Jim to take the job. While Jim loved working with Carmen, assuming responsibility for large chunks of the health bureaucracy wasn't a great fit for what Jim did best. What Jim liked best and what he did better than anyone else I've known, was working with community and health leaders designing and implementing innovative solutions to difficult health issues. As Assistant Secretary for Health, too much of his time was spent dealing with the demands of a large bureaucracy. I think that was one reason that he elected to retire when he did."

But Carmen has had a hard time, with the budget cuts and all.

"And it was good that she was Secretary during that time because she has no problem making hard decisions."

When she had to make cuts, do you think she cut the right things?

"That's where Jim was particularly helpful. Because of the breadth of his knowledge about so many programs, he could help her make the best decisions. I have a lot of respect for the job she did during very difficult times."

Was Jim working harder in that job than when he was here?

"No … Jim always worked hard. But he didn't have the passion. He was doing stuff that we were doing out of here—like Medicaid. He still kept his finger in that, and that was fun. But a lot of it wasn't. You know, maybe I need help getting this job through personnel, that kind of stuff. And he'd help Leah Devlin, or he'd help me and other groups. And then he'd have to go give speeches for Carmen. So he'd have to go talk to a group that he had no idea about and had no interest in. He didn't have any problem relating to them because he could always relate to anyone, but it was something that was painful. I was happy when he retired. Happy for him."

After he retired, when did you notice that he was sick?

"Even before he retired he was complaining of stomach problems. And trouble swallowing."

So he never really had a retirement that was a peaceful one?

"I think he felt alright in the fall, but that was really the last time."

"We're going to miss him," says Don Patterson. "He's done so many things, and I hope we can keep his name on the forefront for a long time. We need to help people remember who he was, because I don't want anybody to forget about him. He was too super a person—a great asset to this state—and a great friend, to tell the truth."

You put your finger on something right then, Don. Because in addition to what Jim did in his work and how he worked and chose his staff and the other things you've been talking about, one of his outstanding attributes was as a friend. And we mustn't say that lightly. He would be as concerned about your personal life. And it wasn't like a good boss asking, "How's your family?" It went way beyond that. I've never, ever seen anything like it.

"Well, that's right. My first wife died in '79. She had a brain tumor. And then my present wife had ovarian cancer in '98. And Jim called me about every other day, wanted to know how things were going. Said, "What can I do for you?" I mean he was very concerned all the time. That's just the kind of person he was, concerned for other people, never put himself ahead of anybody. He was a true friend, the kind you needed. And he's raised a beautiful family. Those kids are super kids. And when he decided, look, I'm going to die and there is nothing they can do for me—I think his mother went through a lot with cancer. Anyway, I asked him, 'Jim, are you going to do any more treatment?' And he said, 'No, the kids are going to come home every other weekend to see me.' Because he would rather have a good quality of life with them. And except for his physical limitations because of his disease, I'd say he had a pretty good quality of life up until the day he died, almost.

"And at our board meetings I sometimes catch myself saying 'Now wait a minute, how would Jim solve this one.' Because I had so much respect for his ability to lead the Foundation and do the right things, and I feel obligated to keep doing it the way he would do it. That's out of respect for him and our friendship." **NCMedJ**

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ISSUE BRIEF

State and Local Partnerships for Meeting the Healthcare Needs of Small and Often Remote Rural Communities

Thomas C. Ricketts III, MPH, PhD

American healthcare has been described as a "non-system," but there have been persistent efforts to coordinate and rationalize how we provide medical care in the United States. These efforts have resulted in what may be called informal systems of care. A perfect example of one of those systems is in North Carolina, a system created for the people of the state's smaller and poorer communities, communities that are most often rural and more often inhabited by racial and ethnic minority citizens.

Almost all of North Carolina could have been called rural at the end of World War II. The 1940 Census classified 72.7% of the state's population as rural or living in communities with fewer than 2,500 residents. A few cities—Charlotte, Durham, Greensboro, Asheville, Raleigh—had modestly large populations, but no city in the state had a population greater than 110,000. The state's economy was strongly linked to agriculture, and the prevailing perception of North Carolina was of a sleepy, rural, somewhat backward state.

World War II created an economic stimulus for the state when military installations were located in North Carolina—shipyards were established in Wilmington to build liberty ships, and facilities were developed to house prisoners of war in the central and the mountain regions of the state. But the war left another legacy beyond economic benefit: the state had experienced the highest medical rejection rate for its draftees of any state in the Union. The causes for rejection were usually chronic problems related to nutrition and poor or unavailable basic medical care and health advice. This embarrassing fact is often cited as the driver of the statewide "Good Health Campaign" promoted in 1949 by prominent North Carolinians, including Kay Kyser, who recruited radio personalities and Hollywood stars to help raise money and direct attention to the healthcare needs of the state. That public effort had a significant impact, but it built on prior efforts to expand health resources. For years, politicians had been debating whether to assist one or both of the private medical schools in the state (Duke University and Bowman Gray) or whether to create a large medical center by expanding the two-year medical school at the state university in Chapel Hill. Governor Melville Broughton appointed a Medical Care Commission in 1944 to study the health and medical needs of the state. That commission recommended the creation of a new, state-supported, four-year medical school in Chapel Hill that would share space with the existing School of Public Health and occupy space adjacent to a new, comprehensive teaching hospital. After years of consideration, the General Assembly supplied construction funds that were combined with money from the Hospital Planning and Construction Act of 1947, the Hill-Burton Act, to build Memorial Hospital in Chapel Hill and to create the teaching hospital. The Hill-Burton program also supported the construction of many North Carolina hospitals and public health facilities in rural communities.

As late as the 1950s, healthcare services in rural North Carolina were considered inadequate. An unflattering review of the quality of general practice in the state was published in the *Journal of Medical Education* in 1956.[1] However, there were examples of excellent medical care in some communities and effective public health structures had long existed in others. The nation's first local health department was established in Guilford County in 1911. Robeson County set up the first professionally managed rural health department in 1912 when county commissioners appointed a full-time county health director charged with the task of creating an administrative unit of county government to ensure the health of the county's citizens. The state's growing appropriations to the state Board of Health soon allowed other counties to organize their own essentially independent public health units.

Walter Hines Page and the Country Life Commission, a national organization committed to "uplift rural folk," helped to bring the problem of hookworm disease in North Carolina and the rural south to the attention of the Rockefeller Sanitary Commission for the Eradication of Hookworm Disease, which in

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1909, began taking steps to eliminate this debilitating infection as one step toward improving the economy of the south. Because state officials considered the direct involvement of the Rockefeller group to be too intrusive on a population distrustful of wealthy northerners, the state Board of Health set up a cooperative Bureau for Hookworm Control to sponsor the campaign in North Carolina. The combined efforts eliminated the hookworm scourge and, in the process, created a lasting focus on public health at the county level. Rutherford County physician, Dr. Benjamin Washburn, who had worked in Wilson County during the hookworm campaign, began forming additional county departments modeled on the Wilson experiment.

A Division of Public Health in the two-year University of North Carolina (UNC) Medical School was created in 1936 with funds from Title VI of the Social Security Act. That Division, under the leadership of Milton Rosenau, continued the tradition of community-based programs and projects, and that orientation became part of the tradition of the independent school of public health that emerged in 1940. This commitment set the tone for the next generation of public health and rural health leaders, both academic- and practice-based, who assumed their positions in the 1940s, 1950s, and 1960s and who viewed the role and mission of state institutions as one of service outside their walls.

Milton Rosenau died unexpectedly in April 1946, soon after being elected President of the American Public Health Association. The University's President Frank Porter Graham, who was largely responsible for the service orientation of the University, followed the recommendation of the School of Public Health's acting directors and named Edward McGavran to become the new dean in April 1947. McGavran—a graduate of Harvard Medical School, a former county health director, director of a Kellogg Foundation public health training program, and a professor of Preventive Medicine at the University of Kansas—firmly fit the mold of the "outsiders" who came to North Carolina to encourage creativity in healthcare delivery and public health.

An addition to the School of Public Health faculty ensured a focus on rural and community-based health services in the state. In 1947, Cecil G. Sheps joined the faculty as an associate professor of public health administration. Sheps, a native of Winnipeg, Canada, and his wife Mindel, a professor of biostatistics, had been involved in the development of the Saskatchewan health insurance system that became the model for the universal, province-based system of healthcare financing in Canada. In a 1953 report to the Medical Society of North Carolina, Sheps maintained that a key ingredient in solving the state's healthcare delivery problems rested on "the development of a program of an extension of services from the University Health System to the state at large … in concert with other similar institutions of the state so far as medical and nursing schools are concerned." That commitment was later to result in discussions that created the Area Health Education Centers (AHEC) concept.

Building AHEC: Bringing Clinical Training to the Community

In 1965, Dr. Reece Berryhill, former dean of the UNC School of Medicine, became director of the new Division of Education and Research in Community Medical Care, created jointly by the UNC Schools of Medicine and Public Health to work in local communities that were forming working relationships with private practitioners. Dr. Berryhill was succeeded in 1967 by Robert Smith, MD, a general practice physician formerly of Guys Hospital in London. In 1967, the Division began an affiliation with Moses Cone Hospital in Greensboro, with financial support from Moses Cone Hospital, to give physicians from UNC-Chapel Hill another local practice option as part of their training in internal medicine and pediatrics. Later, through the Health Councils of Eastern Appalachia, the Division received a grant from the North Carolina Regional Medical Program in 1968 to support additional community-based training and to send clinical specialists to smaller hospitals for teaching and consultation assistance. In 1969, Glenn Wilson, the Vice President of Kaiser Cleveland Health Foundation, was recruited to UNC-Chapel Hill as Associate Dean for Community Health Sciences and as the new Director of the Division of Education and Research in Community Medical Care.

The North Carolina General Assembly appropriated $395,000 for a community-based training program for physicians at UNC in 1969 and again in 1971. These funds were used to support fourth-year medical school clerkships in affiliated community hospitals in Wilmington, Charlotte, Raleigh, Rocky Mount, and Tarboro.

The Carnegie Commission on Higher Education, with University of North Carolina President William Friday as a member, issued its report *Higher Education and the Nation's Health* in 1970. This report called for medical schools to devote more of their clinical training time to community settings using a new kind of entity, the Area Health Education Center. The United States Congress responded by authorizing the development of a limited number of community-based health professional educational partnerships under the Comprehensive Health Manpower Training Act of 1971 (P.L. 92-157). That legislation, which surprisingly did not include the term "Area Health Education Center," but used this term only in the conference report that followed enactment, made available federal funds for demonstration projects that would link academic health centers and community-based hospitals in networks focused on the training of multiple health professions as well as the stimulation of professional continuing education of those already in practice. As this new legislation was enacted, Glenn Wilson at the UNC School of Medicine assembled an interdisciplinary team to begin aggressive efforts to work out affiliation agreements with several additional hospitals and medical centers throughout the state for the purpose of applying to be designated as one of the first federally funded Area Health Education Centers Programs. The initial grant to the UNC School of Medicine to develop the AHEC Program in North Carolina was more than $8 million. The North Carolina AHEC Program would eventually involve collaborative relationships with the four schools of medicine (UNC-Chapel Hill, Duke University, Bowman Gray School of Medicine of Wake Forest University,* and East Carolina University's Brody School of Medicine).

A key element of the AHEC structure was the creation of regional centers that were closer to rural communities throughout the state. There was one completely rural AHEC, termed "Area L AHEC" after the multipurpose regional planning designation for the counties surrounding Rocky Mount and Tarboro. The decision to encourage distributed medical education recognized the state's demographics and gave the medical schools incentives to work with essentially rural hospitals. That initial AHEC focus on rural communities set a pattern for later development and orientation and closely followed the traditions of the University and the state's politics.

For the 1974/1976 biennium, the North Carolina General Assembly appropriated $23,500,000 for capital costs to build regional AHEC centers, $4,548,720 for operating expenses, $1,125,000 for residency grants, and $250,000 for Community Practitioner Stipends. The General Assembly also set targets for training in the AHECs, committing the program to develop 300 new primary care residency positions by 1980. Simultaneous with the establishment of the AHEC program, the state also began funding family medicine training programs. UNC established its Family Medicine Department in 1969 with Dr. Robert Smith as its first chairman, and the Bowman Gray School of Medicine in Winston-Salem opened its department in 1974. Duke University Medical Center added a division of family practice to its Department of Community Medicine in 1972. The General Assembly has continued its support of these programs with direct appropriations and capitated student and resident support.

By 1975, the federal AHEC program had funded programs in 11 states, including North Carolina, where the concept had already received legislative, professional, and public acceptance. There is general consensus that the North Carolina Area Health Education Centers Program was, at its inception, and remains today, the model for the nation, and that is due to the willingness of many partners to cooperate in its development and operations.

North Carolina's Health Services Research Center

Another key element of the rural policy structure fell into place with the founding of the Health Services Research Center at the University of North Carolina at Chapel Hill in 1968. The goal of the proposed center was to help develop more effective ways to "deliver personal health services in community settings" by exploring "new roles for professionals" and productive means to change organizational features of healthcare practice.[2] The Health Services Research Center fit snugly into the rural health policy network because the community-based system it intended to examine was largely devoted to increasing access for rural residents. As sites for its study of experimental comprehensive health centers, the Research Center selected the rural parts of Orange County and all of Caswell County, a 100% rural county. These areas formed the service area for a United States Office of Economic Opportunity (OEO) Neighborhood Health Center that used nurse practitioners. The Research Center soon worked out cooperative research and technical assistance agreements with other clinics being established in Walstonburg, Tarboro, and Hot Springs—all of which were located in very rural sites in the eastern and western parts of the state.

In 1970, three young United States Public Health Service (USPHS) officers (James Bernstein, Ted Parrish, and Michael Samuels) were selected as fellows in the USPHS Program in Global Community Health and were given the opportunity to enroll in graduate programs in the UNC School of Public Health. Each of these young Public Health Service scholars focused their work on problems related to rural primary care and the supply of rural healthcare professionals. All three men were full-time employees of the United States Public Health Service. All three men meshed well with the activities accompanying the development of the Health Services Research Center, with Samuels concentrating on problems of professional recruitment, Parrish on community-based health education, and Bernstein on the appropriate community structure for viable rural health services. Samuels graduated in 1975 and went on to a career in the Public Health Service, during which he served as deputy administrator of the National Health Services Corps and the Health Services and Resources Administration and as deputy to the United States Surgeon General. He later held faculty positions at the Universities of South Carolina and Kentucky. Parrish became active in local North Carolina health program development and is Chair of the Department of Health Education at North Carolina Central University.

James Bernstein took advantage of the commitment to rural communities, which was the focus of the UNC-Chapel Hill Health Services Research Center, where he was mentored by Cecil G. Sheps, the Center's director, and Glenn Wilson, the Associate Dean of the UNC School of Medicine. When James Holshouser became the first Republican governor of North Carolina in the 20th century, he began exploring ways in which he could bring the influence of the governor's office to bear on the extreme shortages of primary medical care in North Carolina's rural communities. He asked Dr. Cecil Sheps, then the acting vice chancellor for health affairs at UNC as well as the director of the Health Services Research Center, to discuss this matter with his colleagues and propose some concrete ways in which the state might address these problems during his four-year term of office. Sheps suggested to the new governor the idea of community-based primary care clinics staffed by advanced practice nurses specially trained to meet the everyday medical care needs of residents, who would be backed up in

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* The Bowman Gray School of Medicine is now the Wake Forest University School of Medicine.

their clinical work by local physicians. The governor asked Sheps to elaborate on this idea and present a detailed proposal for how such an initiative might be taken. Dr. Sheps turned to Jim Bernstein to develop the formal proposal document. Once the governor studied the proposal, he concluded that it outlined a viable program, and he gave it his full support. He translated that support into an executive order that became part of his legislative agenda. Subsequently, the proposal drew wide support from politicians of both parties, including the Democratic lieutenant governor, James B. Hunt. Convinced that such a program would greatly benefit the state, the General Assembly created the Office of Rural Health with an appropriation of $456,000 in 1973.

North Carolina Office of Rural Health

A key element in the early success of the Office of Rural Health and its clinics was the support of the North Carolina Medical Society for the use of nurse practitioners. Two prominent physicians, Drs. Glen Pickard (of Chapel Hill) and Edward Beddingfield (of Wilson), convinced the Society to support a nurse practitioner practice act acceptable to the physician community. That support helped build the legal structure that allowed advanced practice nurses (called family nurse practitioners) to be trained, first at UNC-Chapel Hill and later at other institutions, and the new clinics to open. Even with this broad backing, gaining acceptance of the Office within state government remained a struggle.

Professionals in the Department of Human Resources, recently created during a general government reorganization to include the traditional public health functions as well as new and old programs related to health services, did not believe the Office would survive beyond the Holshouser Administration. After its initial placement in the Governer's Office, the legislature placed the Office of Rural Health within the Division of Facility Services, an agency previously responsible for administering the Hill-Burton Program and licensing hospitals. However, Governor Holshouser firmly insisted that the Office was attached to the Division only for administrative purposes and that any policy decisions were to involve consultation with the Governor's office. Prior to passage of the authorizing legislation and subsequent appropriations, the governor and the principal proponents of the program struck an agreement expressly delineating the direct route of accountability to the governor—a surprising agreement since it bucked the current trend toward greater consolidation of government into cabinet departments. This element of policy independence from other agencies in government, consequently, provided the key to the success of the Office and has remained one of its defining characteristics to the present.

The appropriation for the Office of Rural Health almost tripled in its second year to $1,200,000 and jumped to $1,611,000 in the third year. Funding grew much more slowly afterward as the Office gained recognition as a focused programmatic agency with a bounded set of goals. The Office established strong political stability in large part because Governor Hunt, elected to succeed Governor Holshouser, became a strong supporter of the Office and its concepts and because the Office carefully avoided using its policy independence to compete for resources directed to other agencies. The Office continued its independent role during a reorganization of health agencies under the administration of Hunt's Republican successor, Governor James Martin, during which time it was briefly aligned with the state's health planning functions. It became the Office of Rural Health and Resource Development, placed administratively within the Department of Human Resources, after Jim Hunt was elected for an historically unprecedented third four-year term in 1992. The reorganization that resulted in the Department of Health and Human Services (DHHS), under H. David Bruton, who served as Secretary of the newly named Department. At that time, the Office was renamed the Office of Research, Demonstrations, and Rural Health Development (ORDRHD, more often called the Office of Rural Health), to emphasize its role in fostering innovative approaches to healthcare delivery and financing. In 2000, when Michael Easley was elected Governor, he appointed Carmen Hooker Odom as DHHS Secretary, and she brought Bernstein into the position of Assistant Secretary for Health. Following Bernstein's retirement from state government in the fall of 2004, Torlen Wade became Director of the Office, and it retains a key place in the structure of the Department.

The accomplishments of the Office include the development of more than 80 rural health clinics; the placement and support of more than 2,500 physicians, nurse practitioners, physician assistants, and dentists; and the creation of the Community Care of North Carolina (CCNC, formerly Access II-III) networks that provide capitated care management for Medicaid eligibles. The office also supports a Migrant Health Program that awards small grants yearly on a competitive basis to local health departments and non-profit agencies for primary care services to farmworkers in high-need areas. This work is coordinated with the North Carolina Association of Community Health Centers, which operates an active regional technical assistance system for the Mid-Atlantic Region, as well as supporting the migrant health centers in the state

The Office of Rural Health may serve as the focus of policy relating to rural health issues, but it does not exercise formal administrative responsibility for oversight or even coordination of programs in other state agencies that serve rural communities or affect rural healthcare delivery. Instead, in part through support from private foundations, combined with the ability to create special programs from time-limited special appropriations, the Office serves as a resource and brokering agency that stimulates coordination among program directors and exerts its capacity to add value to programs and projects with funding flexibility. Consequently, few programs or initiatives in primary or community-based healthcare delivery fail to receive some input from the Office, as much because of its experience in working with almost every aspect of the delivery system as for its policy role and its close political ties to the General Assembly and the Governor's Office.

The North Carolina Foundation for Advanced Health Programs

The North Carolina Foundation for Advanced Health Programs, Inc., (NCFAHP) is a statewide non-profit organization charged with the mission of increasing the availability and affordability of healthcare for North Carolina residents. The Foundation, established in 1982 on the recommendation of a special legislative commission studying the issue of healthcare costs in the state, serves as a catalyst for programs that improve the quality of and access to healthcare while controlling costs. It works with business, medical, and civic leaders throughout North Carolina to explore solutions to healthcare problems and to develop specific approaches that meet community needs.

In the early 1980s, the first major initiative by the Foundation helped to expand the quality and number of competing alternative health plans available to North Carolina residents in a program to improve the healthcare marketplace. As part of that effort, the Foundation worked to bring health maintenance organizations (HMOs) to North Carolina for the first time. The Foundation was also instrumental in establishing Preferred Provider Organizations (PPOs) in the state and has encouraged the formation of locally-formed alternative health plans.

Through the hospital-based Rural Health Project, funded by the Robert Wood Johnson Foundation from 1986-1992, the Foundation helped to organize three hospital alliances, which assisted small rural hospitals in developing more cost-effective methods of maintaining and expanding appropriate medical services. The primary objectives of this program were to improve the financial stability of participating hospitals through the development of programs to improve market share, to enhance reimbursement options, and to increase the quality of, access to, and cost-efficiency of health services for rural residents. As an outgrowth of this project, the Foundation has also developed a model to assist small rural hospitals in their transition from acute care medical centers to primary care and specialty care providers. Our Community Hospital in Scotland Neck converted its 20-bed acute care unit into a 100-bed medical services center offering nursing home care and specialty care for senior citizens as well as emergency care and augmented primary care services for the general population.

The Foundation developed a program to improve the care of Medicaid recipients starting in 1986 with a single county demonstration program, the Wilson County Health Plan. That effort, jointly supported by the Kate B. Reynolds Charitable Trust promoted the concept of a "medical home" for Medicaid recipients in this largely rural county. From that demonstration, the Carolina ACCESS program evolved. This was a collaboration with the North Carolina Division of Medical Assistance to implement a federal waiver to demonstrate regionally the effectiveness of the "medical home" concept using a care manager supported with a per-enrollee fee. The program was successfully implemented in 12 counties with the Foundation providing leadership and management. With the approval of the General Assembly, the program was transferred to the Division of Medical Assistance and implemented on a statewide basis and now operates in 99 counties as Community Care of North Carolina (CCNC).

The Foundation also supports and manages projects intended to improve care for the uninsured poor, including a community-based primary care program that has provided the impetus for the development of new start-up community health centers in Wilmington, Kinston, and Wilson County. The Foundation also coordinated the "Covering Kids" demonstration to increase enrollment of children in Health Check/North Carolina Health Choice. Other projects included efforts to improve the management of health services, for example, supporting the implementation of the Baby Love program in 22 primary care centers to improve prenatal care; support of pharmacy access projects, including the 340-B program in the state; and developing networks among rural hospitals to assist in compliance with quality standards.

The NCFAHP is also the recipient of other grants to supplement the work of the Community Care of North Carolina program in its primary care management systems in rural parts of the state. The NCFAHP is the coordinator for one of five national demonstrations to improve the care of the elderly by improving working conditions for caregivers in the Better Jobs Better Care Program sponsored by the Robert Wood Johnson Foundation. The Foundation also managed the National Program Office for the Practice Sights program. That work supported the development of model recruitment and retention systems in other states using the successful methods and approaches of the North Carolina Office of Rural Health.

The East Carolina University Medical School

An important addition to the rural healthcare delivery structure in the state was the East Carolina University's Brody School of Medicine, in Greenville, North Carolina. Predominately rural, with an economy based on tobacco-dominated agriculture, eastern North Carolina has long projected an image as the state's poorest region and has lagged behind the rest of the state in industrial development. National commissions studying methods to expand the supply of physicians had identified North Carolina as a potential candidate for a new medical school. Politicians appreciated an opportunity to develop a stable economic engine for the east as well as to raise the prestige of the regional state university. However, the decision to create the medical school was a contentious one.

The battle to develop the East Carolina School of Medicine began in 1964 when Dr. Ernest Furguson, a general practitioner from Plymouth, North Carolina, and East Carolina College president Dr. Leo Jenkins agreed that East Carolina College (ECC), as it was then known, should build a medical school. Dr. Jenkins asked local physician Dr. Ed Monroe and ECC Professor Robert Williams to conduct a needs assessment, following which, Jenkins began an arduous campaign to locate a medical school on his campus.

The initial proposal from the needs assessment called for the creation of a two-year medical school that would send students to the UNC School of Medicine for the remainder of their education, an idea strongly opposed by the three other Schools of Medicine. Jenkins then went to the North Carolina General Assembly, which authorized and appropriated funds in 1965 to plan a two-year medical school at ECC if accreditation could be obtained, ignoring a recommendation from a panel of consultants who preferred to expand the existing ECC allied health programs. When ECC requested, in 1967, that the General Assembly grant it independent status as East Carolina University (ECU), the legislature rejected that proposal and instead made it one of the constituent universities of the consolidated University of North Carolina system, but it also authorized the creation of a Health Sciences Institute at ECU (which became the School of Allied Health and Social Professions.)

The need for more physicians in the state at that time was evident in statistics. North Carolina ranked 43rd of the 50 states in the ratio of physicians to population and 46th in the ratio of medical students to population. Mortality figures identified the state as one of the least healthy regions in the nation. In 1969, a Committee on Physician Shortage in Rural North Carolina appointed by the Legislative Research Commission acknowledged the need for better access to medical care and as a solution, recommended the expansion of the UNC School of Medicine from 75 to 200 graduates a year and the provision of subsidies to Duke University School of Medicine and the Wake Forest University School of Medicine to train North Carolina residents.

Popular support for a medical school at ECU continued, however, and in 1970, the General Assembly appropriated funds to develop a two-year medical curriculum at ECU, which then admitted 20 students to a one-year program.

Leaders in North Carolina's other three medical schools had heavily invested in training specialists, and they argued that if a crisis in access to primary care existed in North Carolina, it could best be addressed by training physician assistants and nurse practitioners. They also claimed that the problem was not a deficiency of medical students, but the lack of capacity for residency training.

In 1972, the UNC Board of Governors appointed a five-member committee headed by Lt. Governor Robert Jordan to advise it on health manpower needs. The committee subsequently recommended paying the Duke University and Wake Forest University Schools of Medicine a per-student stipend to train North Carolina medical students ($5,000 in 1975; $6,000 in 1976), continuing to enroll 20 degree candidates in the one-year ECU program, and commissioning a team of national consultants for a feasibility study.

The most significant body to study the issue of manpower and the possible need for a second, publicly-supported medical school was the so-called "Bennett Commission," which rendered its report in September 1973. That report indicated that the proposal to build a four-year school of medicine in Greenville was "premature" and that the only hope of success was to expand the school of medicine at Chapel Hill. The North Carolina General Assembly, in the end, did not accept the key recommendation of this report and appropriated funds for the development of what is now the Brody School of Medicine at ECU.

The 1974 General Assembly appropriated funds to expand the ECU school, adding a second year emphasizing family medicine and encouraging the recruitment of minorities. In November 1974, President William Friday proposed to the UNC Board of Governors that the ECU School of Medicine become a full, four-year medical school, and the 1975 General Assembly appropriated funds to make his proposal a reality. Enrolling its first class as four-year medical school in 1977, the school set as its central task the training of primary care doctors for rural and eastern areas of the state, with the intention of alleviating apparent shortages of physicians. The school was renamed the Brody School of Medicine in 1999 in recognition of the Brody family, prominent in business in the eastern part of the state.

The ECU Brody School of Medicine has been active in the training of primary care physicians with the support of the Robert Wood Johnson Foundation's Generalist Physician Initiative, the development of rural community-based residency sites, and participation in the Rural Scholars Program, where medical students from ECU and UNC receive focused clinical skills training in rural settings.

The North Carolina Student Rural Health Coalition

The North Carolina Student Rural Health Coalition emerged as an outgrowth of the success of the Tennessee Student Health Coalition that began at Vanderbilt University in 1969 and developed into a family of effective student activist organizations, which included the Appalachian Student Health Coalition and the West Tennessee Student Health Coalition. While he was a fourth-year medical student at Vanderbilt, Grady Stumbo, directed a related, but more professionally-oriented project sponsored by the Student American Medical Association (SAMA) to assist Appalachian communities. Those projects were the result of a general sense of dissatisfaction among medical students with the relationship between organized medicine and formal medical education and the needs of communities. The contrast between the theoretical component of a medical education at Vanderbilt or the University of Tennessee and the reality of the lives led by Appalachian residents in the late 1960s was too stark to be overlooked by concerned students in a period when social activism was the prevailing ethic. Richard Couto describes the origins and development of those Tennessee projects in *Streams of Idealism*,[3] a title drawn from commentary by Robert Coles,[4] who also figured in the development of social activism among healthcare professionals at the University of North Carolina and Duke University and who remains active in both universities working with medical students and faculty. Donald Madison, a medical school faculty physician at UNC-Chapel Hill and one of the staff recruited by Cecil Sheps to begin the UNC-Chapel Hill Health Services Research Center (now named for Sheps) played a substantial role in the development of the North Carolina Rural Health Center movement. Not only did he take a lead role in writing the proposal to fund the Lincoln Community Health Center in Durham and Durham County, but he played an active role with the development of the Hot

Springs Health Center in rural Madison County in the North Carolina mountains. In the mid-1970s, Madison was asked by the Robert Wood Johnson Foundation to lead the Rural Practice Project, a national program in which multi-disciplinary teams of healthcare professionals and administrative personnel were assembled to begin primary care clinical practices in communities having severe access to care problems in several states.[5,6]

In the early 1980s, students from a mix of health sciences schools organized the North Carolina Student Rural Health Coalition in the Durham-Chapel Hill area, with activity centered at Duke University and UNC-Chapel Hill. The Coalition subsequently sponsored health fairs in rural communities, helped place students and professionals in underserved towns and villages, supported public health awareness in rural communities, and agitated for more attentiveness to the rural healthcare and community development needs of rural North Carolina. Eventually, students from the ECU Brody School of Medicine and North Carolina Central University combined to create the current structure of the coalition, which also includes students from the UNC-Chapel Hill School of Public Health and the UNC-Chapel Hill and Duke University Schools of Nursing.

Students have been active in creating or supporting so-called “People’s Clinics.” Medical students from ECU, UNC, and Duke University and nursing students from North Carolina Central University offer free medical check-ups and other medical services in five community-managed clinics in eastern North Carolina: Fremont in Wayne County; Shiloh in Wake County; Garysburg in Northampton County; Bloomer Hill, which straddles the Nash-Edgecombe county lines; and Tillery in Halifax County. All five clinics are in rural, deprived, predominately minority communities, with few, if any, medical care resources, very high infant mortality rates, and severe economic problems.

Community Practitioner Program

The North Carolina Medical Society Foundation developed the Community Practitioner Program in 1989 with initial support coming from the Kate B. Reynolds Charitable Trust in the form of a $4.5 million grant. The program functions as a coordinating center for the recruitment and support of physicians, physician assistants, and family nurse practitioners who provide primary care in underserved areas in North Carolina. The funds go for loan repayment as well as for practice development. Practitioners receive support in return for five years of service in a qualified community, and they also agree to accept Medicaid and Medicare patients. To date, the Community Practitioner Program (CPP) has assisted 336 primary care physicians, physician assistants, and family nurse practitioners in 126 communities located in 76 economically distressed or medically underserved counties. In 2005, more than 400,000 patients were seen by CPP providers. Of the practitioners who were with the program for the five-year service period, 64% remain in the target communities; 73% continue to practice in rural or economically distressed counties, and 85% remain in North Carolina. In 2006, the program will add a management support capacity, Project Sustain, to continue to assist the community-based practices.

The program has been able to leverage the original Kate B. Reynolds funds to a total of $12 million over the 15-year period. That investment has allowed CCP-supported practitioners to provide approximately $225 million in care to uninsured patients. The CPP is the only non-governmental program of its kind in the nation and other states and medical societies have looked to it as a model for their own efforts.

The North Carolina Hospital Association

The North Carolina Hospital Association created the North Carolina Rural Center in 1996 to help its rural member hospitals cope with the special pressures they face. Initial support from the Center came from the Association’s membership and a grant from the Kate B. Reynolds Charitable Trust. Under the leadership of Jeff Spade, the Center musters the resources of current Association members, private consultants, state government agencies, and university faculty to provide support and advice to rural hospitals and communities. Its initial work focused on the support of networks to bring resources to rural communities through links between larger hospitals and smaller rural hospitals. The Rural Center sponsors an annual small and rural hospitals conference that brings together individuals from all sectors of healthcare and community development. The support goes beyond networking to practical technical assistance in quality assurance and information technology, two areas that are at the forefront of the Center’s agenda for the 21st century.

The Duke Endowment

One of the largest private foundations in the United States, with $2.5 billion in assets at the close of 2004, The Duke Endowment devotes part of its primary focus to the support of hospitals and healthcare in North and South Carolina. It provided over $39 million in health grants in 2004 and supported almost every rural hospital in North Carolina with funds to cover indigent care and special projects, including grants to renovate the obstetrics department in Ashe County in the rural mountains and to develop an injury prevention center in Kinston in eastern North Carolina. In recent grants, The Endowment has emphasized children’s health, with multiple grants to support school-based services. In 2005, its grants were focused on developing access to care for indigent populations with an emphasis on prevention. The Endowment looks to foster cooperation among agencies and organizations to leverage funds for greater impact. For example, specific to rural health, The Endowment, provided core funding for a family practice residency program in Hendersonville, North Carolina. This project involved the joint efforts of the Central and Mountain AHECs, the North Carolina Medical Society, the state’s four medical schools, other tertiary care hospitals in the region, and the North Carolina Hospital Association. The Endowment is targeting Health Information Technology in its 2006 health program along with its traditional focus on access to care. For rural North Carolina, the Endowment supports projects in economic and social development through its "Program for the Rural Carolinas" that recognizes healthcare as an integral part of rural communities.

The Kate B. Reynolds Charitable Trust

The Kate B. Reynolds Charitable Trust was created in 1947 by the will of Mrs. William Neal Reynolds of Winston-Salem and is one of the largest foundations in North Carolina, with assets of more than $500 million. Three-fourths of the Trust's grants are designated for health-related programs and services across North Carolina, and this amounted to $18.2 million in grants in 2004. Many grants have helped support healthcare innovation and service delivery in rural North Carolina as the Trust sought to achieve its primary goal of increasing the availability of health services to underserved groups. The Trust has an explicit emphasis on funding rural areas. A sample of recent grants illustrates this: funds to the Bertie County Rural Health Association and the Tyrell County Rural Health Association for capital projects to support access-oriented facilities; to Blue Ridge Hospital Systems to help improve access in a rural mountain area; to the Pender County Health Department to expand dental hygiene services for low-income children. The Trust works with other funders and agencies to coordinate its work to enhance the impact of its giving; this is facilitated by the participation on its advisory board of leaders in the North Carolina AHEC, the North Carolina Medical Society, North Carolina Hospital Association, and regional civic leaders from across the State.

Bringing It All Together

This brief review has only touched on some of the more prominent of the many people and programs that have helped the people of rural North Carolina receive the healthcare they need. The number and range of programs described here points to a single characteristic of the North Carolina approach to improving rural health: leaders in North Carolina healthcare and public policy have recognized that no one agency, organization or institution could really improve access to care alone—all of the fundamental elements of healthcare delivery had to be involved to truly have an impact. However, to make that happen, there needed to be some focus, some entity that, though it did not "command and control," helped various groups convene and collaborate. That entity was the Office of Research, Demonstrations, and Rural Health Development which, in turn, was supported by a network of connections and relationships that spanned government, the professions, and the institutions involved in healthcare delivery and finance.

The momentum for change was in place before the Office was founded—there were proposals for networks and changes in professional roles when the Office opened. But to make those things work in communities with the effective support of agencies and institutions required some central organization to work out the details at the local level, negotiate with the powers that affected all aspects of healthcare delivery, and, in the end, allow the credit for the small and large victories to be shared. This comprehensive approach was not so much a formal process of consensus, but rather a shared recognition that all stakeholders were invited to join in the work and that these efforts ought to focus at the community level. While large bureaucracies and interest groups might be able to stand apart at the state level, it is in the local community that the dangers and negative effects of isolation and and separation are readily seen. **NCMedJ**

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ISSUE BRIEF

Building Local and State Partnerships in North Carolina:
Lessons Learned

Torlen L. Wade, MSPH, Andrea D. Radford, DrPH, MHA, and John W. Price, MPA

The first state office of rural health was established in 1973 in North Carolina, and over the years, it has evolved into one of the largest of such offices in the nation. Along the way, many lessons have been learned from both successes and failures in the Office's efforts to build local and state partnerships to meet the health needs of rural and underserved communities. This article touches on a few of the key lessons learned.

Guiding Principles

Jim Bernstein, the founding director of the North Carolina Office of Research, Demonstrations, and Rural Health Development, summed up the core belief guiding the Office since its inception as, "If improvement in [health] care or service is the goal, then those who are responsible for making it happen must have ownership of the improvement process." This core belief is put into practice through a state/local partnership approach to projects and a focus on community investment as the cornerstone of all improvement strategies. Jim established five key principles that for more than 30 years have shaped the Office's partnership initiatives and continue to shape them today:

- Ownership is vested with community participants;
- Roles and responsibilities of all participants, both community and governmental, are clearly defined;
- In-depth technical assistance is provided on a continuous basis;
- Accountability is clear and measured; and
- Meeting patient and community needs remains the focus of all activities.

These guiding principles were originally applied, tested, and refined in the work that brought the Office into existence in 1973—the Rural Health Centers Program. Under the Rural Health Centers Program, the Office provided financial and technical assistance to rural communities in developing community-owned and operated primary care centers. In providing this support, the goals were to foster the development of independent community organizations with the leadership, knowledge, skills, and tools to create and manage a community medical center. Unlike the financial assistance provided by the Office, which was viewed as short-term (three to five years) help to communities during the start-up period, the Office's technical assistance was always seen as a long-term commitment. Not only would technical assistance be available to help community boards prepare for their oversight and policy role and to help health center staff carry out their clinical, practice, and financial management responsibilities, it would also remain a key component of the ongoing operation of the center. The principle behind this commitment to long-term technical assistance was that the Office would be more than just a traditional funding

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agency. It would be a partner with the community. While this commitment to partnership began during the feasibility and start-up phases of a new health center, it would continue well after a health center became operational. Office field staff still work with health centers that opened their doors more than 30 years ago. In rural communities, where local resources are limited and where the loss of a clinician can close a health center's doors, being able to turn to the Office for recruitment or emergency fill-in help or for help addressing financial and other crises has been an essential part of the state/local partnership. Each of the 85 health centers developed by the Office as part of the Rural Health Centers Program, is unique. Designed by individual communities to meet their particular needs, the health centers range from single practitioners in remote rural areas to multi-site, multi-provider operations serving several counties.

Throughout the 33-year history of North Carolina's Rural Health Centers Program, there were no major changes in the guiding principles, only refinements. The one significant refinement was an evolving definition of community. In the early 1970s, when there was a critical shortage of primary care providers throughout rural North Carolina, the focus was on securing care for all residents. As the supply of primary care physicians, nurse practitioners, and physicians became more plentiful, the office shifted its attention in the 1980s to providing access to care for low-income and underserved populations. Today, 80% of Rural Health Center Program funds support the direct provision of primary care to low-income and uninsured persons.

Although the principles were originally adopted to guide the Rural Health Centers Program effort, they are now used to guide other community-based initiatives and services within the Office, which are designed to improve the care of underserved and medically vulnerable populations, including the:

- *Medical and Dental Placement Program*, which recruits physicians, nurse practitioners, physician assistants, and dentists to serve in rural and underserved communities. In the last 30 years, more than 2,000 medical and dental providers have been placed in 96 of the state's 100 counties.
- *Farmworker Healthcare Program*, which targets the unique healthcare needs of seasonal and migrant farmworkers across the state by building up local delivery and outreach systems in high-impact areas.
- *Critical Access Hospital Program*, which assists small rural hospitals in securing Critical Access designation and, most importantly, promotes the formation of hospital networks that can improve the quality of services and financial stability. The program also assists partner hospitals with long-range planning, data analysis, grant-writing, and architectural and design assistance;
- *Prescription Assistance Program*, which provides prescription assistance software and technical assistance to community practices that help low-income residents obtain prescription drugs; and
- *Community Care of North Carolina*, which manages the care of Medicaid recipients through community health networks that are organized and operated by local physicians, hospitals, health departments, and departments of social services. Fifteen Community Care networks serve more than 650,000 Medicaid recipients and are creating the management systems needed to achieve long-term improvement in quality, cost, and health outcomes.

Over the Office's history, the importance of the five principles listed above has not changed and perhaps are the most important lessons that can be drawn from the Office's experiences. However, additional lessons have been learned along the way. These lessons can be divided into those that stemmed from work with local partnerships and those learned from work with other state-level partners.

Lessons Learned from Partnerships with Communities

Respect the Community's Perception of Their Needs

While academicians or state officials may have identified a need in a particular community, until the community acknowledges the problem, any attempts toward resolution will have mixed results. Education and outreach may be the necessary first steps in engaging a community to address their healthcare needs. Alternatively, the correct decision may be to step back and wait, but be prepared to step in when the community is ready.

Find and Nurture Local Leaders

Local leaders and champions are critical to developing sustainable healthcare initiatives in communities. Early on, Jim Bernstein recognized that community leadership was the critical component in the success of any community-based initiative. When dedicated leadership was absent, there were almost no prospects for successful community development. On the other hand, strong community leadership can offset other weaknesses in the development process. Leadership was so important that Jim made a concerted effort throughout his career to identify and nurture potential leaders at the community level.

Serve as a Resource

Over time, the Office has developed skill sets in a variety of areas to provide technical assistance to communities. Through this cadre of specialized technical expertise, the Office is able to assist communities in establishing non-profit corporations, organizing fund-raising and community-awareness campaigns, designing and building facilities, recruiting and hiring providers and staff, and overseeing medical operations. Because of the growing complexity of healthcare finance and reimbursement, the Office provides extensive technical support to health centers in all aspects of financial management. Rural health centers, such as Black River Health Services and Saluda Medical Center, developed 30 years ago, still retain a close working relationship with the Office. The Office also serves as a resource to other North Carolina agencies and to staff from other states.

Lessons Learned from Partnerships with State-Level Partners

Find and Create Flexibility within a Traditional Bureaucracy

State governments traditionally do not have a reputation for being the most flexible of institutions with which to work. The Office has balanced the need for reporting and accountability with the need for fast and straight-forward processes. While many policies cannot be changed, the Office has always tried to view rules and requirements from the perspective of those most affected by it. Therefore, whenever possible systems are designed to minimize the impact of bureaucracy while assuring that all state requirements are met.

Learn from Failures as Well as Successes

Not every good idea translates into a successful project. The Office has had opportunities to become involved in healthcare projects that were not tied to its long-term focus on building and supporting community-based systems designed to improve access to care. Although some of these non-core projects went well and made a contribution, other ventures were a struggle because they were not aligned with the Office's core values and skill sets. Non-core projects must be selected carefully to ensure they do not detract from what matters most.

Address Problems at the Appropriate Level, Whether It's Local, State, or Federal

While the Office emphasizes empowering local communities to address their own healthcare issues, there are often regulatory and legislative issues that impact communities, which can only be addressed at the state or national level. The Office has weighed-in on both state and national policy issues. In the mid-1970s, Jim Bernstein was active in developing the Rural Health Clinic Services Act (P.L. 95-210) legislation, which created reimbursement mechanisms for services provided by nurse practitioners and physician assistants in underserved rural communities. More recently, the Office, through the Community Care of North Carolina program, has worked with the North Carolina Department of Medical Assistance to create new provider delivery and reimbursement models that emphasize case management and continuity of care.

Build Bi-partisan Support

Rural health issues when seen from a local perspective are neither Republican nor Democratic issues, they are community issues. By focusing on supporting community-solutions to community problems, the Office has been able to build a broad base of support for its work during both Republican and Democratic state administrations.

Collaborate and Build Partnerships

Much of the Office's work has been accomplished through collaborations and partnerships at both the community and state level. Since its inception, the Office has viewed partnerships and collaborations as an essential part of its mission. Community Care of North Carolina is one example of the importance of collaboration. Its success is dependent on the collaboration and commitment of both state and local organizations. This program has achieved notable improvements in care quality and cost-effectiveness for Medicaid recipients by fostering community-wide collaboration around improved systems of care and by employing disease and case management strategies to improve care. The Office also tries to promote partnerships at the community level among different providers and agencies. In Bertie County, the Office helped to facilitate a closer working relationship between the local hospital, county health department, federally-funded community health center, and regional health system. As a result of this partnership, a multi-agency health campus has been constructed in this rural county allowing residents easy access to several providers and services in one location.

The need for collaborations and partnerships will continue as the Office works with others to address the current and future challenges in providing access to quality healthcare for rural and underserved populations.

Challenges Facing Rural Healthcare

There are several challenges facing rural healthcare. Some have been faced before, while others are new.

Increasing Number of Uninsured

As the traditional employment base of manufacturing and textiles leaves and as increasing numbers of immigrants settle in rural communities, the number of uninsured places additional stress on fragile safety net systems of care.

Aging Infrastructure and Physical Plants

Many of the health centers established by the Office are celebrating 25 or more years of service to their communities. Unfortunately, the physical facilities are beginning to show their age. In addition, the need for up-to-date and reliable computer networks to handle the routine business of healthcare has also increased. Finding significant levels of funding for capital and information technology infrastructure will continue to be a challenge.

Access to Mental Heath Services

Accessing affordable mental health services in rural communities is a growing challenge. Primary care practices and emergency departments often become the providers of last-resort for mental health issues in their communities. There is a growing need to both improve the ability of primary care providers to care for patients with behavioral health needs and to improve the ability of local systems to integrate and coordinate behavioral health services and primary care.

Access to Pharmaceuticals

Even with the implementation of Medicare Part D, many rural residents with limited incomes face challenges obtaining necessary medications. Rural health providers often find themselves cobbling together solutions from sample medications and pharmaceutical company donation programs to meet their patients' prescription medication needs.

Workforce and Staffing Issues

Rural healthcare faced a physician shortage in the 1970s due to the retirement of large numbers of general practice physicians. This shortage was dealt with in part through enhanced recruitment and retention efforts and by the widespread introduction of nurse practitioners and physician assistants into rural areas. Now rural health is facing another projected shortfall in primary care and key medical specialties, and once again, creative and collaborative solutions will have to be found.

Conclusion

More than 30 years ago, Jim Bernstein shared his vision for what a state office of rural health could be and what it could do. His philosophy of nurturing community-based solutions to community healthcare programs has contributed to the development of more than 80 rural health clinics across North Carolina and the implementation of other initiatives targeted at providing care to the underserved in North Carolina. The lessons learned have come from putting his philosophy and vision into practice. **NCMedJ**

COMMENTARY

The Heartland's Heartstrings:

The Power, Challenges, and Opportunities of Rural Health Advocacy in Washington

Jeanne M. Lambrew, PhD

The political power of rural health is legendary in Washington, DC. In September 2003, it caused a breakdown in deliberations over the highly-anticipated Medicare drug benefit. Senator Grassley (R-IA) walked out of negotiations with Representative Bill Thomas (R-CA) because rural Medicare provisions were not high enough on the agenda of items to address. The $25 billion, ten-year rural health package almost derailed the ultimate passage of the $400 billion drug benefit.[1] More recently, rural health funding cut-backs contributed to the surprising defeat of the conference agreement on the Department of Health and Human Services appropriations bill. At least seven Republicans voted against the final bill—more than the margin of loss—that, unlike either the House or Senate versions, zeroed out several rural health programs.[2] The $90 million in funding was ultimately restored to the $601.7 billion bill, but not without a major political embarrassment to Republicans who generally have such disagreements behind closed doors.

> *"North Carolina has also inspired federal policy. Its creation of the first office of rural health and innovative rural workforce policies has had a major effect on national health policy."*

These stories are dramatic pages in a long history of significant successes in rural health policy. In the post-Depression period, the Farm Security Administration created systems in 41 states to provide accessible care—serving as a model for subsequent national reform plans. In the 1950s and 1960s, health planning took hold, offering a rational model and funding for rural facility development. The federal focus on rural health outreach, training, and delivery system demonstrations accelerated in the 1980s. In the 1990s, culminating in a major investment in 2003, Medicare adopted policies that created special payment categories and rates for an array of rural providers.

In 2006, the power of rural health in Washington is still strong, but changing. Shifts in demographics, economics, and politics pose new challenges to rural health advocacy. In addition, health trends, such as consolidation of insurers and erosion of coverage will likely exacerbate problems facing rural health systems. This commentary reviews why rural health has a strong hold on federal policy, upcoming challenges, and the opportunities that rural advocates have to fundamentally change the United States healthcare system.

Rural Health's Hold on Federal Policy

There is a factual explanation for the power of rural health in federal policy. About 54 million Americans live in rural areas—a number that exceeds the number of seniors nationwide. Generally, rural people face larger and more difficult-to-solve health problems. They tend to be older, poorer, and sicker. They face barriers in accessing needed healthcare. Travel times to providers are generally longer in rural than in suburban or urban areas, and attracting and retaining providers is a perennial challenge. Sustaining hospitals, nursing homes, and other services for people with high needs poses a financial as well as a logistical problem.

The ability of these problems to merit increased federal

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attention is enhanced by examples of success. Members of Congress are proud of the innovation and adaptation of their local rural health systems. Many of the payment policies in Medicare for rural hospitals originated to expand on models in states like Montana, North Dakota, and Iowa, homes to powerful Senators like Baucus (D-MT), Conrad (D-ND), and Grassley (R-IA). North Carolina has also inspired federal policy. Its creation of the first Office of Rural Health and innovative rural workforce policies has had a major effect on national health policy.

In addition to the facts and success that propel rural health policy, there is an element of mythology. Many Americans still view rural America as emblematic of bucolic life. We envision family-owned businesses, farms, and the values of small-town life: honesty, decency, and simplicity. This is somewhat disconnected from reality; for example, most rural work is in manufacturing or the service industry, and many farmers are immigrants. Nonetheless, these images are evoked with surprising frequency in the halls of Congress as justification of subsidies for rural health.

And, clearly, our democracy is structured to give rural residents a political edge. The Senate, with two representatives from each state irrespective of their size, gives rural populations a clear advantage. For example, California's population is nearly 73 times higher than that of Wyoming, giving each person in Wyoming a much greater ability to influence Senate policy. And, about half of all Americans live in 10 states, making coalition building relatively easy among the 40 other states that have higher proportions of rural residents.

Because of these facts, myths, and structural advantages, rural health advocates may rank among the most cost-effective lobbies in Washington. There is neither a large rural health political action committee nor a largess in rural communities that gives it an edge in the cut-throat world of Washington. Instead, there is a currency to the facts and stories about rural Americans and the health providers who care for them that has created a strong and relatively unique power base.

Challenges Ahead

The advantages of rural health in federal policy may be needed more—and strained more—in the future. The globalization of our economy has taken a heavier toll on rural America. Job growth has been depressed in rural areas more than in others. The lack of job opportunities has contributed to out-migration of young people and the more rapid "graying" of rural America. This overlays persistent poverty in many rural areas, especially in the south.

These economic and demographic trends have affected rural health systems. Demand is up, given the older and sicker population. The nature of the demand is also shifting as rural areas increasingly become recreation areas; accidents and trauma are rising. This combination has meant that healthcare has grown as an important element of rural economies.

There are also two major trends in the health system that could particularly affect rural areas: consolidation and contraction. *Consolidation* refers to the increasing dominance of large segments of the supply of healthcare in the United States. A handful of major private insurers now dominate coverage in the United States. Hospitals and nursing homes are increasingly part of large chains. Even doctors have tended to join larger groups. While this could offer support for some rural providers, it could mean less focus on local needs as regional needs prevail.

Contraction refers to the continued erosion of private coverage. There was a 13% reduction in the proportion of small business workers covered by their employers between 2000 and 2005. At the same time, large establishments that have often crowded out local, small businesses are less likely to offer insurance than they were in the past. This has led to a surge in the number of Americans who lack health insurance—or whose insurance is still leaving them vulnerable to catastrophic costs. Most economists suspect that these trends will continue.

Both supply-side consolidation and contraction of coverage are being accelerated by federal policy. Medicare's new focus on large regions has meant that more rural beneficiaries have access to private plans. Yet, it remains to be seen how rural providers and the people they serve will fare in plans that cover large areas, often multiple states. And, in Medicaid, the budget reconciliation legislation will, according to the Congressional Budget Office, reduce Medicaid coverage through a set of policies that tighten eligibility rules, raise premiums, and make applying more difficult. Rural people rely more on Medicaid than those in urban areas, and thus could be disproportionately affected.

This contraction extends to federal appropriations as well. While the initial conservative approach to policy was to encourage privatization of government functions at all costs, a backlash from fiscal conservatives has emerged that has led to intense pressure to reduce the size (i.e., spending) of government. This generally has been focused on small programs. These programs historically escaped the budget knife by having local champions. But, as Washington roils in investigations of special interest influence, protecting local funding is called "earmarking" and is subject to intense review and criticism. This is exacerbated by a break-down in bipartisanship. The exclusion of Democrats from the conferences on major legislation has meant a loss of numerous rural voices in the crafting of legislation. Moreover, the concentration of power in party leadership could subvert local and regional differences to a larger set of politics.

Opportunities

Despite these challenges, the elements that have empowered rural health policy in the past are intact. There is still a fact-based claim for different treatment. Arguably, the case is stronger given increased need and the economic importance of rural health systems. Evidence also will accumulate on the limitations of blanket solutions at the top of the policy agenda. The challenges of rural healthcare delivery will not be solved by information technology alone. Pay-for-performance may not work to improve value in small rural hospitals as it could in large urban facilities. And, the idea that empowering consumers with information and accounts to shop for healthcare simply cannot work in most rural health delivery systems. Awareness of this "square peg in a round hole" problem will strengthen the case for separate consideration of rural health needs in public policy.

There is also a new and potentially stronger mythology emerging about rural America. Globalization can allow for new types of economic growth in rural areas. Some areas have focused on regional planning, recasting higher education to train for emerging industries, and taking advantage of the information revolution to remove geographic barriers. If technology has enabled outsourcing to India, why not to rural Indiana, some argue. In addition, as the focus increases on our natural resources, rural Americans may be seen as stewards of our unique national and natural assets. This new set of images fosters an advocacy based on strength rather than weakness and emphasizes what has always been true in rural health: local delivery innovation works.

But, it will also require a more sophisticated advocacy. In an overall system that suffers from poor outcomes, high costs, and access problems unknown in other wealthy nations, advocacy based on equality is a challenge. When our urban health systems face serious problems themselves, does equality make sense? Instead, it may be time to move away from politics of comparisons and toward ideals. Rural health policy advocacy could be based on simple principles to which the whole system should aspire, such as affordable access for all, fair financing of efficient care, and focus on health promotion and prevention. This could justify the continuation of successful Medicare payment policies, increases in funding for training, and new programs to improve access. Embracing the idea that we could do more for less—but this may require an upfront investment—could appeal to the fiscal conservatives. By moving away from arguments based on victimhood or unfair treatment, it rejects the implicit assumption that this is an allocation problem, and rural funding must come at the expense of others.

Finally, many challenges in rural health delivery stem from larger, systemic problems of high costs, coverage gaps, inadequate and unfair financing, and sporadic quality. The next debate on fundamentally changing the United States health system may come soon, as business leaders engage in it as a matter of survival. It could be that the best use of the incredible capital of rural health advocacy may not be in supporting small policies that effectively put a finger in the dyke. Rather, rural health leaders should consider that the best hope for achieving their goals is to advocate for real reform of the system. This may not only precipitate change, but ensure that the unique needs of rural delivery systems are met within the context of a larger redesign of the system.

In closing, the idea of adhering to a large vision even when making local change was something I learned from Jim Bernstein, among others. In my graduate studies at University of North Carolina at Chapel Hill, I had the privilege of working in the Rural Health Research Program and with him. Federal health policy was improved by his actions and example. I hope his legacy will live on through progress in improving the health of rural, and all, Americans. **NCMedJ**

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Forging Local Level Partnerships to Make Health Programs Possible

Rita C. Salain

Over the past several decades, a tremendous reservoir of experience and expertise has developed with regard to the role and importance of community planning and partnership development through which concerted actions to improve the health of rural residents can take place. In this commentary, I attempt to summarize some of this accumulated knowledge and experience and identify some of the critical steps toward meaningful community health action to improve the health of rural people, rural access to healthcare, and rural health program development.

In rural communities, if a primary care physician decides to re-locate to another town or close his/her practice, the community's healthcare options may become drastically limited over night. The same is true if a rural hospital closes or limits needed services because of financial distress. Both of these scenarios place an increased strain on public health providers in the area as well as the other private health providers. In communities with limited resources, one provider making a change impacts all the other providers, families, and individuals. Rural healthcare systems are fragile. Events that affect the ability of rural communities to provide quality healthcare vary, but most rural communities face a similar set of access to care barriers, which include financial, geographic, educational, cultural, and language.

> *"...communities with a demonstrated track record of working well together typically receive more attention and help than communities without a history of collaboration."*

In many rural communities, however, high-quality health services are available and thriving. The difference between a strong, high-quality primary care system and a system that fails in rural communities is often based on whether or not the community has local leadership dedicated to understanding and preserving healthcare that is appropriate and meets most of its citizens' needs. The success of most healthcare systems in rural communities hinges on community leaders who are willing to work together to identify needs, find resources, and invest their time and talent in solving healthcare access problems. Often rural health leadership includes working with adjoining communities to plan and deliver health services.

Creating a successful healthcare system in a rural community goes beyond the leadership of one person. Success depends on rural stakeholder collaboration and commitment. The events that prompt the formation of a partnership among stakeholders vary, as do the methods by which rural communities take action. A small community health planning group could be formed and charged with investigating and defining the problems. The group could be self-appointed or appointed by county or municipal government leaders, community physicians, the hospital, the board of health, etc. A coalition of local leaders or an appointed task force or partnership might be charged with finding outside help or consultation.

Regardless of how the group comes together to develop and maintain the most effective community health planning group, communities will need to identify appropriate constituents as stakeholders, agree on a governance structure that will make diverse participation possible, and explore ways individuals can work together to sustain rural health initiatives over time.

Importance of Stakeholder Support

Several years ago, a colleague from south Georgia asked me why some communities attract all kinds of resources while others

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—with as much need—do not. My response was that communities with a demonstrated track record of working well together typically receive more attention and help than communities without a history of collaboration. Since all resources are finite, governments, corporations, and foundations prefer to invest funds where a successful outcome is more certain. For this reason, opportunities are limited for communities without a community health partnership, health and civic leadership, or a history of rural health development, including networks or other rural health collaborations. The rationalization for this thinking is that there will always be more communities with "need" than resources to meet those needs, and thus, assistance should be invested in areas where there is need *and* the probability of success. Technical support and resources should be invested when a legitimate community-based group asks for help, but the onus belongs to the rural community leaders to ensure that investments will be prudent and useful. Fundamentally, the responsibility for change rests on the shoulders of community leaders and stakeholders who are willing to invest their time, talent, and resources in work to improve health status in their community.

Stakeholders can be defined as "a person or group with a direct interest, involvement, or investment in something, e.g. the employees, stockholders, and customers of a business concern."[1] Not only does having stakeholder support make a community health planning group more attractive to funding agencies, but stakeholder support also helps ensure plans and proposals are relevant, appropriate, and acceptable. Having various stakeholders participating is important in reducing potential duplication and ensuring that problems and solutions are fully defined. In addition, stakeholders should provide accountability and broaden community support.

Across rural communities, the particular stakeholders needed to define and solve problems will vary based on the specific health problem being addressed, the proposed solution(s), etc. At times, a broad-based community group comprised of civic leaders, citizens, physicians, nurses, other business leaders, and elected or appointed officials will be appropriate. Often, input from disadvantaged groups (e.g., the uninsured; poor, minority populations) is crucial to understanding the nuances of the problem and for developing appropriate solutions.

In many cases, the formation of stakeholder groups is guided, in part, by program requirements for funding. For example, if a rural community is applying for a primary care operational subsidy from the federal government [e.g., to become a Federally Qualified Health Center (FQHC)], federal regulations specify that the majority of the organization's governing board members must be users of the service. That is a condition for receiving such a grant.

Many public and philanthropic grant programs have specific requirements. Often, these requirements involve defining and engaging stakeholders. For some, positions on governing boards will be required, while others might suggest the type of local guiding group necessary to become successful applicants. Some local health programs, such as county boards of health, specify who appoints board members, how many can be appointed, the length of their terms, and the professional background or credentials board members must have. This is an important area of local policy, and rural citizens should be sure they understand it.

Contact the Office of Rural Health

To begin, groups formed to address health access problems should request assistance from their respective state Office of Rural Health. These offices, now in every state, are great places to ask for help, and some have resources to plan and solve health status or health system problems. State ORHs are supported in part by federal resources matched with state funds. A list of ORH directors and phone numbers is available on the federal Office of Rural Health Policy (ORHP) Web page (http://ruralhealth.hrsa.gov/funding/50sorh.htm) or by calling 301-443-0835.

Other helpful groups might include hospital associations, medical or family practice associations, universities, associations representing county commissioners, public health officials, foundations as well as other specific health interest groups. The ORH staff should have relationships with many of these groups and be able to connect you with others who can help. Most ORHs work to be a one-stop resource and will help find and broker technical assistance and consultation from a variety of state, federal, association, and foundation groups. Your ORH can connect rural leaders with resources, ideas, people, and tools.

Constituent Identification: Who Should Be Included as Part of the Stakeholder Group?

Depending on the situation or health system problem, a full spectrum of rural health providers, users of health services, civic leaders, representatives of groups experiencing disparate health access or health outcomes, faith leaders, business leaders, and social service providers might initially be convened to address specific health system problems. There are diverse opinions on how to identify the constituents necessary to develop a rural health service program and when to invite these participants, Opinions about who to invite range from issuing an open invitation to selecting a handful of opinion leaders whose influence will be required to make change.

Issuing an open invitation to interested parties works best when a clear statement of the need exists along with specific working parameters, the time commitment required, and the projected timeline. Including specific expectations in the open invitation helps stakeholders determine if they will participate. Clear expectations of involvement, group direction, and a planned way to use stakeholder input are crucial components of successfully developing and maintaining health programs and health assets, as well as being important in keeping a broad-based group engaged.

Depending on the program to be developed, there are times when smaller groups might work better initially. For example, a group of physicians and staff might form as physicians recognize they are providing care to a growing portion of uninsured people. The physicians might notice they have fewer privately insured clients. They might identify that they need help managing coding, billing, and collections from public insurers (Medicaid and Medicare). They may ask for help in assuring that any patient eligible for a program is made aware of it and helped to enroll. They may first coalesce as a small, invited group to clearly define the problem. Later they might seek assistance in defining the problem more broadly—how the growing number of uninsured is impacting the hospital, emergency medical services (EMS), public health, etc. They could then form a larger group to research and quantify the problem, craft potential solutions, and/or develop additional resources. They might ask for help from their Office of Rural Health (ORH). The physicians might seek assistance with improving practice management or developing a Rural Health Clinic.

This example can also be viewed as a potential problem to retaining primary care physicians in a community. As the problems are identified more fully, it becomes clear that the growing number of uninsured is a community-wide problem (as well as a national one). The initial group might broaden to include—in addition to the original physician group—nurses, a hospital administrator, public health leaders, hospital board members, mental health providers (if any), EMS providers, pharmacists, and other concerned stakeholders. As this group grows, it will be important to include the voices of the people who are the major users of services or those who are most in need, (i.e., those who have no insurance, those eligible for but not enrolled in programs, and those with limited income, etc.).

The importance of group diversity may not always be apparent. For example, several years ago while working with a large group of medical providers, hospital administrators; cancer survivors; and public health, business, civic, and faith leaders in a rural region formed a coalition to improve cancer screening, detection, diagnosis, and appropriate treatment. After months of coalition meetings, one of the medical leaders asked why the faith community was at the table. One minister retorted, “Who do you think people call as soon as they get the diagnosis that they or a family member has cancer?” The faith leaders in that coalition made key contributions to the work and opened doors for screening where the need was great.

Representatives of disadvantaged groups almost always need to be at the health service development table, regardless of the eventual governance structure adopted by the group. Disadvantaged people might not be included at an entrepreneurial health table or with a group convened to improve the technical components of managing an efficient, effective primary care practice, for example. If, however, the issues to be solved deal with improving access to health services, full community participation can significantly benefit the planning process.

The *timing* of invitations is also important. It typically does not work to invite representatives of the uninsured, poor, or the underinsured *after* key decisions have been made. Too often, groups make the mistake of waiting until key decisions have been made to invite other representatives to the table. A serious consequence of delayed inclusion is that the newly invited individuals will not have the historical perspective of the group’s planning and thinking, nor will they have the ease of association and rapport, all of which have been building since the group was formed. Ground rules how the group functions are formed early in the process, thus making it harder for new members to understand the group’s informal rules. Delayed inclusion can also cause new members to be hesitant in offering opinions, which in turn, might lead to false conclusions about the new member’s willingness to actively participate.

Including as many stakeholders as possible from the beginning reduces the likelihood of criticism that key decisions were made without sufficient input from key groups who will use the planned health services. If a group finds they need to add members later in the process, they should provide a comprehensive orientation to new members, including where the group is in their thinking, planning, and studying of options.

Deciding Which Corporate Structure Will Make Diverse Stakeholder Participation Possible

Each community health planning group will need to agree on a governance structure for themselves. When considering an appropriate corporate structure for the group, form should follow function and necessity. Several corporate structures might work well. Sometimes groups form an informal board, task force, or coalition. Over time, the group might decide to form a 501(c)(3) or another corporate model. Other times, groups form and decide the work can be handled without formal incorporation. That same group might decide that by-laws and operating procedures will be useful and that appointing an organization to serve as the fiscal agent is prudent. Some groups might attach to existing organizations, such as hospitals.

The group should adopt a structure that facilitates collaboration and productivity. Even when the corporate structure is prescribed by a funding partner, the execution of that structure is largely in the hands of the community leaders. A good way to ensure a full spectrum of stakeholder participation is to specify diversity in the corporate structure (i.e., prescribe a ‘balanced’ group with all viewpoints represented) and to be vigorous in assuring diverse opinions, experience, and expertise are invited and respected.

Sustaining Health Service Initiatives

Being able to sustain a program or a new service once it is up and running is often a challenge. In addition to developing a program that provides high-quality health services and has a system for referring patients to accepting specialists when necessary, the group must make sure the new program or service exhibits efficient management, can demonstrate effectiveness, can be sustained, has broad community acceptance, and is seen as an important economic component in the community.

Ensuring Efficient Management

One of the first steps toward sustainability for a primary care or programmatic service is to ensure managerial efficiency. For example, if the health services to be provided are covered by insurance (i.e., Medicaid, Medicare, or private insurance), the providers must be properly enrolled as a provider. Staff must know how to code, file, and collect payment for services delivered. This is not easy in the rapidly changing health insurance market. Efficient practice and program management is essential.

The North Carolina Office of Rural Health pioneered the development of publicly supported practice management technical assistance to improve retention of primary care providers. Several states in the southeast (Alabama, Arkansas, Georgia, Louisiana, South Carolina, and Texas) now provide or broker primary care practice management services developed as a part of the Robert Wood Johnson Foundation's (RWJF) Southern Rural Access Program. The practice management component of that Program was modeled after the successful work of the RWJF *Practice Sights* initiative of the early 1990s, incorporating lessons learned from that project. The RWJF National Program Office for that initiative was directed by Jim Bernstein and his colleagues in Raleigh. The Southern Rural Access Program is phasing out now, but several states intend to continue offering practice management support. The Office of Rural Health in most states can advise if free or low-cost rural practice management assistance is available.

Evidence of Effectiveness

Another key component of sustainability is assuring that the service developed is effective and efficient and, thus, warrants being sustained. To make this case, a program evaluation is required. Armed with key information on effectiveness, cost, and utility, the next step is to find a long-term funding partner. This is more easily accomplished with unbiased, supportive data, and a clear description of what was done, for whom, by whom, at what cost, and to what end or outcome. Not every effort will require a funding partner, but many will.

Securing Financial Support

Sustaining health services in many rural communities still requires securing long-term funding. Because of the disproportionate percent of rural people who are uninsured or under insured, often additional resource support must be found. Funding might be found by securing a direct federal grant (generally not a long-term strategy), foundation gifts or grants, private donations, state funding, or local support for services. Many counties or parishes support the hospital, EMS, the public health department, public mental health services, and some invest in the retention and recruitment of primary care providers. Working with like-minded organizations in adjacent and or nearby communities is also a very effective way to support services by spreading costs and sharing resources.

Action Steps

The following steps, or similar ones, are generally thought of as community health system development, community encouragement, etc. There are a variety of approaches, both formal and informal, that can be used to develop a rural health action plan. Rural community groups are not alike, so steps, catalysts for change, and resources will vary.

- A rural community leader, clinician, or health administrator becomes aware of a health problem that needs to be addressed.
- A small group (or groups) is (are) formed to investigate the problem.
- Problem(s) are researched, information is shared and the group begins to investigate solutions.
- The group, based on the information gathered (i.e., specific data), decides that the health status or system problem is one they have the will to address, and they then begin to develop a plan for how to deal with the problem.
- Clinical leadership is brought together (if not already present) to participate in planning and solution development.
- The local group, including clinicians and other health providers, asks for information, support, data, technical assistance, facilitation expertise, etc., from the ORH, other technical assistance providers or other associations, foundations, or corporations—to help define the most significant problems and search for resources.
- The group forms a larger, multi-disciplinary, planning group charged with developing a strategic plan for health. The plan will ideally include short- (one-to-three year) and long- (five- to-ten year) term goals and specific measurable objectives. The plan can include working with other organizations in adjacent counties or parishes, and, at times, a regional initiative will form.
- The group either forms a specific governance structure or works with an existing structure (i.e., rural hospital, not-for-profit) to develop and implement the plan and provide frequent feedback to the community.
- The plan is put into action.
- The group collects specific data, evaluates the results and resources invested, and shares that data.
- The group continues to work the plan, make necessary changes, engages in strategic planning, forms additional partnerships, and continues the quest to secure and find resources to improve health status.

Broad Community Use of Services

Important to sustaining health services is for all the community to use local health services. The civic, business, faith community, and other opinion leaders must use health services in the community. Citizen leaders should not by-pass local health services. Rural providers must have a strong mix of insured clients to help carry the disproportionate load of self-pay, Medicaid, and Medicare patients they serve. Medicaid and Medicare often require deep fee discounts (sometimes below the cost of providing services). As a reassurance to all—healthcare providers should make it clear that they are formally linked with other regional providers and have referral agreements with other facilities and specialists when required.

Healthcare and the Economy as a Sustaining Factor

Another key to sustainability is for rural civic and government leaders to understand that health services are one of the most useful, sustainable economic engines in a rural community. Healthcare is big business. According to the National Coalition on Health Care in 2003, "the United States spent 15.3% of its Gross Domestic Product (GDP) on healthcare."[2]

Health services bring money into the community from the state and federal government (Medicaid and Medicare). Rural health dollars "roll over" about 1.5 times in the community. In many rural communities, the healthcare sector accounts for ten to 20% of all jobs in the community,[3] and health sector jobs often pay well and are sustainable jobs. Many times the healthcare sector is the largest employer in the county or parish.

The federal Office of Rural Health Policy (ORHP) invested in helping community leaders understand the economic impact of the healthcare sector through funding support for the *Rural Health Works Program*,[4] managed and pioneered by the University of Oklahoma. The *Rural Health Works Program* is especially useful because standard employment data, gathered through the Census, is used to calculate the economic impact of the healthcare sector on the rural economy. The database (IMPLAN) is used to calculate the payroll of businesses engaged in health services, including public organizations and then calculate the economic impact of those jobs and dollars spent in the community. Other models are available to measure the economic impact of healthcare in the local economy. Some calculate the dollar value to the community of each primary care physician. Many hospitals can quantify their economic impact on the community.

Business leaders, civic leaders, economic development staff, and elected officials are more likely to help sustain, attract, and grow programs and encourage health businesses if health services are viewed as a part of the economic vitality of the community. In addition to the direct economic impact of health services, the significant difference health makes in family life (i.e., affecting one's ability to earn a living, decreasing morbidity, and helping people enjoy a higher quality of life) is universally understood.

Summary

The quintessential difference between most successful rural health programs and unsuccessful ones is local leadership. The ways in which a community invites, values, develops, nurtures, and supports the involvement of diverse stakeholder groups form an important part of the base for local rural health program success. Successful programs are initiated by local stakeholder groups who are committed to collaboration, have a working governance structure, a good understanding of their health and healthcare challenges, and a plan for sustainability. A key first step for rural community health planning is to contact one's local state Office of Rural Health. Most ORHs will provide information, guidance, and technical assistance. There are many challenges in rural health, but there are also great successes. North Carolina communities fare better than many because the North Carolina Office of Rural Health has demonstrated how effective state and local leadership work together to directly benefit rural communities and rural people. **NCMedJ**

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COMMENTARY

Rural Physicians and Community Leadership:
Skills for Building Health Infrastructure in Rural Communities

Steven D. Crane, MD

Few physicians at the beginning stage of their careers are so audacious as to describe themselves as "community health leaders." Nevertheless, nearly every physician who finds him/herself practicing in a rural community will often be inexorably drawn into discussions about greater health-related needs in the broader community. Once a healthcare professional is able to step back and take a panoramic view of the "health" of the community in which his/her practice is located, he/she often realizes that there are many health needs and barriers to care, and he/she quickly learns that it takes more than individual effort to meet these needs. Whether through the initiative of practicing physicians or others, community-wide initiatives to define existing problems, to plan a range of options for meeting these needs, and the effort to fund and then administer these emerging programs will usually require physician involvement … and even leadership. This commentary addresses some reasons why rural physicians need to become involved in solving some of these rural health problems, and how they can effectively provide needed clinical leadership even if they haven't previously thought of themselves in such a role.

> *"Physician leadership is a critical factor in developing community programs."*

The status of rural healthcare in North Carolina can be described as precarious at best. Many rural communities continue to be plagued by shortages of resources to serve the growing needs of a rural population that is increasingly aged and uninsured. The shortage of physicians in rural communities remains a chronic problem.[1] Despite some progress in the last decade in dealing with this maldistribution, significant disparities persist between metropolitan and rural areas.[2] Although most counties in North Carolina from 1998 to 2003 experienced an increase in the ratio of primary care physicians to 10,000 population, 38 of the state's 100 counties lost ground. Of the counties with increasing primary care shortages, about half were due to loss of physicians, and about half were due to rapid population growth that outpaced the supply of physicians.[3] Furthermore, in 2003, nearly 20% or 1.4 million North Carolinians under age 65 lacked health insurance coverage, with more than 300,000 having joined the ranks of the uninsured since 2000.[4] The combination of primary care provider shortages and declining health insurance coverage continues to threaten the healthcare safety net, particularly in rural communities.

The March/April 2005 edition of the *North Carolina Medical Journal* provided a comprehensive view of the various components of this safety net, which includes federally qualified health centers (FQHCs), Area Health Education Center (AHEC) teaching clinics, free clinics, public health departments, rural health centers (RHCs), hospital emergency departments, and efforts to integrate multiple service providers in service to the poor and uninsured.[5] As rural communities struggle to serve the health needs of their citizens, various combinations of these programs have been developed to address local health concerns. In all of these programs, physician involvement and leadership are critical components of developing successful safety net services in rural communities, but there are important barriers that prevent effective physician involvement and, perhaps, the successful implementation of vital programs.

The Western Carolina Experience

Henderson, Polk, and Transylvania counties are rural counties in the western, mountain region of North Carolina. The efforts by healthcare providers in these counties to improve access and quality of care for low-income, uninsured patients in their communities have significantly strengthened the local healthcare safety net. These efforts have included:

- The development of one of the first migrant health centers (Blue Ridge Community Health Services, Inc.) funded by

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the Health Resources and Services Administration (HRSA) as a federally-qualified health center (FQHC).

- An AHEC teaching clinic (the Mountain AHEC Rural Track Family Practice Residency Program).
- A free clinic staffed by family practice residents and private practice physicians in Henderson county.
- An expanded array of primary care and preventive health services by the Henderson County Department of Public Health with AHEC and private physician backup.
- Two additional rural health centers (the George Bond Health Center in Bat Cave and the Saluda Medical Center in Polk county).
- Expanded Community Care Network for managing the chronic illness [asthma, diabetes, depression, and attention deficit hyperacticity disorder (ADHD)] needs of Medicaid patients in the three counties with broad support from the private medical community in the three counties.

Collaboration has helped bring additional resources into the area to deal with the growing challenges, and spreading the risk and burden of uncompensated care has helped individual care providers while offering clients additional choice. Although in retrospect, each of these safety net initiatives has achieved a level of success, none of them would have been undertaken without vision, communication, cooperation, some measure of good fortune, and the intimate involvement of rural physicians. There are many ways physicians may impact the development of a particular program. In general, most involve some combination of advocacy of patients' interests, providing specific health or medical expertise, or serving as the arbitrator between agencies. This arbitration role often flows directly from the physician's role as patient advocate and medical expert, helping agencies set aside what can be competing interests for the common good of patients and the community. These programs also did not appear overnight. Where the region is today can be traced back to efforts that began more than 15 years ago and have progressed with one small step or success at a time.

Although program development in smaller communities can at times be more difficult due to fewer available resources, small size can also work to a community's advantage, as there may be fewer players involved, and problems, if they occur at all, may happen on a smaller scale. Personal relationships between agency representatives are often very important in any setting, but are particularly valuable in rural communities where individuals may serve multiple roles in different organizations.

Importance of Physician Leadership

Physician leadership is a critical factor in developing community programs. Physicians frequently bring unique clinical credibility to a project, knowledge and experience about health matters, access to key decision-makers in healthcare, and are granted the widest scope of practice within healthcare to establish direct patient care programs. Although outside consulting physicians can lend important advice and guidance, involving local physician leaders in health services planning is absolutely necessary for successful community health projects. A serendipitous effect of local physician involvement is the simultaneous nurturing of their community health leadership skills, which may be an important factor in retaining physicians in rural practice. Evidence supports that both community leadership preparation and having a sense of "belonging" to a community are determinants of whether physicians stay in or leave rural communities.[6] Others have also found evidence that underscores the importance of a "sense of place" in rural physician retention.[7,8] It is likely that physician involvement in these efforts, and the enthusiasm that can come from it, will be infectious and can lead to significant community health action.

Barriers to Physician Leadership: Time and Training

As important as it is for local physicians to be involved in community health leadership, time and lack of training in basic leadership skills can be significant barriers. Most physicians in rural practice have considerable patient care demands that often preclude involvement in planning activities during usual business hours. To include valuable physician input, planning groups may need to meet very early in the morning or after clinic hours, or they may need to structure meeting agendas to include physician partners in key discussions where the physicians' special perspectives are necessary and leave more administrative details to other meeting times. Group practices might be able to help cover a physician leader's clinic time so he/she can participate in an important community health project. Rural hospitals can also help fund physician time as a needed consultant to a developing program. Many rural communities have employed physicians, (e.g., those in academic, community health, or public health agencies), who have some built-in administrative time, which could be re-programmed to assist in developing community health programs. Finally, part-time or semi-retired physicians can be important sources of physician involvement in program development.

Although many physicians will be pushed into leadership roles at some level, most will have no formal instruction in management skills. Many have a limited understanding of how other disciplines, groups, or agencies impact healthcare, or they may have limited contact with other community leaders outside of healthcare. Basic tasks, such as organizing and chairing meetings, understanding general accounting practices, developing business plans, or writing grant proposals are important skills that nearly every community health project needs, but are often in short supply. It is not sufficient to recognize a health need and have an idea that could address it; ideas must be communicated to others. All stakeholders need to be included in planning and implementing a project. Most projects will require monitoring to assure that they are having the desired outcome, and any worthy project will need to be sustained.

For physicians to be effective leaders in their rural communities, there should be ways they can receive these skills either in residency training or as they find themselves in rural practice. Our Rural Track Residency Program includes an explicit curriculum in community leadership that includes a module in public health evaluation and planning, a direct longitudinal experience providing direct patient care to an underserved population, mentorship with faculty actively engaged in community health activities, and a required hands-on community project that allows residents to put these skills to practical use. Similar curricula could be added to other residency training programs for those planning careers in rural areas.

For practicing physicians, distance learning opportunities or rural leadership training programs could be an important way those interested rural physicians could acquire the skills and contacts that could quickly enhance their ability to serve as a community health leaders. The University of North Carolina School of Public Health runs a certificate program in Health Care Management, which is a 14-credit-hour program offered primarily on-line that is designed to give course participants basic healthcare management skills.[9] The North Carolina Office of Research, Demonstrations, and Rural Health Development could develop a program to identify interested rural physician leaders and support their involvement in this certificate program. The Office could also create networking opportunities for rural physician leaders, who are trying to increase their communities' capacity to address local healthcare needs and develop new programs. **NCMedJ**

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Mental Healthcare in Rural Communities:
The Once and Future Role of Primary Care

John A. Gale, MS, and David Lambert, PhD

The provision of mental healthcare in rural communities has been a vexing challenge for clinicians and patients for many years. There is a chronic shortage of specialty mental health providers, particularly psychiatrists and psychologists, which has shifted much of the burden of care to primary care. Primary care clinicians have historically lacked the training and time within their busy practices to feel comfortable providing mental healthcare, particularly since the shortage of specialty mental health clinicians deprives them of consultation and referral sources. People who live in rural areas must often overcome significant travel distances, stigma, and lack of insurance and other resources to access the scarce mental health services that do exist.[1]

Despite this difficult picture, rural primary care and specialty mental health clinicians have persevered to provide some level of mental healthcare to people in rural areas. Over the last decade, improvements in clinical screening tools, treatment protocols and guidelines, and information technology have significantly enhanced the potential to increase access to and improve the quality of mental health services in rural communities, particularly to underserved populations. Recent policy initiatives hold much promise to provide the structural and financial support necessary to help rural communities realize these improvements.

> *"...60% of rural residents live in mental health professional shortage areas ... [and] ... 65% receive treatment for mental health problems from their primary care providers...."*

In this commentary, we first present a general discussion of the issues related to the delivery of mental health services in the United States with particular attention to how these issues complicate the delivery of services in rural areas. Next we describe the renewed call for integrating primary care and mental health in rural areas (hence "the once and future role of primary care" in our title) and related clinical and policy support to do so. We close by briefly describing the policy interventions and resources needed to further these integration efforts and to improve access to services for rural underserved populations.

Our Fragmented Mental Health Delivery System

The mental health delivery system in the United States is characterized by a fragmentation of services, separation of funding streams and delivery systems, poor reimbursement, inadequate access to specialty mental health providers, and the mal-distribution of existing resources. These issues greatly complicate the delivery of services in rural areas.

The United States mental health system is not a coordinated system of specialty mental health services but, rather, a fragmented collection of services and providers that has come to be known as the *de facto* mental health "system."[2,3] The term "system" is used to convey an understanding of where persons receive services, rather than to suggest a coherent whole that has developed according to a set of organizing principles.[4] Regier and colleagues identified four sectors where individuals may seek assistance for their mental health needs: (1) *specialty mental health*, (2) *general medical/primary care*, (3) *human services*, and (4) *voluntary support networks*. Our discussion will focus on the first two sectors, which make up the formal treatment system in most communities.

The *specialty mental health sector* is made up of psychiatrists,

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psychologists, psychiatric nurses, and social workers practicing in various public and private inpatient, outpatient, residential, and community agency settings and is the sector that comes to mind when people think about mental healthcare. The *general medical/primary care sector* is made up of general and family physicians, pediatricians, internists, nurse practitioners, and physician assistants providing a range of healthcare services, including, but not limited to, mental health services.

Contributing to this fragmentation of services has been the historical separation of funding streams and governmental responsibility for oversight of service delivery. Mental health and substance abuse services have traditionally been viewed as separate and apart from the general medical system. These services have typically been reimbursed at lower levels than general health services and often through separate pots of money. The separation of funding streams continues through the use of carve-out programs by many state Medicaid programs and commercial insurance companies in which a behavioral managed care organization is responsible for the management and approval of mental health services. Responsibility for the oversight of the delivery of mental health and substance abuse services at the state level is typically housed in a separate state mental health agency. Some states further fragment these services by assigning responsibility for the oversight of substance abuse services to a separate substance abuse agency.

Populations Served

The delivery of mental health services has historically been based on the specialty care model in which mental health specialists treat mental health problems and primary care providers assess and refer patients to these specialists as necessary. The use of this specialty care model fails to explicitly acknowledge the reality that most people seeking mental healthcare fall into one of two broad populations.[5] The first is the special population of adults with serious and persistent mental illness and children with serious emotional disturbances. The second population is the general population of individuals who frequently have more modest and episodic mental health needs (in comparison to the special population).

Members of the special population, who are often covered by Medicaid as a result of their mental health diagnosis and/or disability, are best served by the specialty care system and often require specialized services, such as congregate housing, vocational services, and crisis services. Members of the general population, whose needs may often be appropriately met within the primary care system, are often "encouraged" to seek services through the specialty mental health system due to reimbursement and/or health plan coverage issues. Given the separation of services and delivery systems, poor reimbursement rates, the reliance on the use of the specialty model by third party carriers, and the growing demand for services within the general population, the supply and distribution of specialty mental health providers and services are inadequate to meet existing needs, particularly in inner cities and rural areas.

The Special Challenges of Delivering Mental Healthcare in Rural Areas

Rural residents, like their urban peers, experience a wide range of mental health and substance abuse problems. National mental health epidemiological studies show little or no differences in the prevalence of mental health problems among adults across rural and urban areas.[6,7] While the prevalence of mental health disorders is similar, the composition and context of mental healthcare is profoundly different in rural and urban areas.[4] The New Freedom Commission on Mental Health (2004) suggested the following framework in which to consider these differences:

- *Accessibility.* Rural residents travel further to receive services than urban residents; are less likely to have insurance benefits for mental healthcare; are less likely to recognize mental illnesses and understand their care options; and enter care later, sicker, and with a higher level of cost.[8,9]
- *Availability.* Rural areas have chronic shortages of mental health professionals (60% of rural residents live in mental health professional shortage areas); few comprehensive services; and providers that are physically isolated from each other and their patients.[10,11] Rural residents rely more heavily on informal supports and indigenous healers than do urban residents and are more likely to be treated in a primary care setting (65% receive treatment for mental health problems from their primary care providers).
- *Acceptability.* Even when scarce services are available and accessible in rural communities, they may not be acceptable to people living in a rural area because of stigma, which is particularly intense in rural areas where anonymity is difficult to maintain; cultural issues; and limited or non-existent choice of providers.[12,8]

In many ways, mental health providers in rural mental health systems are even more "de facto" than those in urban areas.[13] Rural mental health practice is characterized by a lack of available services, scarcity of resources, severe shortages of specialized mental health practitioners and providers, the under-utilization of services, the impracticality of specialization, and a recognition that clients must be supported beyond the narrow range of medically necessary specialized mental health services.[14]

At present, more than 90% of all psychiatrists and psychologists and 80% of master's-level social workers work exclusively in metropolitan areas, a workforce distribution that has remained remarkably constant over the years. This maldistribution has persisted for more than 30 years despite repeated efforts to overcome existing market forces and encourage more mental health providers to practice in rural areas. The failure of these efforts can be traced to the challenges faced by mental health clinicians who chose to practice rural areas. They are often called upon to treat patients outside of their fields of expertise, reach complex decisions without the advice of other professionals, interact with patients in a variety of nonclinical roles, and are

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Piloting Mental Health Integration in the Community Care of North Carolina Program

The Community Care of North Carolina (CCNC) Program is a statewide initiative comprised of 15 networks serving more than 660,000 Medicaid enrollees in approximately 1,000 participating practices. In these networks, providers are expected to take responsibility for managing the care of their enrolled Medicaid population. Each network designates clinical and administrative leadership to work in partnership with the state to design and develop clinical improvement and cost containment initiatives. In recent years, networks in the CCNC program began to see an increasing number of Medicaid enrollees at primary care provider practices with both behavioral and physical healthcare needs. As a result of efforts in mental health reform and changes in the local service delivery infrastructure, four CCNC networks working in concert with their local management entities (LMEs) began piloting (in July 2005) a collaborative approach to managing the Medicaid enrollees with both behavioral and physical health needs and to serve them in the most appropriate setting. This mental health integration pilot is a state-level collaboration between the Division of Mental Health; the Division of Medical Assistance; the Office of Research, Demonstrations, and Rural Health Development (CCNC Program Office); and the North Carolina Foundation for Advanced Health Programs, Inc.

In the mental health integration pilots, the networks aim to do the following: increase the comfort level of primary care providers (PCPs) in identifying and treating people with depression who present in their offices; improve communication between the PCP and behavioral healthcare providers; implement psychiatric telephonic consultations; ensure, through improved coordination, that patients are able to access care at a point in the system where their health and behavioral health needs can be optimally met; and, adopt uniform process and outcome measurements for program evaluation. These pilot projects are targeting both the adult and pediatric populations (cohorts broken out by age, birth to five years and five years and older) using the "Four Quadrant Clinical Integration Model"[1] as the foundation for communication, collaboration, assessment, referral, and clinical management of care. As described by Barbara Mauer, the four quadrant model serves as a conceptual framework for collaborative planning in local healthcare delivery systems—using the framework to decide which providers will do what and how coordination for each person served will be assured.[1] The four quadrant model categorizes individuals based on the degree of clinical complexity, health risk, and functional status. For example, quadrant IV is indicative of those with both high behavioral health and physical health needs.

Data collection will be comparable across projects since common forms and tools have been developed and adopted, including a telephonic consultation form, behavioral health assessment form, case consultation request form, and provider surveys. In addition, based upon the patient's age, a common set of primary screening tools were chosen: the Ages and Stages Questionnaire (ASQ),[2] Parents' Evaluation of Developmental Status (PEDS),[3] Pediatric Symptom Checklist (PSC),[4] and Patient Health Questionnaire (PHQ-9).[5] All four pilot networks are implementing a universal screening tool and a clinical pathway for depression. Evaluation efforts by individual pilots are examining the following: impact of incentives to PCPs for completion of behavioral risk screening; value of different population management strategies; identification of primary care provider screening tools that work best for anxiety, bipolar, and attention deficit disorder; value of co-location models with a behavioral specialist in the PCP practice; impact of integrating with the school system; impact of ongoing educational sessions and "collaborative rounds" to improve communication and collaboration between PCPs and mental health providers; and, use of dedicated case managers.

North Carolina has invested in the development and implementation of the CCNC network infrastructure, which provides an ideal testing ground for innovative models and strategies. The foresight to invest in the development of community-based networks able to partner with the state in managing our most vulnerable citizens is a result of dedicated and visionary leaders at both the community and state level. The lessons learned in the mental health integration pilots will be used to guide the formation of Medicaid mental health policy and assist in forming targeted statewide training and technical assistance. The strategies and plan design models developed and implemented in the pilots will support the replication and expansion efforts in other networks and communities. A model that is able to integrate behavioral and physical healthcare needs will demonstrate the value of a chronic care management model that is patient-centric and able to identify and meet all the needs of an individual.

NOTES

1 Mauer, BJ. Behavioral Health/Primary Care Integration–the Four Quadrant Model and Evidence-Based Practices, Winter 2004, National Council for Community Behavioral Health Care, 2002.

2 Ages and Stages Questionnaire (ASQ) is a parent completed questionnaire. The questionnaire is age specific for children from four to 60 months of age. Questions are in five areas: communication, gross motor, fine motor, problem solving, and personal/social. Sensitivity is 72%, and specificity is 86%.

3 Parents' Evaluation of Developmental Status (PEDS) is a parent-completed questionnaire. The same ten questions are used for all children from birth to eight years of age. Sensitivity is 74-80%, and specificity is 74-80%.

4 Pediatric Symptom Checklist (PSC) is a questionnaire with 35 short statements of problem behaviors to include both externalizing and internalizing. The questionnaire is used for children ages four to 18 years. Sensitivity is 80-95% (all studies except one showed this level of sensitivity), and specificity is 68-100% (scattered across studies).

5 Patient Health Questionnaire (PHQ-9) is a symptom checklist for depression screening. Responses range from "not at all" to "nearly every day." Based on the response, a score is assigned.

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subject to professional isolation and a high potential for burnout.[15,16] Rather than wishing for resources that we don't have and that history tells us that we may not achieve, we need to develop a national rural mental health plan that rationalizes our current system and capitalizes on our existing strengths and resources.

The end result is that many rural Americans rely heavily on the primary care system as their source of mental healthcare.[17] In fact, many rural residents express a preference for receiving mental health services through their primary care providers, given the issues of stigma and the perceived lack of confidentiality due to the small town environment (in which everyone knows your business). In many ways, these pressures are positioning rural communities to lead the way in developing rationalized systems of care in which primary care providers are an integral part of the mental health delivery team.

Renewed Calls for the Integration of Mental Health and Primary Care

Although discussions of the integration of primary care and mental health in rural areas date back to the early 1970s, a number of national reports and studies have signaled a renewed interest in and policy support for efforts to strengthen integration efforts among rural providers. The Surgeon General's Report on Mental Health acknowledged the crucial role of primary care in providing mental healthcare.[1] The President's New Freedom Commission on Mental Health (2003)[18] promoted integration of primary care and mental health to help address access problems in rural areas. The National Advisory Committee on Rural Health and Human Services' Report to the Secretary (2004) and the national Institute of Medicine's Quality Through Collaboration: The Future of Rural Health Report (2005)[19] call for integrating mental health with rural primary care. Mental health expansion and new access points grants, created under the President's New Access Initiative, provide funding for Community Health Centers (CHCs) to deliver behavioral health services.[20]

Resources Needed to Enhance the Integration of Mental Health and Primary Care Services in Rural Areas

Over the past decade substantial progress has been made in developing tools and resources to support the integration of mental health and primary care services. These tools and resources include a variety of screening tools, evidence-based practices, and best practice models. Legislative changes provide cost-based reimbursement for Rural Health Clinics employing doctoral-level psychologists and clinical social workers. The Bureau of Primary Health Care provides grant funding to support the development or expansion of mental health services by CHCs. The Bureau also supports the development of Health Disparities Collaboratives by CHCs using Ed Wagner's chronic care model to treat patients with chronic conditions including depression.[21]

It is no longer a question for a rural practice of how to get started but, rather, how to sustain these activities over time in a day-to-day practice setting.[22] The delivery and coordination of mental health services in a primary care practice require a balance between the provision of integrative services (e.g., coordination with primary care providers in the practice as well as external specialty care providers, engaging patients in the treatment process, educating clinicians and staff, etc.), which are frequently not reimbursable and more traditional assessment and counseling services which are.[22]

Additional tools and policy interventions are needed to further the expansion of these efforts. These include: (1) the development and implementation of electronic medical records to support clinical integration and communication; (2) continued provision of mental health expansion and new start grants by the Bureau of Primary Health Care; (3) the development of federal and state policies to compensate for the limited access to specialty mental health services; (4) support for the expanded use of telemedicine technology to provide access to psychiatric consultative support in rural communities; and (5) the provision of third party reimbursement and support for the delivery of mental health activities in rural practices, including reimbursement for integrative activities and the inclusion of these primary care practices in Medicaid and commercial behavioral managed care plans.

The integration of mental health and primary care services is a policy goal whose time has come. Due to long-standing resource constraints, rural communities and practices have led the way in developing integrated models of care, often in the face of limited financial and administrative support. For further progress to be made, we must acknowledge the challenges related to the integration of these services and develop policy interventions, training tools, and technical assistance to overcome them. **NCMedJ**

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Leadership Development for Rural Health

Tim Size

Rural health has come a long way, but has a long way to go. With hindsight, some might minimize Jim Bernstein's leadership, now unaware that much of what he did for rural health was initially just an idea, a hope. It is this midwifing of a vision into reality that is the very essence of leadership. Henry David Thoreau described Jim's caliber of leadership when he wrote the oft repeated lines, "If a man does not keep pace with his companions, perhaps it is because he hears a different drummer. Let him step to the music which he hears, however measured or far away."[1] Jim Bernstein leaves a legacy that continues to challenge all of us to care and to achieve more than we first thought possible, whomever our drummer, whatever our position.

On July 15th, 2005, the National Advisory Committee on Rural Health and Human Services advisory to the Secretary of the United States Department of Health and Human Services, adopted a Special Resolution to honor James Bernstein, which concluded with the following: "The Committee believes that the best way to honor Jim is to consciously work to help develop the next generation of rural health leaders. Jim was a master of creating change by working within the existing policy framework and helping others to build sustainable programs that addressed long-standing problems. The Department should play a lead role by developing a program that identifies emerging leaders from and for rural communities and provides them with the training and resources to play a lead role in ensuring access to quality healthcare in their states and communities. This program warrants long-term support by the Department, and it should focus on rural needs within the larger policy context that affects us all. The Committee urges the Secretary to take the lead on this initiative, which will serve as a reminder of all of Jim Bernstein's fine work."[2]

While I can see/hear Jim wincing at the focused personal attention, I know he would put up with it to help further develop rural health, a process that must include understanding our past. I believe he would also be the first to remind us of the many people who are called to exercise leadership in both large and small ways.

> *"Leaders recognize that none of us are called to always lead, that sharing or conceding leadership to others is also a key role."*

This commentary is a personal statement without presuming to be writing the definitive word on what we need to know to further develop rural health leadership. My intent is to express belief as belief and not individual belief as universal truth, a convention too common today in our national "dialogue." The reader is invited to engage with what he or she reads here, taking what might be useful, and hesitating a moment to think through what might be useful, but doesn't immediately seem so. This is a "conversation," not a lecture.

What Is Leadership Development and Why Do We Need It?

The weekend I received the opportunity to write this commentary, our church was celebrating those living or dead who made a contribution to our faith and various communities. That service brought forth the image that individuals who exercise leadership are like a river's current—a part past where we now stand, a part yet to come. We have an ongoing need to remember and to look toward the next "generation." Rural leaders will arrive without the assistance of any of us, but deliberative leadership development will foster more effective and diverse leadership. A key responsibility of those here now is to mentor and to create structures for mentoring, in order to maximize the flow and effectiveness of tomorrow's leaders.

Leadership is the capacity to help transform a vision of the future into reality. This commentary focuses on *leadership* development more than *leader* development to emphasize that throughout our organizations and communities, we have and need individuals who may not be formally designated as leaders, but who can and do exercise leadership. Leaders recognize that none of us are called

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to always lead, that sharing or conceding leadership to others is also a key role. None of us are called to lead on every issue; all are called to interact and support the vision and ideas brought by others.

We need to recognize that in addition to individuals having the potential to exercise leadership, the potential of leadership also exists "corporately," in groups of individuals, whether they are teams, organizations, or communities. Individually and collectively, at all levels, we are called to lead in one place or another and are "born" with traits that can both enable and interfere with that opportunity and responsibility. Wherever the individual or group starts, learning and growth are possible. We need to structure leadership development for groups and communities as well as individual leaders.

Leadership development, formal or informal, is not just for the chronologically young. I have a friend who for many years has been a newspaper reporter and columnist as well as the chaplain for a mission that works with our city's poor and addicted people. He has arrived at "retirement" age, but many of his readers are now seeing a columnist who speaks with a profoundly clearer voice. Some of the paper's readers who disagree with him would undoubtedly welcome the news of his retirement; so be it, leadership necessarily brings out in good measure both supporters and detractors.

Leadership comes in many contexts. Jim Bernstein and I talked more than once about the similarities and differences in our vocational situations. We held in common that we were born and raised "elsewhere," but became deeply rooted in our adopted home states. I work with mid-western rural communities facing relatively more racial homogeneity and less extreme poverty. These communities have a strong tradition of agricultural cooperatives that enabled our development of a cooperative of community hospitals—hospitals that work with and challenge both our state and our universities. Jim worked with southern rural communities facing more racial diversity and often extreme, community-wide poverty. He was able to be innovative from a position inside of government. Jim was notable in the respect and understanding he offered those working in a variety of circumstances.

A friend recently shared with me a few of the leadership challenges she faces, which are unique to her role as the chief executive officer of a hospital in a rural community. This commentary will not catalog such challenges, but her comments serve as a reminder for the "in the trenches" reality that rural health leadership development initiatives must address. "It is easy to become isolated, I am the only person doing what I do in our community. We are much smaller than most of our urban counterparts, so I need to juggle the crunch of many required 'to dos' without the luxury of additional staff who can take the ball from start to finish. And when first arriving, it was not unusual to have a 'new gal/guy in our community trying to tell us what to do' type greeting. 'She or he will be gone and never give us another thought.' "

The Role of Nature and Nurture

At one time, people tended to believe that leaders were born, not made. Now we tend to see leadership as a set of traits that can be nurtured. But what about nature, the traits we are born with? A while back, I was asked when I became an advocate. The answer was that we all receive some traits at birth, or shortly thereafter. "One of my most vivid memories of home in the late 1950s is the endless kitchen argument with my devout Baptist mother on the theory of evolution. Her particular tenacity on this issue may be traced to her childhood memories of her guardian's friend, William Jennings Bryan, the famed attorney on the then winning side of the 'Scopes Monkey Trial.' But like many women of her generation raised in the shadow of the old south, she had a finely tuned nature of smiling and cajoling while not giving an inch."[3] On the way to the rest of my life, I realized that what we did have in common was an innate passion to talk, and to never concede. Yes, nature matters, but it need not be determinative. Subsequently, with the help of a very well-financed Kellogg leadership program, others were able to teach me not to use a rhetorical cannon when a rifle was sufficient, and that once in a while, a concession wouldn't kill me.

America has a complex heritage when it comes to how it thinks about leaders—accepting contradictory leadership styles. We call the strong, individualistic characters, such as played by John Wayne, classic American leaders. Democrats and Republicans honor Jimmy Carter's leadership, whose less autocratic emphasis on partnership makes him a contender for "the country's most successful ex-President." We understand that leadership is not limited to the classically cinema-charismatic or those holding formal power, as Rosa Park's "simple" act of saying "no" will forever testify.

How our culture holds these apparent contradictions is not well understood. Robert Frost's poem "Mending Wall" set on a New England farm is most famous for the line "Good fences make good neighbors," a frequent citation of American individualism. But it is a better example of not reading a whole poem. Frost goes on to say, "I let my neighbor know beyond the hill, and on a day we meet to walk the line and set the wall between us once again…." Even this icon to self-sufficiency is expressed within the cultural context of selective cooperation.[4]

To develop as a leader, we must understand how leadership has unfolded in our own lives. A key initial transition is to recognize and accept "for better, for worse" what characteristics one has "hard wired" and then begin to see how one can develop further. This is also a precondition for those intending to take on the role of leader recruiter or mentor.

In my own development, a key step forward happened in my mid-20s while working as an "assistant superintendent" at a university hospital. As quickly as a light switch is turned on, I was lucky one day to realize that maximizing program successes was not the same as minimizing program failures. This eventually led to a transition from state government, which I experienced as being risk adverse, to an organization in the non-profit sector, which has allowed calculated risk taking. The operative word is

"I experienced." Jim Bernstein is the obvious counter example, having taken many risks and had many successes from a base within state government.

Risk taking requires comfort with failure, one of life's most powerful teachers. A while ago, I was asked to address how I maintain energy in the face of so many failures. I was taken off guard because I didn't think of myself as having had that many failures. Upon reflection, I was able to easily come up with a list of ten failures, many of which in less charitable circumstances would have involuntarily led me to "pursue a new career opportunity." I just hadn't been keeping a tally, and I still don't.

For us to have integrity as leaders, we have to continue to work to know who we are as we relate to our work. A timeless illustration is found in Chinese philosopher Chuang Tzu's "Woodcarver," written about 2,300 years ago:

> Khing, the master carver, made a bell stand
> Of precious wood. When it was finished,
> All who saw it were astounded. They said it must be
> The work of spirits.
> The Prince of Lu said to the master carver:
> "What is your secret?"
>
> Khing replied: …
> "What happened?
> My own collected thought
> Encountered the hidden potential in the wood;
> From this live encounter came the work
> Which you ascribe to the spirits."

The best explanation of this poem I know is in Parker Palmer's renowned work on vocation, an *Active Life*:[5]

> …we both act and are acted upon, and reality as we know it is the outcome of an infinitely complex encounter between ourselves and our environment. In this encounter we do some shaping, to be sure, but we are also shaped by the relational reality of which we are a part. We are part, and only part, of the great community of creation. If we can act in ways that embrace this fact, ways that honor the gifts we receive through our membership in this community, we can move beyond the despair that comes when we believe that our act is the only act in town…. When authentic action replaces unconscious reaction, the active life becomes not (in the words of Chuang Tzu) 'a pity' but a vital and creative power.

As noted by Parker Palmer, how we choose to frame or understand our relationship with others and our environment is critical to our growth as leaders. My best example occurred in graduate school, or more specifically in the dormitory elevator in graduate school. It was Chicago's oldest and slowest Otis elevator—it took an "eternity" to go the 12 stories to my room. One day it hit me that my frustration wasn't the result of the elevator, but my unrealistic expectation of its behavior. Subsequently, I still thought it was slow, but I didn't worry about it. So how do we frame rural health leadership? What kind of elevator is it? If we make the right investments, what kind of elevator can it become?

Servant Leadership and Rural Health

The concept of "servant leadership" is a perspective held by many throughout the rural health community, and I believe is a major frame for understanding the attributes of leadership we need in rural health. Robert Greenleaf, the man who coined the phrase servant-leadership described it as "the servant-leader is servant first…. It begins with the natural feeling that one wants to serve, to serve first. Then conscious choice brings one to aspire to lead."[6] I don't believe he is saying "natural" as in the sense "natural athlete," but that at some point in life, the feeling arises to serve, which in turn leads to a decision to exercise leadership. What are the attributes of servant leadership; what characteristics or skills must we look for when we recruit a leader or should we look for when we learn, teach, and reinforce? For me, a good start to that question is to compare the attributes of "servant" and "traditional" leaders. Cooper McGee and Duane Trammell do just this in "Hero as Leader to Servant as Leader."[7]

Examples of Traditional Leadership Skills

- Highly competitive; independent mindset; seeking personal credit.
- Understands internal politics and uses them to win personally.
- Focuses on fast action.
- Controls information in order to maintain power.
- Accountability is more often about who is to blame.
- Uses humor to control others.

Examples of Servant Leadership Skills

- Highly cooperative, interdependent; gives credit to others generously.
- Sensitive to what motivates others to win with shared goals and vision.
- Focuses on gaining understanding, input, buy-in from all parties.
- Shares big-picture information generously.
- Most likely listens first, values others' input.
- Accountability is about making it safe to learn from mistakes.
- Uses humor to lift others up.

Our Health Needs Collaborative Leaders

I had the opportunity to serve on the national Institute of Medicine's (IOM) Committee on the Future of Rural Health Care. For me, the major breakthrough in the Committee's work as documented in the report, *Quality Through Collaboration: the Future of Rural Health*,[8] was that the IOM's Six Quality Aims (originally constructed for the healthcare of the individual) apply equally well to a population health perspective, or said another way, "the community as patient."

This perspective that we need to "balance and integrate personal healthcare with broader communitywide initiatives that target the entire population,"[9] developed after the committee applied the IOM report, *Fostering Rapid Advances in Health Care: Learning from System Demonstrations*,[9] to rural health. Examples of applying the IOM's Six Quality Aims for a population health perspective include:

- *Safety*: Road construction designed to reduce auto accidents.
- *Effectiveness*: Public schools act to reduce risk of obesity/diabetes.
- *Community-centered*: Regional provider networks respect community preferences.
- *Timeliness*: Timely identification of epidemics.
- *Efficiency*: Public reporting of population-based measures of health status.
- *Equity*: Developing, maintaining rural jobs.

The Committee on the Future of Rural Health Care synthesis was that "rural communities must build a population health focus into decision-making within the healthcare sector, as well as in other key areas that influence population health. Most important, rural communities must reorient their quality improvement strategies from an exclusively patient- and provider-centric approach to one that also addresses the problems and needs of rural communities and populations."[8] This vision constitutes a major opportunity for rural health leaders to lead the health of our country, all of it. The "central thesis" of the recently published compendium *Reinventing Public Health, Policies and Practices for a Healthy Nation* makes the same point "to effectively improve population health and reduce health disparities, policy making in a variety of domains must take into account policies that address the fundamental social, economic, and ecological determinants of health."[10]

As an example, in Wisconsin, a voluntary coalition has developed a Strong Rural Communities Initiative (SRCI) to support the state's health plan by implementing sustainable rural models for medical, public health, and business collaboration to enhance preventive health services in rural Wisconsin. In *Wisconsin County Health Rankings 2005*,[11] a report by the Wisconsin Public Health and Health Policy Institute at the University of Wisconsin-Madison, 52% of metro counties in Wisconsin are in the top (best) quartile for Health Outcomes compared to only 11% of non-metro counties; 30% of non-metro counties are in the bottom (worst) quartile compared to 16% of metro counties. The specific purpose of SRCI is to improve health indicators for selected rural communities in Wisconsin and significantly accelerate establishing collaboration for prevention as the norm, not the exception, in rural Wisconsin.

The complexity of creating a healthy state requires a higher level of cooperation than any of us have yet experienced. This requires a significant expansion in our commitment and ability to develop collaborative leadership. Again, from *Quality Through Collaboration: the Future of Rural Health*:[8]

> Strong leadership will be needed to achieve significant improvements in health and healthcare in rural communities. Comprehensive community-based efforts will require extensive collaboration, both between stakeholders within the healthcare sector, and between healthcare and other sectors. It will be necessary to mobilize all types of institutions (e.g., healthcare, educational, social, and faith-based) to both augment and support the contributions of health professionals. Rural communities engaged in health system redesign would likely benefit from leadership training programs.[8]

Principles of Collaborative Leadership

The significant challenges we face today in healthcare require a form of leadership that is less authoritative and more collaborative. Ronald Heifitz and colleagues at the Stanford Graduate School of Business say it very well. These "problems require innovation and learning among the interested parties, and, even when a solution is discovered, no single entity has the authority to impose it on the others. The stakeholders themselves must create and put the solution into effect since the problem is rooted in *their* attitudes, priorities, or behavior. And until the stakeholders change their outlook, a solution cannot emerge."[12] It is important to not confuse being collaborative with endless stanzas of singing "Kum By Ya;" collaboration frequently requires strong external catalytic action.

Max DePree, in *Leadership Is an Art*,[13] offers a model for employer-to-employee relationships based on his experience that productivity is maximized by designing work to meet basic employee needs. His vision of the art of corporate leadership brought employees into the decision-making process. DePree's experience is primarily within the world of the Fortune 500, but many have found him to offer a useful framework for non-profit and public sectors.

While DePree was a successful leader of a Fortune 500 Company, some may describe him as impractical, a common descriptor thrown by the "pragmatists" at "collaborators." Robert Greenleaf offers a suggestion that may be helpful in thinking through this dilemma: "For optimal performance, a large institution needs administration for order and consistency, and leadership so as to mitigate the effects of administration on initiative and creativity and to build team effort to give these qualities extraordinary encouragement."[14]

As the executive director of a cooperative of rural hospitals for more than 25 years, it is easier for me than for many to see rural health through the lenses of collaboration, the opportunities it creates, and the threats it endures as a model for organization and community work. We have adopted and adapted DePree's eight leadership principles as a guide for both our internal and external relationships. To illustrate these leadership principles, the following is as described in the article "Managing Partnerships: The Perspective of a Rural Hospital Cooperative."[15]

There Is Mutual Trust—Develop relationships based primarily on mutual trust so that the cooperative go beyond the minimum performance inherent in written agreements. "While responding to a rapidly changing market in 1984, the implementation in six months, 'from scratch,' of a rural-based health insurance company in Wisconsin was only possible due to the prior existence of a basic level of trust among the key actors."

Commitment Makes Sense—Participants may join a cooperative to explore its potential; they remain only if they perceive that they are receiving a good return on their investment of time and money. "RWHC offers a broad array of shared services from which hospitals pick and choose according to their individual needs; commitments are made because they have been structured in a way that attempts to maximize the 'fit' for each individual participant."

Participants Needed—Each organization must know that it is needed for the success of the cooperative. "It is a major mistake to ever take for granted the participation or commitment of any member. The RWHC communication budget is ample testimony to the importance of early and frequent communication and consultation."

All Involved in Planning—The planning is interactive, with the plan for the Cooperative being the result of, and feeding into, the plans of the individual participants. "One theatrical but powerful example of ignoring the need for local input and preferences involved the Cooperative within months of its incorporation in 1979. Two regional health planners were practically driven from the bare wood stage of Wisconsin's historic Al Ringling Theater after their presentation of a unilaterally developed plan for local consolidations and closures. The plan was not implemented and did not contribute to further discussion of how rural healthcare in southern Wisconsin could be improved."

Big Picture Understood—Participants need to know where the organization is headed and where they are going within the organization. "RWHC has a motto: 'say it early and keep saying it.' A number of RWHC's more significant initiatives, such as improving rural hospital access to capital, various quality improvement projects, and advocacy for major education reform within the University of Wisconsin's health professional schools has been multiyear if not indefinitely long efforts."

Participants Affect Their Own Future—The desire for local autonomy needs to be made to work for the Cooperative through the promotion of collaborative solutions that enhance self-interest. "When RWHC began operations, many observers were highly skeptical about whether or not it would last, let alone make any real contribution—that rural hospitals' traditional need for autonomy would prevent any meaningful joint activity. Some shared services have been undersubscribed as hospitals have chosen local options when, at least from the perspective of RWHC staff, a cooperative approach offers a better service at a lower cost."

Accountability Up Front—Participants must always know up front what the rules are and what is expected of them. "Discussions at RWHC board meetings are frequently comparable to customer focus groups and equally valuable. Participation in all Cooperative shared services requires a signed contract, not so much as to permit legal enforcement, but to ensure that all parties in the partnership have thought through upfront the expectations of all the participants."

Decisions Can Be Appealed—A clear non-threatening appeal mechanism is needed to ensure individual rights against arbitrary actions. "The use of the cooperative strength of RWHC hospitals has been used to enforce an appeals process in a variety of circumstances, including a potential breach of contract by a large health insurer; individually, few could have justified the necessary prolonged legal challenge to enforce the contract but through concerted joint inquiry into the legal options available, further legal action became unnecessary."

Recruiting Rural Health Leaders

When recruiting organizational leaders, the recruitment and interview process must seek individuals who in addition to technical competence, also have demonstrated leadership in their prior work and activities. John Gardner, in his classic work, *On Leadership*,[16] notes six characteristics common to individuals who exercise organizational leadership. These characteristics are exhibited in many roles, for example, as the head of an organization, as a manager, or in a volunteer position:

- They think longer term—beyond the day's crises, beyond the current fiscal year.
- In thinking about the program or organization they are heading, they grasp its relationship to the larger organization or community—conditions external to the organization.
- They reach and influence constituents beyond their immediate area of responsibility.
- They emphasize the intangibles of vision, values, and motivation and understand intuitively the non-rational and unconscious elements in their relationship with their constituents.
- They have the political skills to cope with the conflicting requirements of multiple constituents and expectations.
- They think in terms of renewal. The leader or leader/manager seeks procedural and structural change consistent with an ever-changing reality.

In addition, as argued throughout this commentary, collaboration needs to be a core competency for leadership of those organizations claiming to work in or with rural communities. The following are a few examples of principles relevant to collaboration to keep in mind or discuss when recruiting or developing a leader.

Collaborative Leadership Isn't Always Traditional—If leadership is serious about maintaining and developing collaborative relationships, the following must be kept in mind:

- Management practices necessary for successful collaboration are not commonly seen in traditional, vertically organized institutions.
- Most administrators have had little experience, and even less training, regarding leadership within the context of collaborative models.
- The "natural" administrative response will frequently come out of traditions that may be inconsistent with the actions needed to support networking.

- The development of collaborative relationships has a different timescale than those based on authority—more time on the front end paid off later with less participant resistance.

Personal Attributes of a Collaborative Leader—A partial list of the personal attributes relevant to seeking or developing a collaborative leader include:

- Experience/potential for leading collaborative enterprises or networks, cultural competence across diverse communities and populations.
- When looking at alternative investments: the objectivity of an academic, the pragmatism of a businessman or woman, and the creativity of an artist.
- Appreciation for the dualities inherent in American culture—individualism and community, competition and collaboration; a realistic understanding of the health system challenges we face balanced by an "irrational" optimism and faith that we each can make a difference.
- A vision that leadership needs to be simultaneously top down and bottom up within organizations, as addressed by Max DePree.

Collaborative Leadership Skills and Experience—Below are a set of general questions intended to stimulate conversation regarding an individual's collaborative leadership skills and experience.

- What is the role of "trust" in your work with colleagues or partners? What examples can you offer of your ability developing trust in these "partnerships"? How did you do it? How was the relationship affected?
- How have you been able to make your collaborative partners feel useful?
- How have community partners been invited into your organization? What did you see as benefits and challenges in these instances? How would you do it differently today?
- In what ways have you worked to promote collaborative solutions that have enhanced the self-interest of both internal and external partners?

Summary

Leadership is the capacity to help transform a vision of the future into reality. Individuals who can and will exercise leadership are like a river's current—a part past where we now stand, a part yet to come. We have an ongoing need to remember and to look toward the next "generation." A key responsibility of those here now, is to mentor and to create structures for mentoring, in order to maximize the flow and effectiveness of tomorrow's leaders. When recruiting organizational leaders, the recruitment and interview process must seek individuals who in addition to technical competence, also have demonstrated leadership in their prior work and activities.

To exercise effective leadership, we must work to know who we are, how we relate to others, and the environment around us. "Servant leadership" is a perspective held by many throughout the rural health community and offers a key set attributes of leadership useful to rural health. To implement the Institute of Medicine's recommendations in *Through Collaboration: the Future of Rural Health*, we must develop leaders skilled in collaboration, both internal to their organization and across organizations.

The National Advisory Committee on Rural Health and Human Services had it right when they said to the Secretary and to the rest of us, "the best way to honor Jim is to consciously work to help develop the next generation of rural health leaders." There are, of course, a multitude of leadership institutes, programs, and courses throughout America; this is not a call for yet another separate entity. But it is a call to each of us in rural health to assure that we are deliberate in how we identify "emerging leaders from and for rural communities and provide them with the training and resources to play a lead role in ensuring access to quality healthcare in their states and communities."[17] Let's get started. **NCMedJ**

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COMMENTARY

What Outcomes Should We Expect from Programs that Pay Physicians' Training Expenses in Exchange for Service?

Donald E. Pathman, MD, MPH

Training to become a physician is expensive, as the four out of five medical students who graduate in debt will confirm.[1] Young physicians' educational debt averages over $109,000 and increases by more than $4,000 each year.[2]

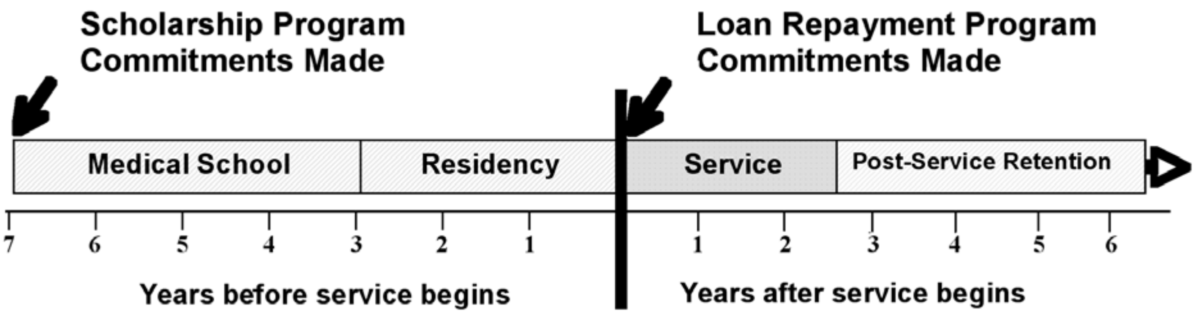
On the bright side, rising educational costs and students' fears of acquiring six-figure debts have created a market for government programs that link support for medical training costs to a period of obligated clinical work in physician shortage areas. One of the two most common types of such programs are service-requiring scholarships, which pay tuition and other costs for medical students while obligating them to a period of service that will begin when they complete residency five-to-seven years later (see Figure 1). The other common program type is loan repayment. Loan repayment programs recruit physicians as they complete residency and are ready to begin service in exchange for paying off the traditional education loans they acquired years earlier. Programs of both types typically require one year of service for each year of training cost support they provide.

These training support-for-service programs are a seemingly natural solution to both students' and the public's needs. They have grown in popularity over the past 25 years in tandem with rising tuition costs, with both federal and state agencies making ready use of them. The National Health Service Corps (NHSC)[3] currently fields an obligated physician workforce of about 1,700 scholars and loan repayers, and the Indian Health Service (IHS)[4] and Bureau of Primary Health Care[5] offer similar, but far smaller programs for physicians to work in Native American and Native Hawaiian communities. Most states also sponsor their own physician training support-for-service programs. There were a total of 69 state programs in 1996 with an estimated workforce of 1,300 practicing physicians.[6] These state programs doubled in number from 1990 to 1996 and very likely have grown further since.[6]

After 25 years of growth in these programs, the healthcare workforce advocates who lobby for them and legislators who create and fund them are not completely clear about some of their important aspects, including what outcomes can be expected. Without clear expectations, programs cannot evaluate themselves appropriately or be externally monitored, leaving program failings sometimes unrecognized and opportunities for strengthening programs unrealized.

This commentary takes the occasion of this special issue of the *North Carolina Medical Journal* dedicated to the life and work of Jim Bernstein to review what available research says

Figure 1.
Timeline of physicians' training years, signing of commitments with service-requiring scholarship and loan repayment programs, service periods (typically two-to-four years) and post-service retention.



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about the outcomes possible from physician training support-for-service programs. Under Jim's 30-year leadership, the North Carolina Office of Rural Health became a nationally recognized leader in recruiting physicians to needy practice settings, in large part by perfecting programs of this type. Sixteen years ago, Jim guided and encouraged me and my colleagues at the University of North Carolina at Chapel Hill (UNC-Chapel Hill) as we undertook our first evaluations of these programs, and the Office's ongoing councel has been invaluable.

> *"The key to long retention within service communities is to allow physicians to serve in well-run practices in communities that fit their needs, where they and their families can be happy and professionally fulfilled."*

The information and conclusions of this commentary are based on the findings of the most methodologically sound descriptive and outcome studies of the past 20 years, which are primarily cohort and cross sectional designs with appropriate comparison groups. Studies that were unable to control for statistical confounding, evaluations designed to find only positive outcomes (typically undertaken for program advocacy purposes), and testimonials were not used. The NHSC's Scholarship and Loan Repayment programs, the two largest programs in the United States, have been studied far more than other programs and, therefore, receive more attention in this discussion.

The Overarching Program Goal and Intermediate Measurable Outcomes

The fundamental public goal of support-for-service programs is to improve physician staffing in shortage area communities. To date, no studies have assessed whether communities that rely on service-obligated physicians indeed enjoy greater workforce growth in the long run than if they had relied only on traditional non-obligated physicians on the open market. Aside from the programs' overarching goal, there has been no general agreement on the measurable outcomes that legislators and the public should expect of these programs and, therefore, no agreement on the criteria by which programs should be evaluated. The outcomes most often discussed and studied reflect the intermediate accomplishments presumed to be necessary if programs are to achieve their long-term goal of improving physician staffing in shortage areas. These intermediate outcomes have included whether programs:

- fill all of their funded positions,
- select suitable physicians into the program and match them to individually appropriate communities,
- have their physicians serve in genuinely underserved communities,
- have high proportions of their physicians complete their service obligations, and
- have high proportions of their physicians remain many years in their service communities following their obligations.

These intermediate outcomes are considered, in turn, below.

Program position fill rates. Some programs, including the NHSC, have many more applicants than their funds can support and regularly fill all funded positions; other programs have many unfilled positions for lack of applicants.[7] Fill rate information for some programs is not reported or publicly available. Because many programs are able to fill all available positions year after year, any program that repeatedly fails to do so should assume that physician interest is being harmed in some way. Common ways programs reduce physician interest include offering unfavorable contract terms (e.g., financial benefits too small; penalties or service requirements too great), offering too few service site options from which physicians may choose, having poor program marketing, and/or having poor management. Mississippi's Family Medicine Education Loan/Scholarship program, for example, with its unprecedented ten-year service obligation, signed-up a total of only seven students from 2001 to 2004 despite having funding for 20 new students each year.[7] The legislature appropriately lowered the program's service requirement, but only to six years, which may still prove too lengthy to interest students.

Selecting appropriate physicians and matching them to individually appropriate sites. Appropriate physician selection criteria—the right demographics, backgrounds, motivations, and career interests—get much attention from some programs,[8] but available data suggest that they are generally not important to achieving program outcomes. Studies repeatedly find that the demographics and backgrounds of obligated and non-obligated physicians are generally not related to how satisfied they are in rural and underserved area practices nor how long they remain there.[9-11,a] Further, no studies have demonstrated that obligated physicians with certain demographics or motivations provide better care to patients in underserved practice settings. The quest for perfect

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[a] Background characteristics *are* very important to who will freely choose to practice in rural and underserved areas (i.e., important to recruitment), but this is irrelevant when selecting among applicants to support-for-service programs. Recruitment factors are not the issue with physicians asking to work in these areas; only retention factors, and individual characteristics are not relevant to retention.

selection criteria sometimes reflects programs' unwillingness to accept responsibility for their shortcomings, shifting blame instead to their allegedly ill-prepared or overly self-centered workforces ("deadbeats").

Rather than particular physician characteristics, data suggest that only concordance between the needs and interests of obligated physicians and the practice site opportunities available through their service programs are key to the success of their physicians in underserved areas—physicians' satisfaction, communities' satisfaction, and physicians' retention. Whether a physician is male or female, was raised in a rural or urban area, graduated from a public or private school, or trained in family medicine or pediatrics are criteria that are generally irrelevant to program outcomes. No type of background or training will bring physicians meaningful contentment, enthusiasm for work, and long retention when the work and community settings don't fit them. Success for obligated physicians does often depend, however, on whether their program offers practice opportunities that meet their preferences, for example, to work in a community health center that provides hospital care for its patients and to live in a town large enough to support their spouse's law practice.[10,12] Physicians will usually succeed in practices that meet their career and family needs.

Matching participants to truly needy communities. Programs differ in the types of communities and practices where physicians are allowed to serve their obligations, in the number of specific sites they may choose from, and in how the match occurs. State programs, as a group, give greater latitude in the number and type of practices available, some allowing physicians to work in any practice in any rural county of their state.[6] For these programs, no listing of practice choices is created; physicians find their own sites from across eligible geographic areas. The most restrictive programs are the federal and a few state programs that have adopted a secondary program goal to support the physician staffing needs of publicly sponsored practices, like federally qualified health centers (FQHCs), Indian Health Service clinics, and prison health centers. Participants in these more restrictive programs must choose a practice site from a short list of limited options. Some programs go through elaborate steps to identify the few "most needy" sites eligible for physician placements—most notably the NHSC, which has designated health professional shortage areas (HPSAs), priority ranking of HPSAs, and annual restrictive Health Professionals Opportunity List (HPOL) of specific eligible sites from among priority HPSAs.

Using set criteria to rank need would seem to be a reasonable approach to limiting physician placements to the neediest communities. In practice, however, devising criteria of need and carrying out the designation and physician-to-community matching processes have proven problematic and contentious. The process by which HPSAs are designated, for example, has been criticized as politically influenced and evaluations have failed to find that communities with more critical HPSA ratings have worse physician shortages.[13,14] Site eligibility lists are notoriously out-of-date, which frustrates physicians who are trying to locate an appropriate service site. Using explicit NHSC site designation criteria serves principally to mollify practices (and their Congressional supporters) that aren't deemed eligible for physician placements and to justify the policy of using support-for-service programs as a staffing mechanism for publicly supported clinics. Using short service-site availability lists to serve these political ends and to meet the immediate staffing needs of subsidized practices may or may not be worth the greater likelihood that communities will receive ill-fitting physicians who are dissatisfied with their site assignments and more likely to leave as soon as their obligations are fulfilled.

Service completion rates. The proportion of physicians who complete their obligations with service is often the most sacredly held of outcomes for programs, but perhaps shouldn't be. The common view is that physicians owe society for the medical training and bright future afforded by program dollars, and they have a responsibility to needy communities to provide service as promised when they accepted program funding. Support-for-service programs obviously cannot improve medical staffing in underserved communities if participating physicians opt not to fulfill their obligations with service.

When many early NHSC scholarship participants of the late 1970s paid off their program obligations monetarily instead of providing service,[15] Congress quickly increased penalties for buying out contracts to three times the dollar amount physicians had received plus interest. Buy-out rates plummeted, and service completion rates have been around 90% ever since. Today, with these penalty rates, buying out a contract with the NHSC Scholarship Program or with the few state programs that charge similarly high penalties,[6] will often cost physicians a prohibitive $250,000 to $700,000. With these high penalties and the courts upholding the government's right to levy and enforce them, service completion rates can nearly always be made to look good.

Forcing service with harsh penalties, however, comes at a cost to programs and communities. Requiring disinclined physicians to work in needy communities increases the costs of monitoring physicians to make certain that they abide by their contracts and increases the costs of defending against litigation brought by unhappy participants.[16] A less happy and potentially disgruntled workforce is quicker to leave their service sites as soon as their obligation periods are over.[10,11,17] Among state scholarship programs, any buy-out penalties beyond simply repaying principal plus low interest are associated with lower participant satisfaction levels and shorter retention, which perpetuates physician shortages and the need for ongoing staffing assistance for repeatedly abandoned service sites.[18] Compelling service completion with financial penalties is not a perfect solution.

Loan repayment programs show some of their advantages over scholarship programs in their high obligation completion rates despite low buy-out penalties. Loan repayment participants sign program contracts when they are older and much better informed of their career options (see Figure 1). They sign up at the time they are ready to begin serving their obligations and can know their and their family's needs and know exactly where they will serve and if the site fits their needs. Very few loan repayment programs, accordingly, have found a need to set any buy-out penalties; as a group, their service completion rates average 93% without them.[18] It is the physician-program-community fit and the financial attractiveness of the program that prompts physicians to complete their obligations with service (the "carrot"), not financial and legal threats (the "stick").

High penalties are a common aspect of programs that establish post-educational service commitments for young students, especially scholarship programs (there are other types of programs that commit students and not all use penalties). It is reasonable to question the wisdom, and even the justice, of compelling students who commit to scholarship programs as 22-year olds, but realize seven years later, through natural maturation, that the program no longer fits their more mature career and family needs. An alternative is a third type of program, the *service-option loan*, which also recruits medical students, but achieves better outcomes by holding service as an *option* to repaying program dollars at low, affordable traditional education loan rates.[6] While only 45% of states' service-option loan participants opt to provide service, those who do demonstrate excellent satisfaction and retention in their service communities.[18] The 55% who pay off their program contracts are no different and require no greater public expense than the vast majority of all medical students; that is, they fund their education with what amounts to a publicly sponsored loan. If a 45% service completion rate for a given program leaves too few physicians available for needy communities, the program can offer more contracts up front in anticipation that not all will serve.

Retention. Beyond merely completing obligations with service, there has long been the hope that obligated physicians will remain in their service communities for years afterwards. Program impact becomes much greater if two or four years of obligated service in a needy community is lengthened through post-obligation retention to ten or more years of work there. Unfortunately, there is a common misperception that serving an obligation is a financially necessary, but undesirable, career step for many physicians, and retention in service communities after obligations are fulfilled, therefore, often cannot be expected. In fact, data show that physicians participating in state-run support-for-service programs remain in their service sites as long on average as other young physicians remain in practices of all types nationwide. Physicians obligated to state-run loan repayment programs remain substantially *longer* than other young physicians.[18]

When particular programs experience poor retention, it is sometimes rationalized that high turnover is inevitable in needy communities, which are allegedly too unattractive to retain physicians and their families. However, available studies find that retention for both obligated and non-obligated physicians is generally unrelated to community characteristics,[17,19] and retention is no shorter in underserved areas than in non-underserved areas.[9,19]

The key to long retention within service communities is to allow physicians to serve in well-run practices in communities that fit their needs, where they and their families can be happy and professionally fulfilled. When service programs are operated as a short-term solution for chronically under-staffed practices—placing physicians in sites without adequate regard to fit and allowing them to be paid poorly, without benefits and treated as temporary, replaceable workers—physicians can be expected to leave promptly after fulfilling their obligations.[10-12]

Influencing the practice location choices of program alumni. For most observers, the retention of program alumni within service sites is a sign of program effectiveness. For its first 20 years the NHSC saw service-site retention as a key program outcome[15,20,b] and touted that half to two thirds of its physicians remained in their service sites beyond their service obligations.[20,21] In the early 1990s, however, longitudinal studies showed that most of those who remained in their service sites did so for only a few weeks or months.[17] A large, recent evaluation found that only 20.7% of NHSC Scholarship program alumni remained more than one month past their obligations.[22] The NHSC of the mid-1990s began speaking of the importance of NHSC alumni remaining in underserved area practices anywhere and stated that retention in service sites was not really the objective. Several studies[23,24] confirm that NHSC alumni are indeed more likely to be practicing in underserved areas than other physicians, but it is not known whether this is due to their NHSC participation or to their pre-existing career plans, which attracted them to the NHSC in the first place. The important unanswered empirical question is whether retaining obligated physicians within service sites as apposed to within any underserved area will better solve physician shortages in the long run.

Secondary Goals

Improving staffing in publicly sponsored clinics. Support-for-service programs, as discussed earlier, are sometimes used as staffing mechanisms for publicly-supported clinics, which can either help or harm their primary goal of correcting physician shortages in service communities. If lists of eligible service sites are limited to a few publicly supported clinics, which tend to be those that are chronically understaffed (the "most needy") and less well managed,[25,26] then retention following service obligations will be poor. These same clinics will need another obligated physician every two-to-four years, perpetuating a "revolving door" staffing pattern and leaving the communities vulnerable whenever no new replacement physician is available. Alternatively, physicians can be given an ample number of

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[b] "Retention of Corps providers has been seen as integral to that self-sufficiency [of local healthcare delivery systems]. Indeed, as one measure of its success, the new program looked to the number of Corps members who chose to remain in their communities at the end of their NHSC service."[20]

sponsored clinics in a variety of settings from which to select a service site. A wider selection leads to better community-physician matches and fosters competition for physicians among clinics, promoting more favorable employment contracts and better management. In the long run, this yields better retention and more stable physician staffing for publicly supported practices and their communities.

Correcting the demographic composition of the physician workforce. Another secondary goal for some programs, particularly the various federal scholarship programs, has been to minimize the debt incurred for a medical education for students from minority, poor, and rural backgrounds.[27,28] The hope has been that a financing avenue that requires less debt will encourage more students from disadvantaged backgrounds to undertake medical training. Whether the availability of service-requiring scholarships and service-option loans is instrumental in the career decisions of minority and poor students is unknown; it has not been formally studied.

With the goal of correcting the demographic imbalance of the United States workforce, the NHSC Scholarship program supports a disproportionately high number of African American physicians. As a group, however, African Americans in rural NHSC settings have proven less satisfied in their service practices and no better retained than other NHSC physicians.[29] This appears to be due to a mismatch between the urban orientation of most African American physicians[30] and the NHSC's practice of assuring that most of its physicians serve in rural settings.[29] Support-for-service programs that target a special demographic group must anticipate the unique needs of those individuals and adjust their operations accordingly, like tailoring their lists of eligible service sites or offering part-time work options. Secondary goals of any kind taken on by programs can affect their ability to achieve their primary goals in unanticipated ways.

Recommendations

Based on the literature, the following recommendations are offered to strengthen the outcomes and impact of physician training support-for-service programs.

- Legislators should be clear about the long-term goals of the support-for-service programs they create and fund. They should provide guidance to programs on how to balance the goals of improving physician availability in underserved areas in the long term with any other goals they set, such as to provide staffing for publicly supported clinics.
- Programs should be clear on the goals and specific outcomes they are pursuing and should be certain that the outcomes are appropriate to the goals. High buy-out penalties, for example, generally will not support a goal of stable, long-term staffing in underserved communities.
- Programs should regularly monitor and publicly report their outcomes. Several types of outcome data should be used:
    - Community and patient demographic data for the communities and patients where obligated physicians serve;
    - Program data on position fill rates, service completion versus financial buy-out versus default rates, and three-, 12-, and 36-month post-obligation retention rates;
    - Data from obligated physicians addressing their satisfaction, their perceptions of their fit with the community, their perceptions of the service program and service practices, and their suggestions for improving each of these. These data should be obtained through annual surveys of participants, exit interviews, and tallies of grievances.
    - Data from service practices addressing perceptions of their assigned physicians' volume and quality of practice and their physicians' fit with the community and the service program.
- In the interests of underserved communities, programs should be willing to accept outcome data and change their operations to improve outcomes.
- Programs should not tolerate poor management of their obligated physicians by practice, and legislators should not fund programs that tolerate mismanagement of this valuable public resource.

Conclusions

Twenty-five years of program evaluations have clarified many of the outcomes possible from physician training support-for-service programs. Studies have demonstrated that loan repayment programs, as a whole, have better outcomes than scholarship programs. The central importance of good community-physician matching clearly has been shown.

Information from formal research and programs' self evaluations has sometimes influenced today's programs. For example, studies demonstrating the strengths of loan repayment programs prompted Congress recently to allow the NHSC to make more loan repayment and fewer scholarship awards and led some states to expand their loan repayment programs.[6]

Other evaluation information remains generally unheeded. Despite the demonstrated importance of physician-community matches, very few programs offer site match or contract assistance to physicians and communities. Some programs have yet to make key strategic choices, like the desired balance between meeting the short-term staffing needs of publicly-supported practices and the long-term staffing needs of underserved areas. Many programs, even those with the best of intentions, tend to cling to traditional modes of operation, despite evidence showing more effective approaches.

Excellent outcomes are quite achievable from physician training support-for-service programs. In the interests of medically underserved communities, programs should have explicit outcome objectives, regularly monitor their outcomes, openly acknowledge weaknesses, and embrace change when needed. **NCMedJ**

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COMMENTARY

North Carolina Medical Society Foundation's Community Practitioner Program

Robert W. Seligson, MBA, and Pamela P. Highsmith, MEd

Introduction

Thanks to the vision, wisdom, and passion of many dedicated North Carolinians, there exists today a largely unheralded 15-year-old program responsible for providing primary care to thousands of patients in underserved communities—patients who otherwise may have gone without medical services. Each year, physicians, physician assistants, and family nurse practitioners assisted by the North Carolina Medical Society Foundation's Community Practitioner Program (CPP) provide more than 400,000 visits to patients largely on the margin of today's healthcare system. More than half of all patients seen by CPP participants are uninsured or are Medicaid or Medicare eligible, and yet these patients are able to receive quality, continuous primary care by a provider who knows them in a community-based office setting.

> *"CPP works by enabling providers who are willing—indeed eager—to work in rural, economically distressed and medically underserved communities across North Carolina."*

CPP Beginnings

In 1989, the Kate B. Reynolds Charitable Trust granted $4.5 million to the North Carolina Medial Society Foundation to help medically underserved communities in North Carolina attract and retain needed medical practitioners. It was determined early on that collaboration with other healthcare stakeholders was key, thus an Advisory Board consisting of representatives of the Family Medicine Departments of each of North Carolina's four medical schools, Area Health Education Centers (AHEC), the North Carolina Office of Research, Demonstrations, and Rural Health Development (ORDRHD), the North Carolina Hospital Association's Rural Health Center (RHC), the North Carolina Department of Commerce, the Kate B. Reynolds Charitable Trust (KBRCT), the North Carolina Medical Society (NCMS), and rural practitioners was established. Close collaborative relationships, particularly with ORDRHD, AHEC, and RHC, created synergy and complimentary roles while avoiding duplication of efforts. These relationships exist today. The Advisory Board and the program's first director, E. Harvey Estes, MD, Emeritus Professor of Community and Family Medicine at Duke University, determined that the program's primary means of assistance should be educational loan repayment. On occasion, the program has also awarded moving expenses, support for continued educational training, or direct payment for a needed piece of major equipment. The program has also provided consultative services to improve the management skills of medical office staff and has worked collaboratively with chronically underserved communities, assisting local leaders in conceiving and developing a viable local healthcare infrastructure capable of sustaining healthcare providers over the long term.

During its 15-year history, the program has assisted 128 rural, economically distressed and/or medically underserved communities in 76 of North Carolina's 100 counties (see Figure 1). It has provided support to 347 physicians, physician assistants, family nurse practitioners, and medical practices. Of the estimated 400,000 patient visits provided annually, by these

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practitioners, 34% are Medicaid recipients, 26% are Medicare recipients, 18% are uninsured, 41% are minority, and 55% suffer from chronic diseases. Since the program's inception, CPP providers have contributed an estimated $226 million in free or discounted healthcare services.

The Community Practitioner Program

CPP has three primary goals

- Improve access to healthcare for uninsured and underinsured populations in rural, economically distressed, and medically underserved communities across North Carolina, prioritizing federally designated Tier I, II, and II counties and whole or partial Health Professional Shortage Areas (HPSA).
- Provide cost-effective quality healthcare to underserved communities by helping the assisted CPP providers succeed and remain in their communities, operating financially viable practices despite low-Medicaid and Medicare reimbursement rates, a high number of uninsured patients, and often less sophisticated business operations.
- Develop and support a fellowship of primary care providers skilled in treating low-income, uninsured, and underinsured populations.

CPP works by enabling providers who are willing—indeed eager—to work in rural, economically distressed and medically underserved communities across North Carolina. The program provides financial assistance to participants in the form of educational debt relief in return for a commitment of five years in a target community. By paying up to half of their educational debt ($100,000 on average), CPP allows healthcare professionals to practice primary care medicine in areas of the state that need them most rather than choose more lucrative practices in urban areas to pay off medical school loans.

Because CPP is a private program, funded with non-public dollars, it is able to be more flexible than similar governmental programs. As a result, it has a remarkably successful retention rate. Sixty-four percent of CPP participants remain in their high-need communities beyond their initial five-year commitment, 73% continue to practice in rural or economically distressed communities, and 85% remain in North Carolina.

Due to the previously mentioned collaborative relationships, CPP operates with almost no physician recruiting expenses. Providers are referred by collaborating organizations including the ORDRHD, RHC, the state Department of Health and Human Services and its Division of Public Health. In addition, referrals are received from in-state medical schools for residents who are ready to begin practice and who express an interest in a rural or low-income community setting.

CPP Today

CPP is managed by the North Carolina Medical Society Foundation under the day-to-day supervision of Pamela P. Highsmith, Associate Executive Director of the North Carolina

CPP Snapshot

- 128 rural, economically distressed and medically underserved communities in 76 counties
- 347 physicians, physician assistants, family nurse practitioners, and medical practices supported
- $12 million spent on program costs to date
- An estimated 400,000+ patient encounters annually:
  - 34% Medicaid
  - 26% Medicare
  - 18% Uninsured
  - 41% Minority
  - 55% Chronic diseases
- An estimated $226 million in healthcare to the uninsured
- Retention rates for CPP medical providers:
  - 64% remain beyond initial five-year commitment
  - 73% continue to practice in rural or low-income communities
  - 85% remain in state

Quotes from Providers

"CPP support allowed me to start a rural health practice in a severe shortage area that couldn't afford to hire another physician. I have added two employees, allowing me to see more patients. By next year I will be hiring another physician to increase our patient load, as there are still many residents without a primary care doctor."

Kelly Rothe, DO
Burnsville

"CPP has allowed us to work with uninsured patients, Hispanic immigrants, and Medicaid patients and still maintain a viable practice. This is important because our community does not have a public clinic to provide a safety net for these high-risk populations."

Kit Helm, MD, and Sondra Wolf, MD
Franklin

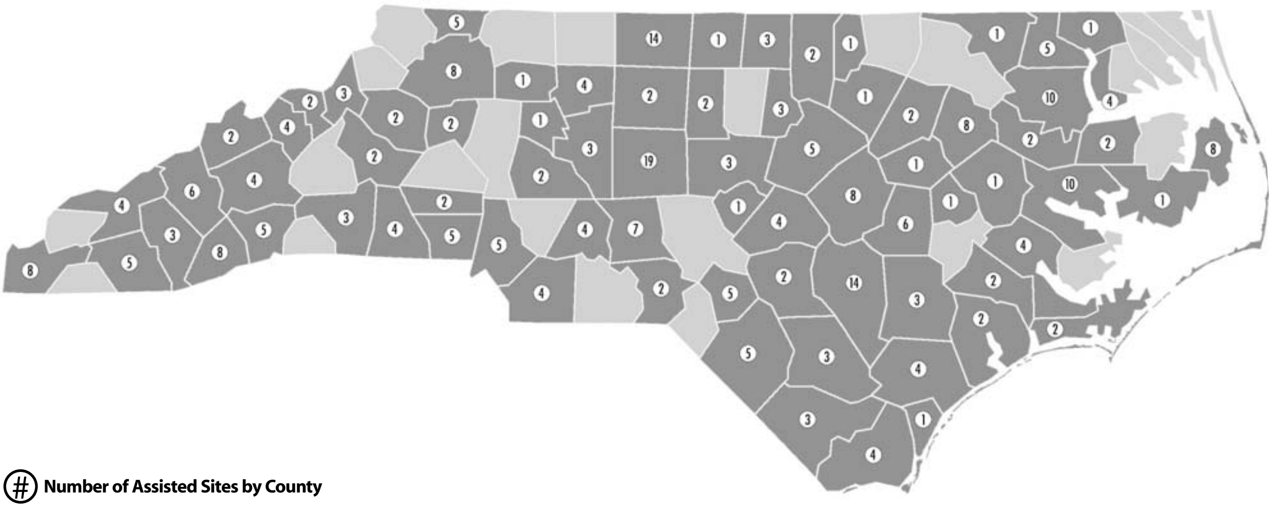
"Because of a longstanding family physician shortage, when my husband and I opened our family practice in Asheboro with CPP support, we acquired many patients who had not seen a doctor in over 20 years!"

Beth Hodges, MD
Asheboro

"CPP allowed me to practice in a rural site that, although underserved, does not meet the federal assistance guidelines. Without this help, I would have likely chosen another area. Since I have been here, I have made a tremendous impact on the needs of the Hispanic community because I am one of only two Spanish-speaking practitioners in the county."

Daniel Frayne, MD
Linville

Figure 1.
Community Practicioner Program Assisted Site—2005



(#) **Number of Assisted Sites by County**

Medical Society Foundation. Oversight is provided by the North Carolina Medical Society Foundation's 15-person Board of Trustees, chaired by Justine Strand, MPH, PA-C, Associate Clinical Professor and Chief, Physician Assistant Division, Department of Community and Family Medicine, Duke University. The program currently has an Interim Director, Cathy Wright, who will serve in this capacity until a full-time Project Director is identified.

CPP aims to support a minimum of 100 providers—primary care physicians, physician assistants and family nurse practitioners—in practice across the state at all times. At current funding levels, approximately 20 providers are added to the program each year as participants fulfill and complete their five-year commitments.

With a solid track record as a base, the North Carolina Medical Society Foundation has committed itself to continuing the program and to enhancing the support provided to recipients, as they attempt to survive in a reduced payment environment. This commitment is strengthened by projections of growing shortages of primary care providers, particularly in rural areas. A campaign is underway to secure needed funding and to build an endowment for its continued operations for the foreseeable future. **NCMedJ**

COMMENTARY

The Special Role for Rural Hospitals in Meeting the Needs of Their Communities

Serge Dihoff and Jeffrey S. Spade, CHE

North Carolina's rural hospitals occupy a special and significant role in the fabric and soul of rural communities. Rural residents traditionally relate to their community according to a handful of common "identifiers." Chief among these identifiers are community churches, high schools and their sports teams, volunteer fire departments and rescue squads, social clubs, and local hospitals. These common identifiers validate for the rural resident the community as their own, are a source of pride, and, in many instances, a point of friendly competition between communities. These community identifiers form the heart of the rural community infrastructure. At the most basic level, the rural hospital as a community identifier exists, from the perspective of rural residents, apart from the relative importance of the hospital's services, the quality of care of the hospital, or the economic support the hospital offers the community.

North Carolina's rural healthcare system was initially organized around the concept of a hospital serving its home county. Passage of the Hospital Survey and Construction Act of 1946, better known as the Hill-Burton Act, began a proliferation of hospital construction in the poor, rural communities of America—places where no hospitals would have been possible before. As a consequence, many rural communities throughout the country built their own local hospital. Community hospitals were founded in 72 of North Carolina's 100 counties, thus establishing the leadership role that rural hospitals fulfill within their communities today.

North Carolina's 61 rural counties are served by nearly 60 rural hospitals. Rural hospitals are usually smaller than the average North Carolina hospital, with rural hospitals caring for an average daily census of 77 acute care patients in 2004 versus an average of 135 patients for all North Carolina hospitals (see Table 1). In 2004, North Carolina rural hospitals cared for 227,612 inpatients, approximately 3.28 million outpatients, and an estimated 1.05 million emergency patients. The numbers speak for themselves—millions of visits for care and hundreds of thousands of hospitalized patients. North Carolina's rural residents depend heavily on their local hospital for valuable, timely, and necessary inpatient, outpatient, and emergency care services.

Rural Healthcare Networks

North Carolina's version of a *network* is a patient-focused system of care consisting of private and public organizations that provide an array of medical and social services to the community.

Table 1.
Averages for North Carolina Hospitals, 2004

	Average Rural North Carolina Hospital	Average North Carolina Hospital
Average Daily Census (Acute)	77	135
Annual Discharges	5,055	9,133
Annual Outpatient Visits	75,983	141,217
Annual Outpatient Surgeries	2,926	5,684
Annual Emergency Visits	21,867	30,859
Total Employees	590	1,343
Percent Net Revenue from Medicare/Medicaid	51%	49%
Patient Operating Margin	-2.3%	-0.2%
Uncompensated Care as a Percent of Gross Revenue	7.9%	7.2%
Average Age of Plant	10.1 years	9.5 years

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A successful rural network should include the local rural hospital, along with its tertiary care referral center, in a highly-integrated collaborative, coordinated with community-based organizations such as public health, primary care, dental health, emergency medical services, social services, transportation, mental healthcare, and long-term care. The composition of a rural health network varies by community, but in communities across North Carolina, rural health networks consistently deliver efficient, effective, and coordinated quality health services to rural residents.

Jim Bernstein's design for successful rural hospital and health networks can be summarized in four basic concepts:

- To build community systems of care that assure access to healthcare services focused on meeting the health needs of rural residents.
- To provide the planning, implementation, and operational support required by rural hospital networks to achieve higher levels of integration while continuing to meet patient needs.
- To integrate national and local initiatives that complement state priorities and programs in order to improve the access, quality, and cost-effectiveness of patient care for Medicaid, low-income, and uninsured patients.
- To focus on patients, not the provider, as the key denominator in rural health network development.

Critical Aspects of Rural Hospitals

What are the critical aspects of rural hospitals in relation to the communities they serve? First, rural hospitals are central to the healthcare and social service networks that undergird every rural county and community. The healthcare "quilt" of a rural community is comprised of a broad spectrum of healthcare organizations, community agencies and services, government-sponsored health services and providers, and a vast array of human service organizations that provide essential health-related benefits to the residents of rural communities. Rural hospitals touch every component of this community support system, from public health departments, Medicaid, and social services to Healthy Carolinians projects, community health centers, and free clinics. In addition to their healthcare mission, rural hospitals offer the community knowledgeable health professionals, leadership, desperately needed resources and space, in-kind support, and the basis for collaboration and coordination. The rural hospital is an invaluable resource and lifeline that ensures the viability of rural communities and their associated healthcare networks.

Another crucial aspect of rural hospitals is their role as catalysts for the development of local access points for healthcare. Both primary care and specialty care physicians are dependent on the local hospital for a range of healthcare services from outpatient and emergency care to complex inpatient care. Many rural communities would lack access to even basic healthcare services without the support of their local, rural hospital.

> *"...rural hospitals contribute billions of dollars in local and regional economic value and bring tens of thousands of jobs to rural North Carolina economies and communities year after year."*

Today, rural hospitals are highly involved in the recruitment and retention of vital healthcare providers, such as physicians and nurses. In 2005, 36 rural North Carolina counties were designated by the federal government as whole or partial healthcare professional shortage areas (HPSAs). Since many rural North Carolina counties are considered HPSAs, the contribution of rural hospitals as the regional anchor for trained health professionals is paramount. More than 3,665 physicians practice in rural North Carolina counties. Many physician practices would not be viable without the ability to diagnose, treat, and care for patients at a local hospital. Furthermore, more than 19,100 registered nurses, 6,211 licensed practical nurses, and 1,826 pharmacists practice in rural North Carolina. The healthcare services provided by these valuable, highly skilled health professionals are directly tied to the services supported by rural hospitals.

Financial Vulnerability

Vulnerable is the most distinctive description of the status of rural North Carolina hospitals. Vulnerability is a concern for rural hospitals in many respects: fiscal, operational, service development, availability and affordability of physicians and clinical professionals, medical technology, reimbursement, physical plant and facilities, and community support. Rural hospitals are like rare, protected birds that face near extinction due to the fragility of their environment. Rural hospital boards and executives, along with their caregivers and medical leaders, work tirelessly to ensure their local rural hospital survives to meet the healthcare needs of their communities. However, this constant struggle with vulnerability is a battle that many rural hospitals will not weather without considerable assistance and attention.

One important measure of vulnerability, fiscal vitality, is the greatest threat to the survival of rural hospitals. Operating a rural hospital is often a budget-year-to-budget-year exercise of hoping limited and constrained revenues will cover increasing expenses. Line item costs, such as staff salaries and benefits, drug purchases, the cost of medical supplies, malpractice insurance premiums, and utility charges rise yearly, often increasing faster than general price indices and at rates beyond the hospital's control. On the revenue side, state and federal hospital payments are constrained to pre-determined rates of increase, squeezing the ability of rural hospitals to ensure that revenues meet expenses. Federal payment policies, which automatically pay rural hospitals less revenue per unit of service than urban hospitals, also contribute to the poor financial stability of rural hospitals. Continually walking the "financial tight rope" without a strong fiscal safety net defines the day-to-day existence of many rural hospitals in North Carolina.

The lack of fiscal stability and a weak revenue base hurts rural hospitals in many fundamental aspects. Due to advances in medical treatments and therapies; the aging population and the continued rise of chronic disease; and the revolutionary pace of change in information technology, hospitals that are responsive to the health needs of their communities should be continually investing in the development of new services, advancing their medical technologies and capabilities, and upgrading their facilities. To stay current with these necessary advances, hospitals must have access to capital funding. Unfortunately, the tenuous financing of rural hospitals renders them risky investments for Wall Street financiers, meaning access to badly needed capital is severely restricted, especially among small rural hospitals. As a case in point, of the 88 outstanding hospital bond issues currently underwritten by the North Carolina Medical Care Commission, only 32 (or 36% of active issues) were financed for rural hospitals. Only five of the hospital bond issues supported rural hospitals with fewer than 100 beds.

Dependence on Primary Care-Oriented Therapies

One vulnerability of rural hospitals that is not well documented or understood is their dependence on primary care-oriented therapies, treatments, procedures and diagnostic services to generate revenues. For most rural hospitals, 60% or more of revenues are attributable to outpatient services, such as radiological exams, laboratory tests, physical therapy, outpatient surgery, diagnostic cardiology, and various examinations involving fiber optic procedures. The availability of these primary care diagnostic services and procedures in a local setting is crucial to the health of a community. For rural hospitals, these services form the basis of the hospital's revenue infrastructure, supporting more significant, but costly, medical and emergency care services, and community services, such as intensive care units with highly trained professionals, emergency departments with trauma physicians, and obstetrical care with newborn nurseries and specialized labor rooms. These expensive, yet critical, emergency health services are usually the first to be trimmed or closed when hospital revenues fail.

Competition for primary-level outpatient services, by full-service medical practices, outpatient diagnostic center entrepreneurs, and outpatient surgery centers, can irreversibly harm the service and revenue base of rural hospitals. Several North Carolina communities have already faced the terrible prospect of closing their local hospital due to the drastic loss of primary outpatient services and revenues. When a rural hospital is near closing, the first question the community asks is "How can we continue to have local access to emergency medical care?" Competition among rural hospitals and other providers for primary-level medical, diagnostic, and surgical services is not necessarily a detrimental strategy on its own accord. However, great care must be taken in planning and developing these services in competition with rural hospitals, especially in smaller, isolated communities, in order to protect and preserve the community's long-term investment in critical and emergency health services. Rural communities that have faced this disastrous prospect often find that they are at a point of crisis—both their community health and economic viability will erode.

Dependence on Government Payments

A summary of rural hospital traits and characteristics would not be complete without emphasizing their dependence on government payments as a constant concern for North Carolina's rural hospitals. By virtue of their location, rural hospitals serve proportionately more elderly, poor, uninsured, and disadvantaged patients than their urban counterparts. As a consequence, rural hospitals are highly dependent upon Medicare and Medicaid for sources of revenue (51% of rural hospital revenues). Some rural North Carolina hospitals depend on government payers for more than 70% of their revenues. This dependence presents serious difficulties because government payers only reimburse hospitals at the financial break-even point, or less. In addition, government payment sources can be unpredictable due to federal and state budget constraints, leading to budget freezes, or even worse, budget cuts. Rural hospitals also have a substantial uncompensated care burden (7.9% of gross charges in 2004). As a result, in 2004, the average rural North Carolina hospital received 2.3% less revenue than it actually cost to provide patient care services —a situation that is untenable in the long run.

One development in rural hospital financing is worthy of special mention, namely the Critical Access Hospital (CAH) program. A CAH is a small, rural hospital with 25 acute beds or less. North Carolina has 21 CAHs. The CAH program is designed to help small, rural hospitals manage the detrimental impact of fixed-payment government reimbursements on their hospital finances. In North Carolina, CAHs are reimbursed for their inpatient and outpatient costs for serving Medicare and Medicaid beneficiaries. The CAH program has had a stabilizing effect on small, rural hospital finances. However, CAH reimbursement does not address the fiscal burdens of caring for uninsured patients, nor does it provide an adequate level of reimbursement for investments in renovations and upgrades to buildings, capital equipment, and medical technology, or to establish new healthcare services. As a consequence, the financial picture for North Carolina's CAHs has improved, but many small, rural hospitals, including CAHs, still face the perils of substantial operational losses and fiscal vulnerability.

Workforce Vulnerability

In addition to the instability of financial resources, human resources are another basis of vulnerability for rural hospitals. For obvious reasons, hospitals are extremely dependent on highly trained, knowledgeable, and caring staff to deliver exceptional and beneficial health services. However, the demand for primary care physicians and specialists (like general surgeons), registered nurses, mental health professionals, therapists, radiology technicians, pharmacists and pharmacy technicians, laboratory technologists, emergency medical service professionals, medical record coders, insurance billing experts, and hundreds of other skilled hospital professionals is placing an incredible burden on training programs and hospital recruitment and retention efforts. Across North Carolina, nearly every professional category experiences regular cycles of workforce shortage or adequacy. Demand and supply of various healthcare professionals change rapidly based on local market conditions. While all hospitals are equally susceptible to workforce shortages, rural hospitals are particularly vulnerable. The inability of rural hospitals to recruit or staff a few nursing positions alone can place routine medical services at risk of being limited or curtailed, reducing local access to essential healthcare. Furthermore, the expenses associated with recruiting, hiring, training, and retaining skilled healthcare workers are continually rising. Finding health and hospital professionals that desire to live and work in rural North Carolina is also challenging.

Rural Hospitals and the Local Economy

Looking beyond healthcare, rural hospitals are vital to the economic health of the community as well. Rural economic development and the viability and sustainability of rural hospitals are closely linked. Employers in rural communities frequently cite the availability of local healthcare services as a determining factor in business development. Less well known, however, is the contribution of rural hospitals to the economic vitality of their communities. North Carolina categorizes all counties into one of five economic development tiers. The economically challenged counties are in Tier 1 with the economically advantaged counties in Tiers 4 and 5. Of the 36 counties in the two lowest economic categories (Tier 1 and Tier 2), 33 of the counties are rural. Furthermore, these 33 economically disadvantaged rural counties are served by 28 rural hospitals. The importance of rural hospitals as an economic engine is best understood by examining some revealing statistics from 2001. North Carolina's rural hospitals accounted for an estimated $2.96 billion in direct economic output and $1.23 billion in direct salaries and benefits paid to an estimated 29,467 rural hospital employees in 2001 (see Table 2). When induced and indirect economic impacts are added to the direct economic benefits, rural hospitals generated an estimated $6.44 billion in economic output and $2.2 billion in salaries and benefits paid to an estimated 61,265 rural workers. The evidence is simple and straightforward; rural hospitals contribute billions of dollars in local and regional economic value and bring tens of thousands of jobs to rural North Carolina economies and communities year after year.

Table 2.
Economic Benefit of Rural North Carolina Hospitals, 2001

	Direct Impact	Indirect and Induced Impacts	Total Economic Impact
Economic Output	$2.96 billion	$3.48 billion	$6.44 billion
Labor Income	$1.23 billion	$0.97 billion	$2.20 billion
Employment	29,467	31,798	61,265

Source: IMPLAN 2001, North Carolina Office of Research, Demonstrations, and Rural Health Development

Summary

Rural North Carolina hospitals are a treasure to be valued, nurtured, understood, and embraced. Just as Jim Bernstein understood and envisioned many decades ago, rural hospitals and health networks are vital components of the rural communities they serve. Attention must be given to the value of preserving, enhancing, and investing in rural hospital and healthcare networks in order to ensure that effective, quality healthcare services remain consistently available and accessible for North Carolina's rural residents and communities. **NCMedJ**

Running the Numbers

A Periodic Feature to Inform North Carolina Healthcare Professionals
about Current Topics in Health Statistics

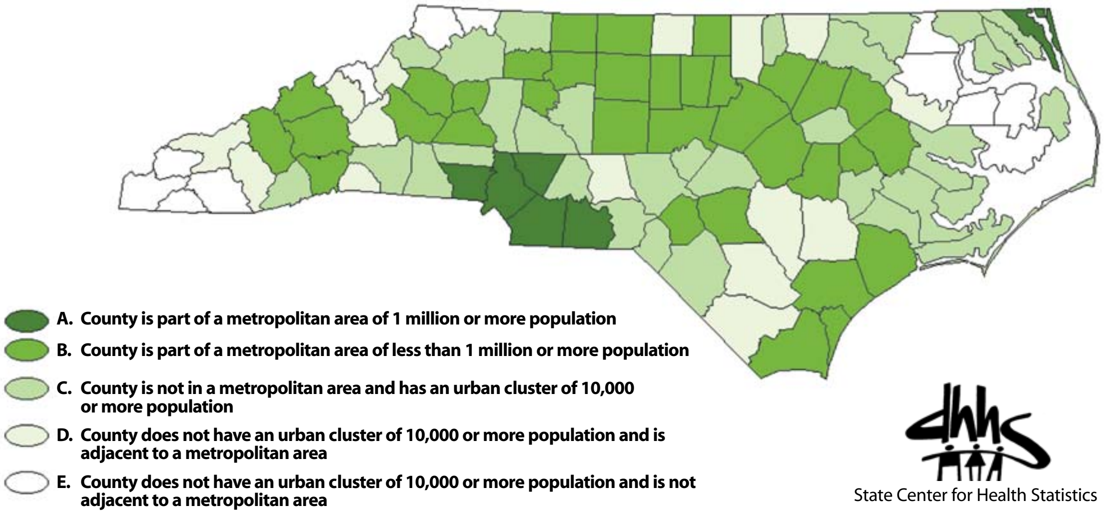
From the State Center for Health Statistics, North Carolina Department of Health and Human Services
www.schs.state.nc.us/SCHS

North Carolina Death Rates by a Rural-Urban Gradient

Death rates in North Carolina vary substantially across demographic categories, such as age and gender, and also by geographic area. For example, the death rates for many causes of death are highest in the older age groups, and counties in eastern North Carolina often have the highest death rates in the state. One important dimension of variation in health measures is the rural-urban continuum.

Urbanization in an area is an important characteristic affecting access to health services. Also, communities at different urbanization levels vary in their demographic, environmental, economic, and social characteristics. These characteristics strongly influence the magnitude and types of health problems that communities face. In this short report, we show death rates for selected causes of death by five levels of urbanization. This presentation is descriptive only. The causes of the health differentials by degree of urbanization are numerous and varied.

Figure 1.
North Carolina—Urban/Rural Catagories, 2003



We divided the 100 counties in North Carolina into five groups, from most to least urbanized (see map). This classification system is based on the United States Department of Agriculture's (USDA) 2003 Urban Influence Codes. These groups are roughly defined as: A. county is part of a metropolitan area of 1 one million or more population (six counties); B. county is part of a metropolitan area of less than 1 one million population (34 counties); C. county is not in a metropolitan area and has an urban cluster of 10,000 or more population (32 counties); D. county does not have an urban cluster of 10,000 or more population and is adjacent to a metropolitan area (15 counties); and E. county does not have an urban cluster of 10,000 or more population and is not adjacent to a metropolitan area (13 counties).

We present age-adjusted death rates for selected major causes of death for the combined 2000-2004 period. Age adjustment removes the effect of differing age distributions on the death rates. In general, rural counties have an older population and would tend to have higher unadjusted death rates for most chronic diseases just due to the age of the population. In 2004, the percentage of North Carolina's population that was age 65 and older was 11.9%. This percentage increases steadily from 9.4% in the most urban counties (category A) to 18.7% in the least urban counties (category E).

In 2004, the percentages of North Carolina's population of 8,541,000 residing in each of the five standard USDA urban/rural categories were: 15.3% in category A, 53.7% in category B, 22.8% in category C, 5.8% in category D, and 2.4% in category E. The table below shows age-adjusted death rates for each of these county groups and the state total, for selected causes of death.

Table 1.
2000-2004 North Carolina Age-adjusted Death Rates (Deaths per 100,000 Population) by Selected Causes of Death and Urban/Rural Category

		Most Urban				**Most Rural**
	NC Total	**Categ. A**	**Categ. B**	**Categ. C**	**Categ. D**	**Categ. E**
All Causes	897.6	889.1	874.9	936.5	961.2	906.0
Heart Disease	233.9	224.1	222.2	257.2	257.7	229.0
Cancer	197.4	192.3	196.1	202.5	201.3	197.3
Stroke	67.5	63.7	67.0	69.1	73.4	63.9
Diabetes	27.5	24.9	26.0	29.2	35.5	30.3
Chronic Obstructive Lung Disease	46.0	45.3	45.5	46.4	48.0	51.1
Alzheimer's Disease	25.5	35.0	24.8	23.9	22.5	21.9
Motor Vehicle Injuries	19.6	15.1	17.5	24.6	29.1	27.2
Other Unintentional Injuries	24.8	22.3	24.2	26.6	27.7	31.0
Suicide	11.7	10.7	11.2	12.8	12.6	13.5
Homicide	7.3	7.7	6.5	8.6	9.0	6.9

For deaths from all causes, heart disease, cancer, stroke, and diabetes, the age-adjusted death rates tend to be higher in the more rural counties, with the exception of category E (the most rural counties), where the death rates are lower than for category D. In looking at the unadjusted death rates for these causes of death (not shown in table), the category E counties have by far the highest death rates, reflecting their much higher percentage of the population that is age 65 and older.

For chronic lung disease, the most rural counties have the highest age-adjusted death rates. For Alzheimer's disease, the highest age-adjusted rate occurs in the most urban counties, with decreasing rates for the more rural counties (though the highest unadjusted Alzheimer's death rate occurs in the category E counties). For motor vehicle injuries, other unintentional injuries, and suicide, the most rural counties have the highest death rates. For homicide, the category C and D counties have substantially higher death rates.

The somewhat lower age-adjusted death rates observed in the Category E counties for many of the causes of death is consistent with the findings of other studies and may, in part, reflect the fact that these counties contain places where healthy people go to retire or retreat. The rural/urban differences in death rates observed here are purely descriptive, and we have not tested any of these differences for statistical significance. However, given that five years of data were used, all of the death rates shown in the table are fairly stable and based on at least 200 deaths in the numerator, with the exception of suicide (149 deaths) and homicide in the category E counties (66 deaths). Many factors account for the patterns shown here, including rural/urban variations in socioeconomic status and access to healthcare.

Contributed by Paul A. Buescher, PhD, and LeRoy Clark, BS
State Center for Health Statistics, North Carolina Division of Public Health

Coming in the March/April 2006 issue of the

North Carolina Medical Journal

a look at Prostate Cancer

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North Carolina MEDICAL JOURNAL

Readers' Forum

An Update From:

King LP, Siminoff LA, Meyer DM, Yancy CW, Ring WS, Mayo TW, Drazner MH. Health insurance and cardiac transplantation: A call for reform. J Am Coll Cardiol. 2005 May 3;45(9):1388-1391.

A Heartfelt Story for the Rich

One in four donated hearts in the United States comes from the ranks of the uninsured, according to a study in the *Journal of American College of Cardiology*. Socioeconomics has always been a factor in organ donations because of the expense of long-term care for a new organ. Nevertheless, the doctors and ethicists who did the study say the finding is a glaring inequity in a national organ donation system that strives for fairness.

You should not ask a group of people, in this case nearly one-quarter of heart donors, to contribute to a pool of resources not available to them," says Tom Mayo, director of Southern Methodist University's (SMU) Maguire Center for Ethics and Public Responsibility and an author of the study "Health Insurance and Cardiac Transplantation: A Call for Reform." "A system that derives such a substantial benefit from people who, if the tables were turned, would not qualify for a transplant for financial reasons raises serious questions of justice and the equitable allocation of life-saving medical resources."

By studying a database of nearly 300 organ donors, researchers from University of Texas (UT) Southwestern Medical Center, SMU, and Case Western Reserve University found approximately 25% of the donors had no health insurance. Half of those uninsured donors are between the ages of 45 to 64 years, the most common age group to receive a heart transplant. The estimated cost of a heart transplant is $391,000. Read more about this story and the study by going to http://smu.edu/experts/ or call SMU Office of News and Communications at 214-768-7650.

Thomas Mayo, JD
Director
Maguire Center for Ethics and Public Responsibility
SMU
Dallas, TX

Laura A. Siminoff, PhD
Professor of Bioethics, Oncology and Family Medicine
Case Western Reserve University
Cleveland, OH

Mark H. Drazner, MD
Cardiologist
UT Southwestern Medical Center
Dallas, TX

(reprinted with permission from Southern Methodist University)

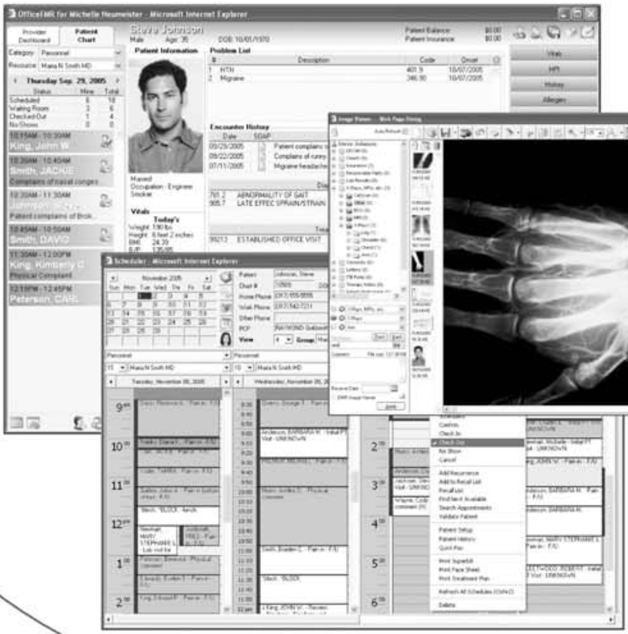
To The Editor:

The November/December 2005 issue of the Journal featuring access to dental care provided a balanced and sobering assessment of dental care access and treatment in North Carolina. In spite, of the efforts on the part of many people, advocates, clinicians, and policy makers alike, dental care for too many of our citizens is unattainable. Like obesity and the use of tobacco, the health consequences of diseased mouths are well known and the cost in misery and dollars well documented.

As noted in the variety of articles, the problem of access to dental care for all is complex and not likely to be solved by any one effort alone. However, that does not prevent the need to do so. All involved—providers of dental care, those who pay the bills, patients, community leaders, and those who make the laws—must come to a common understanding of the importance of affordable, equitable, and accessible dental care as a basic necessity. When such agreement is reached, the power to improve this area of our people's health will exert itself. Until then, I fear that we will still search for solutions in isolation and struggle to make them effective.

Thank you for an excellent issue.

Olson Huff, MD, FAAP
Senior Fellow
North Carolina Child Advocacy Institute
Asheville, NC



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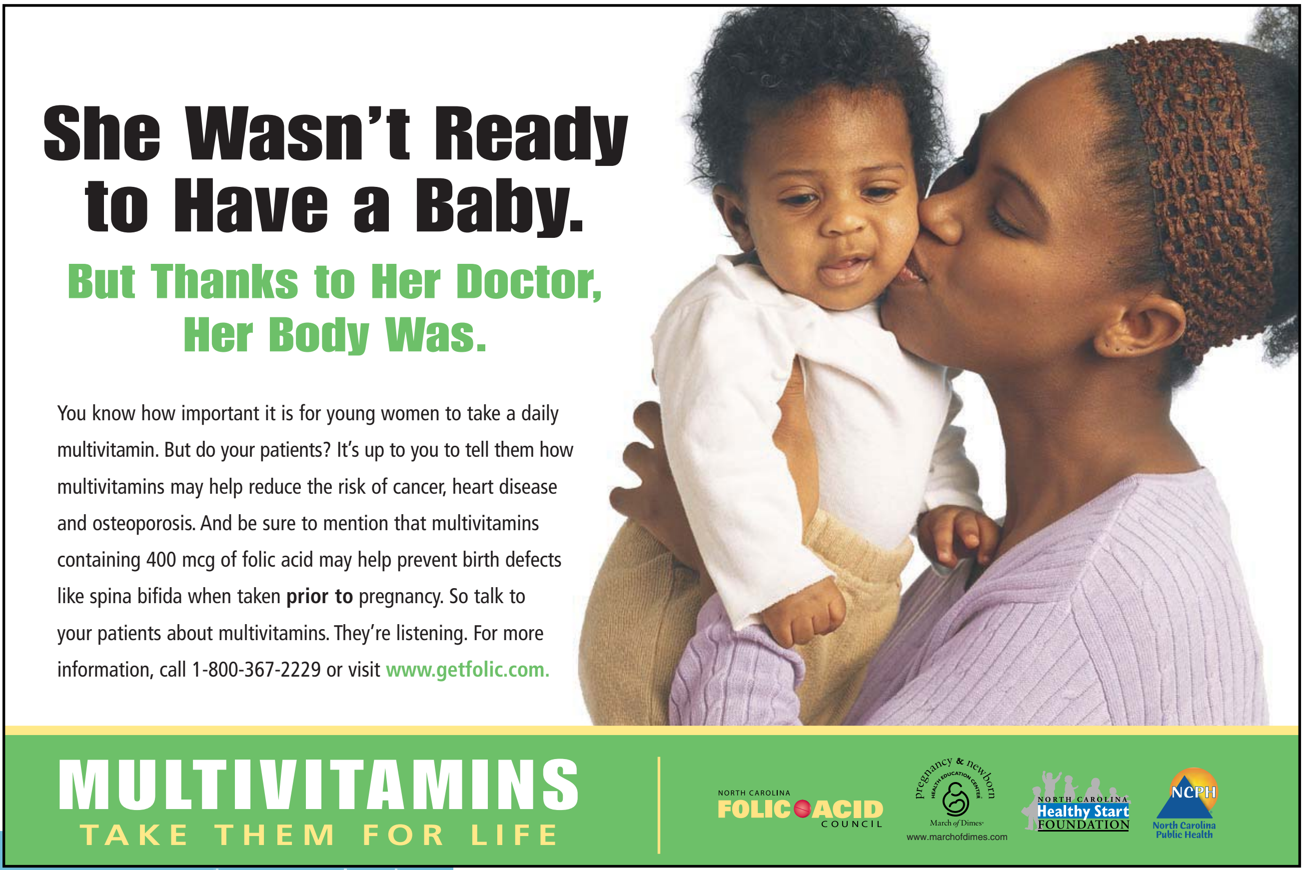

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LUMBERTON — Southeastern Regional Medical Center (SRMC) is the lead agency in a partnership with the Robeson County Health Department and other health and human service agencies in the county. "The mission of the partnership is to coordinate and implement countywide health initiatives in an effort to create an environment that supports good health among the citizens of Robeson County," said Luckey Welsh, SRMC President and CEO. "We are proud to take a lead role in these grassroots programs toward better healthcare."

Examples of the partnership include free health screens for the early detection of diabetes, heart disease, and cancer, as well as the Community Health Education Center, SRMC's health library located in Lumberton's prime shopping mall. The library offers pamphlets, Internet access and a staffed help desk to answer questions regarding health issues.

Of recent note is the implementation of Project HEALTH, an acronym for Healthy Eating and Active Lifestyles for Tomorrow's Health. Project Health addresses rising concerns of childhood obesity in targeted Robeson and Columbus County schools. A three-year commitment has been guaranteed through a $450,000 start-up grant by the N.C. Health and Wellness Trust Fund Commission. After the three years, the program will be sustained by SRMC and the partnership.

Also included in the partnership effort is the SRMC Diabetes Community Center. The center offers a comprehensive Diabetes Self Management Program that is nationally recognized by the American Diabetes Association.

See Health Partnership, Page 4B

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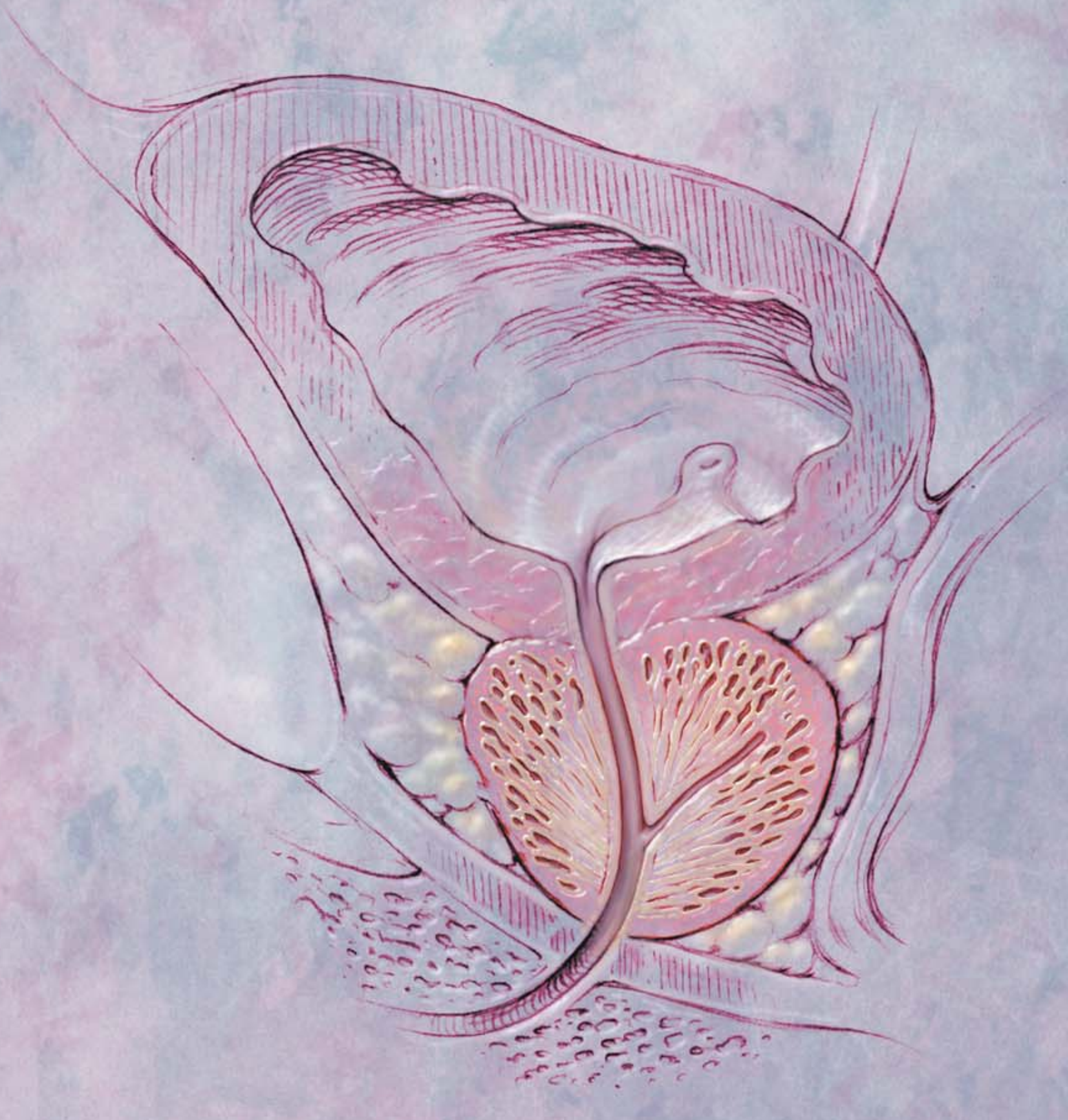

Prostate Cancer: Screening, Diagnosis, Treatment, and Follow-Up **Care**

Also in this Issue

Medical Homes for Children with Special Healthcare Needs... and Implantable Left Ventricular Devices...

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March/April 2006, 67:2

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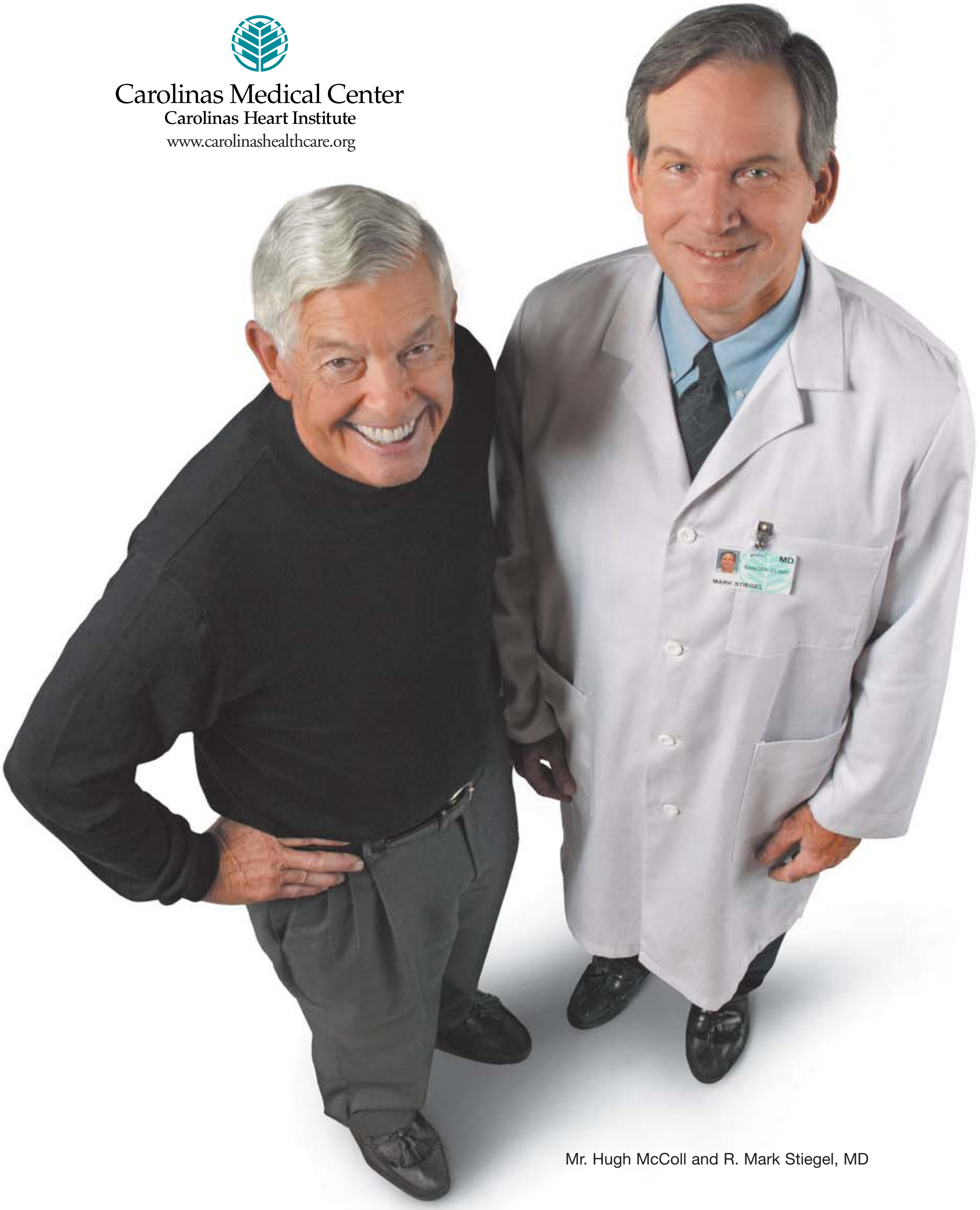

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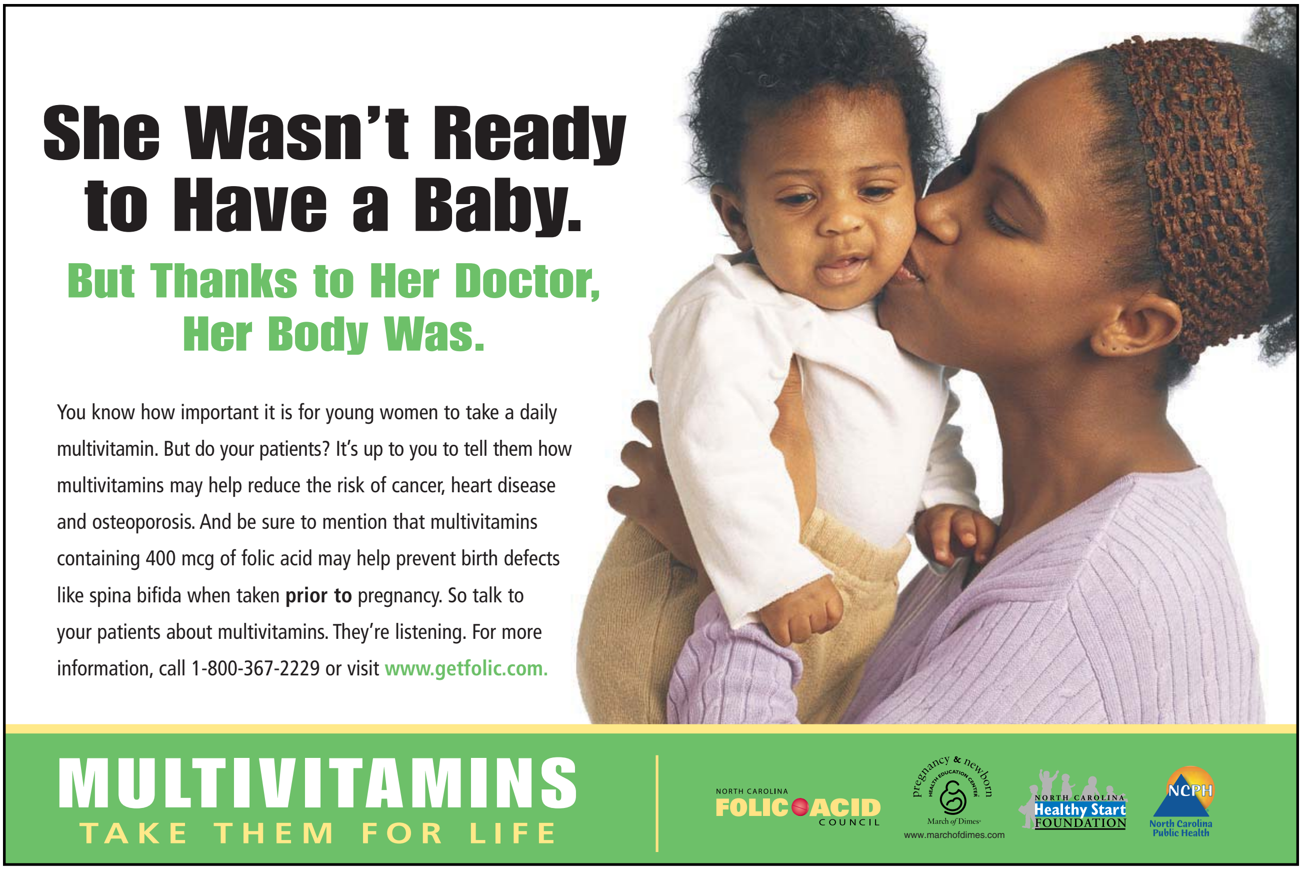

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In 1983 the North Carolina General Assembly chartered the North Carolina Institute of Medicine as an independent, nonprofit organization to serve as a nonpolitical source of analysis and advice on issues of relevance to the health of North Carolina's population. The Institute is a convenor of persons and organizations with health-relevant expertise, a provider of carefully conducted studies of complex and often controversial health and healthcare issues, and a source of advice regarding available options for problem solution. The principal mode of addressing such issues is through the convening of task forces consisting of some of the state's leading professionals, policy makers and interest group representatives to undertake detailed analyses of the various dimensions of such issues and to identify a range of possible options for addressing them.

Members of the North Carolina Institute of Medicine are appointed for five-year terms by the Governor, and each task force convened by the Institute typically includes at least one-third of its membership from among the appointed members. Topics to be addressed through task force efforts are chosen following requests from the Governor, the General Assembly or agencies of state government. In some cases, topics are selected on the basis of requests from a number of stakeholder organizations across the state where this type of analytical process is considered to have potential value.

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March/April 2006, Volume 67, Number 2
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Prostate Cancer: Screening, Diagnosis, Treatment, and Follow-Up Care

COMMENTARIES

SPECIAL DATA REPORT

DEPARTMENTS

> *"The possibility of an American man acquiring prostate cancer during his lifetime is approximately 15%."*

A new feature of the North Carolina Medical Journal

Tarheel Footprints in Healthcare

Recognizing unusual and often unsung contributions of individual citizens who have made healthcare for North Carolinians more accessible and of higher quality

Recognizing Ann Probst, CNA, North Carolina's "Nurse Aide of the Year"

Anyone familiar with long-term care knows that the job of being a nursing assistant in a busy nursing home is both hard and demanding. Every facet of a resident's life in a skilled nursing facility is affected by the quality of care and compassion and skill of these direct care workers, who often have responsibility for as many as 20 residents at a time.

Ann Probst, CNA (left), from the Lutheran Home–Albemarle, since 1980, pictured here with one of her residents, Ms. Daisy Curlee

The North Carolina Health Care Facilities Association, the trade association for nursing homes in our state, has recognized the importance of direct care workers in the effort to provide quality health and life care to their residents. For this reason, six years ago the Association began its "Fabulous 50" program to honor ten nursing assistants in each of its five districts each year. An honoree in each district is singled out for special recognization, with one being selected statewide as the "North Carolina Nurse Aide of the Year." This year, the Association has chosen to honor Ann Probst, a 25-year veteran of nursing assistance serving the residents of Lutheran Home–Albemarle.

Many of her colleague CNAs, nurses, and family members joined together in nominating Ann Probst for this distinguished award. She has been described by those who work with her as a "transformational leader" because of the example she sets for others and for the way in which she instills the very highest level of concern for resident welfare in her everyday practice. One of the things for which she has been known is her unfailing commitment to the idea that each long-term care resident is an individual with unique gifts, if only those who serve them day-to-day can find the time and the means of unlocking those qualities of the person that define them as personalities. Her effort to know her patients as individuals have led her to use her own personal resources to decorate resident rooms for the holidays; to make her own special clothing to reflect the seasonal themes at different times of the year; to arrange for certain residents to attend church services in the facility or special crafts activities (and to arrange for their return to their rooms when these activities are over); to remind staff on different shifts to make it possible for certain residents to enjoy a televised sporting event of particular interest, to continue a hobby (e.g., coin collections or sewing), to acquire special apparel (like a jogging suit) when residents are experiencing difficulty dressing; to have activities like coloring books and games on hand for the visiting grandchildren of residents; or to be certain that patients are observed for critical signs of health and function of importance to nursing supervisors, who may not be in a position to make such detailed observations on a daily basis. It has been discovered that she anonymously paid the cable television bill of a resident whose family no longer could afford this luxury because the resident so enjoyed the experience of watching television at certain points in the day.

For Ann Probst, and the 49 other "Fabulous 50" nurse aides who have been honored this year, being a nursing assistant is a life's work offering the opportunity to serve dozens of persons at a point when they need both high quality, skilled nursing services, as well as the personal care of one who is dedicated to assuring a quality life experience when one is most vulnerable. Ann Probst's legacy is assured as both her daughter and her granddaughter have chosen to follow in her very large Tar Heel footsteps, choosing to become CNAs as well. For all these years of dedicated service to the people of this state in such a demanding role, the *North Carolina Medical Journal* is pleased to salute Ms. Ann Probst, CNA.

ARTICLE

Medical Homes for Children with Special Healthcare Needs in North Carolina

Savithri Nageswaran, MD, MPH, Marcia S. Roth, MPH, Catherine E. Kluttz-Hile, BSN, MA, and Anita Farel, DrPH

Abstract

Background: *The American Academy of Pediatrics defines a medical home as medical care for children that is accessible, continuous, comprehensive, family-centered, coordinated, and compassionate. North Carolina uses the medical home concept as a model for providing high quality care to children with special healthcare needs (CSHCN). However, until recently, information on medical homes for CSHCN in North Carolina has not been available.*

Methods: *Using North Carolina data from the National Survey of Children with Special Health Care Needs (2000-2002), we describe the characteristics of children having a special healthcare need. We conducted bivariate analysis of socio-demographic factors with medical home and its five components (family-centered care, effective care coordination, personal doctor or nurse, usual source of care, and referrals for specialty care) and multivariate analysis to identify the predictors of having a medical home.*

Results: *Fifty-six percent of CSHCN in North Carolina have a medical home. White CSHCN are 1.7 times more likely to have a medical home compared to non-white CSHCN. CSHCN with no functional limitations are 1.6 times more likely to have a medical home compared to children with some or severe limitations of their functional status.*

Conclusions: *Current, population-based information about CSHCN and their families is essential for assessing needs and evaluating pediatric initiatives at the state level. Disparities among CSHCN due to race and functional status should be considered in organizing services for CSHCN in North Carolina.*

Background

Children with special healthcare needs (CSHCN) are those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally.[1] Using this definition, an estimated 9.3 million children in the United States have special healthcare needs, accounting for 13% of all children.[2]

In order to improve the quality of care for CSHCN, the Maternal and Child Health Bureau (MCHB) has adopted the "medical home" concept as a model of care for CSHCN. Increasing the proportion of children with special healthcare needs who have access to a medical home is one of the national health objectives.[3] The American Academy of Pediatrics defines medical home as medical care of infants, children, and adolescents that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, culturally effective, and delivered or directed by well-trained physicians who provide primary care and help to manage essentially all aspects of pediatric care.[4]

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[a] The federal Maternal and Child Health Block Grant is designed to help states ensure the health of mothers and children, with a special focus on the most vulnerable populations (e.g., those who are hard-to-reach, low-income, children with special healthcare needs, and/or racial and ethnic minority populations).

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There is wide variation among states in the way that services and systems of care for CSHCN are developed and implemented. Federal support through the MCHB Title V Program[a] provides an important foundation and is further shaped by state appropriations, third-party reimbursement, specific characteristics of delivery systems, and the population of CSHCN within each state. In North Carolina, services for CSHCN are organized through the Specialized Services Unit of the Children and Youth Branch in the Women and Children's Health Section of the Division of Public Health. The Medical Home Initiative for Children with Special Health Care Needs was designed by the Division of Public Health to provide a comprehensive approach to the development of medical homes for children, particularly CSHCN.[5] The Division of Public Health collaborates with the North Carolina Pediatric Society, private pediatric practices, healthcare demonstration projects (e.g., the Community Care Networks), the state Medicaid Program, parent advocacy organizations, (e.g., the Family Support Network of North Carolina, the Exceptional Children's Advocacy Center), medical schools, and specialty clinics linked to tertiary medical centers in planning and implementing programs for CSHCN.

Information on the characteristics of CSHCN and the presence of medical homes among CSHCN in North Carolina is essential for designing and implementing programs tailored to the needs of CSHCN in North Carolina. This information can also serve as a baseline for future evaluation of the state's performance. Until recently, state-level data on CSHCN and on the presence of medical homes were not available. The National Survey of Children with Special Health Care Needs provides an opportunity to obtain state-level prevalence estimates, to describe the needs of this population of children, and to identify areas that need improvement in the systems of care for CSHCN.[6]

The objectives of our study are: (1) to describe the characteristics of CSHCN in North Carolina, (2) to analyze information about the implementation of the medical home and its component parts (family-centered care, effective care coordination, personal doctor or nurse, usual source of care and referrals for specialty care) among CSHCN in North Carolina, and (3) to identify the socio-demographic factors associated with having a medical home presence in this population.

Methods

Data Source

The National Survey of Children with Special Health Care Needs was sponsored by the MCHB and conducted by the National Center for Health Statistics (NCHS) between October 2000 and April 2002. A random-digit-dial sample of households with children younger than 18 years was selected from each of the 50 states and the District of Columbia. The respondent for the survey was the parent or guardian who was most knowledgeable about the child's health. The methodology of the survey has been described elsewhere.[7] All survey data are publicly available at the NCHS website.[8] This study analyzed data about North Carolina's children with special healthcare needs collected by the National Survey. The weighted response rate for North Carolina was 63.1%.[7]

Variable Description

A child was identified as having a special healthcare need if he or she met any one of the five screening criteria listed in Table 1. Of the 5,548 children screened in North Carolina, 884 (14%) were identified as CSHCN. The CSHCN screener is a validated tool used to identify children with special healthcare needs.

The medical home is a composite outcome and a dichotomous variable (yes/no) derived from 12 questions on the survey to capture the five components of the medical home concept—namely, receipt of family-centered care and effective care coordination, presence of a personal doctor or nurse, access to a usual source of care, and absence of problems in obtaining referrals to specialists. The components, family-centered care, effective care coordination, and usual source of care were, in turn, derived from five, three, and two questions, respectively (see Table 2). If a child did not meet all of the five component

Table 1.
Proportion of Children in North Carolina with Special Healthcare Needs Identified through the CSHCN Screener Questionnaire (N = 5,548)

Screening Questionnaire Item*	Proportion of all children (%)
Child needs or uses more medical care, mental health services, or educational services than is usual for most children of the same age because of a medical, behavioral, or health condition that is expected to last 12 months or longer	7
Child needs or uses prescription medication because of a medical, behavioral, or health condition that is expected to last 12 months or longer	11
Child has a limitation in abilities to do the things that most children of the same age can do because of a medical, behavioral, or health condition that is expected to last 12 months or longer	3
Child needs or gets special therapy, such as physical, occupational, or speech therapy because of a medical, behavioral, or health condition that is expected to last 12 months or longer	2
Child has an emotional, developmental, or behavioral problem that is expected to last or has lasted for 12 months or longer for which he or she needs treatment or counseling	3

* Items not mutually exclusive

Table 2.
Criteria Used to Define a Medical Home in the National Survey of Children with Special Health Care Needs[*†]

Presence of a usual source of care	
	The child has a usual source for sick care
	The child has a usual source for preventive care
The child has a personal physician or nurse	
Experiences no difficulties in obtaining referrals to specialists when needed	
Receives effective care coordination when needed	
	The child has professional care coordination when needed
	Physicians communicate well with each other
	Physicians communicate well with other programs
Receives family-centered care	
	Physicians spend enough time with the child
	Physicians listen carefully to the family
	Physicians are sensitive to family's values and customs
	Physicians provide needed information
	Physicians make the family feel like a partner

* Based on respondents' report

† For actual questions, please refer to the Program and Collections Procedure manual of the National Survey of Children with Special Health Care Needs[7]

criteria, then he or she was considered not to have met the criteria for having a medical home. This strategy of deriving the medical home variable was based on the method reported previously.[9,10] The questions from the survey used to derive the medical home variable are supported in the literature.[11]

Age, gender, race, functional status of the child, metropolitan status of residence, income level of the household, mother's education, and adequacy of insurance were the independent, categorical variables of interest. Income level of the household was categorized as income less than 200% of Federal Poverty Guidelines (FPG) and more than or equal to 200% FPG, because, at 200% FPG, all children in North Carolina are either eligible for Medicaid (Health Check) or the State Children's Health Insurance Plan (Health Choice).

Functional status of the child was derived from two questions and categorized into "no limitation of activities due to the child's condition" and "some or severe limitation of activities." Adequacy of insurance was derived from five variables. To be considered to have adequate health insurance, a child needed to have: (a) public or private insurance at the time of the interview, (b) no gaps in insurance coverage in the year prior to the interview, (c) insurance coverage that usually or always meets the child's needs, (d) costs not covered by insurance that are usually or always reasonable, and (e) insurance coverage that usually or always permits the child to see needed providers. If the child did not meet any one of the criteria mentioned above, insurance was considered inadequate.

Statistical Methods

Following univariate analysis, bivariate analyses were conducted to determine the association between each one of the independent variables and having a medical home and its five components. The Pearson chi-square test was used to examine the association between categorical variables. Independent variables that were statistically significant for the presence of a medical home in bivariate analysis were included in multivariate analysis. We used a logistic regression model for multivariate analysis. Some cells in these data had a small number of observations. Since estimates derived from a small number of observations are not valid population estimates, the NCHS recommends using the relative standard error (RSE) to measure an estimate's reliability. Accordingly, if an estimate had an RSE [(standard error/ estimate) x 100] of greater than or equal to 30, then the result was considered inaccurate and, hence, was not used for further analyses. In order to obtain population-level estimates, appropriate survey weights were used in the analysis. Since the study is exploratory, we did not correct for multiple comparison and considered a p value of less than 0.05 to be statistically significant. Stata Intercooled version 8.2 was used for statistical analysis. The Office of Human Research Ethics at the University of North Carolina at Chapel Hill approved this study.

Results

There are an estimated 280,770 children with special healthcare needs in North Carolina, representing 14% of all children less than 18 years of age. The proportion of children meeting the criteria for special healthcare needs is presented in Table 1.

Most of North Carolina's CSHCN are boys (61%), white (71%), and live in a metropolitan area (70%). Only 57% have adequate insurance. Forty percent live in households with incomes less than 200% FPG. Fifty-eight percent of CSHCN have some or severe functional limitations. Fifty-six percent of the mothers of CSHCN have graduated from high school. A majority of CSHCN (81%) were older than five years of age at the time of the survey.

Among CSHCN, 91% have a usual source of care, 86% have a personal doctor or nurse, 78% receive family-centered care, 48% receive effective care coordination, and 81% report no difficulty obtaining referrals. Fifty-six percent of the children have met all five components of the medical home in North Carolina, and an additional 29% have met four of the five components. Of the 29% who met four components of the medical home, more than half lacked family-centered care.

Results of bivariate analysis of the independent variables with a medical home and its five components are presented in Table 3. A higher percentage of white CSHCN (60%) compared to non-white CSHCN (45%) have a medical home ($p = 0.007$). Access to a medical home is lower among CSHCN with functional limitations compared to those who do not have functional limitations (51% versus 62%, p = 0.02). While 60% of CSHCN with adequate insurance have a medical home, only 49% of CSHCN without adequate insurance have a medical home (p = 0.02). Age, gender, metropolitan residence, mother's education, and income status were not significantly associated with having a medical home based on bivariate analysis.

Differences were identified in the association of socio-demographic factors and the five components of the medical home (see Table 3). Family-centered care is associated with race, functional status, and adequacy of insurance. CSHCN who are non-white, lack adequate insurance, and have some or severe functional limitations receive family-centered care less often than their counterparts. While 11% of CSHCN with no functional limitations have difficulties obtaining referral to specialists, 24% of those with some or severe limitations have referral problems (p = 0.02). Access to a usual source of care was associated with mother's educational status: CSHCN whose mothers have a high school education or more have greater access to a usual source of care compared to CSHCN whose mothers did not have a high school education (95% versus 86%, p = 0.001). Race and household income were associated with access to a personal doctor/nurse.

Race, functional status, and adequacy of insurance were the

Table 3.
Bivariate Association of the Medical Home and Its Components with Socio-Demographic Factors among CSHCN in North Carolina[*]

Characteristic	Usual source of care (%)	Personal doctor/ nurse (%)	No referral problem (%)	Effective care coordination (%)	Family-centered care (%)	Medical home (%)
Age, years						
0 to 5	91	84	82	74	76	59
6 to 17	91	87	81	39	70	55
Sex						
Male	90	86	80	51	69	55
Female	92	85	84	40	74	57
Race						
Non-white	89	77[‡]	81	29	57[†]	45[‡]
White	92	89	81	57	76	60
Residence						
Metropolitan	91	85	81	53	70	55
Non-metropolitan	91	88	80	37	74	57
Poverty status, % FPL						
> 200	92	90[§]	84	50	74	59
< 200	89	81	80	52	69	53
Functional status						
No limitation	90	85	89[§]	70	82[§]	62[§]
Some/severe limitation	91	86	76	42	63	51
Adequacy of insurance						
Adequate	90	85	85	55	77[†]	60[§]
Not adequate	92	87	75	36	61	49
Mother's education						
More than high school	95[‡]	88	83	48	74	58
High school or less	86	82	79	44	68	53

* Population-level estimates. Shaded values have relative standard errors ≥ 30 and are not valid population-level estimates. "Medical home" present if all five criteria (usual source of care, personal doctor/nurse, no referral problems, effective care coordination and family-centered care) were met.

† P < 0.001

‡ P < 0.01

§ P < 0.05

Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics, State and Local Area Integrated Telephone Survey, National Survey of Children with Special Health Care Needs, 2001.

independent variables used in the logistic regression model to evaluate the association of socio-demographic factors with the presence of a medical home. None of the other variables (age, gender, residence, income status, and mother's education) confounded the relationship of the three independent variables with having a medical home.

The results of the multivariate analysis are presented in Table 4. In North Carolina, white CSHCN are 1.7 times more likely to have a medical home compared to non-white children, adjusted for functional status and adequacy of insurance. Children with no functional status limitation have 1.6 times the odds of having a medical home compared to children who have some or severe functional status limitation. After adjusting for race and functional status, adequacy of insurance was not associated with having a medical home.

Discussion

Fifty-six percent of CSHCN in North Carolina meet the operational definition of having a medical home. Children who are not white and children with functional limitations are significantly less likely to have a medical home compared to their counterparts.

Compared to national data,[10] a higher percentage of CSHCN in North Carolina have a medical home (56% versus 53%), receive family-centered care (71% versus 67%) and have effective care coordination (48% versus40%), and have no difficulty obtaining referrals (81% versus 78%). While the percentage of CSHCN in North Carolina with a usual source of care is similar to national averages, only 86% of CSHCN in North Carolina have a personal physician or nurse compared to 89% nationally. However, these differences in results between North Carolina and national data are small.

Race is an important correlate for not having a medical home in North Carolina. Previous studies have shown racial and ethnic disparities among children with special healthcare needs in access to healthcare, health-services utilization, and impact of a chronic health condition on families of CSHCN.[10,12,13] Our study provides further evidence of racial disparities in access to healthcare among children with special healthcare needs. This current information about racial disparities should be examined further.

Similar to CSHCN across the United States, severity of functional limitations was another independent predictor of not having a medical home. Disparities in healthcare of CSHCN associated with their functional status have been reported by other states.[14,15] Future studies are necessary to understand these variations in functional limitations and the causes for these disparities among children with special needs.

Although adequacy of insurance was associated with having a medical home in the bivariate analysis, the association was not significant after adjusting for functional status and race in a multivariate model. There is substantial evidence to show that being insured positively influences the healthcare experiences of CSHCN.[6,16-18] A significant difference may have emerged if insurance status were dichotomized as uninsured versus insured and the type of insurance as private versus public. Unfortunately, the sample size was too small to evaluate the association of having a medical home with insurance status or type, and we had to use adequacy of insurance as a proxy for insurance status.

The association between poverty and limited access to medical care of CSHCN is well documented in the literature.[6,10,13,17] The impact of having a child with special needs on the family is more pronounced in low-income families.[6,10,18] Although there was not an association between income and having a medical home in our study, it would be premature to conclude that level of income is not associated with access to a medical home in North Carolina. Income status was categorized into less than 200% FPG and greater than or equal to 200% FPG. The resulting smaller sample sizes did not permit analysis of multiple categories of income status in the logistic regression model. In fact, CSHCN from households with incomes less than 100% FPG had lower odds (unadjusted) of access to a medical home compared with those from households with incomes less than 400% FPG in bivariate analysis (data are not presented, but are available from the authors).

Table 4.
Adjusted Odds Ratios of Socio-Demographic Factors with Medical Homes in a Logistic Regression Model[*,†]

Characteristic (referent group)	Adjusted odds ratio (95% C.I.)	Standard error	P value
Race (All other races and multiracial)			
Non-Hispanic white	1.7 (1.1,2.7)	0.39	0.02
Adequacy of insurance (Not adequate)			
Adequate	1.5 (0.99,2.2)	0.29	0.06
Functional status (Some/severe limitation)			
No limitation	1.6 (1.1,2.3)	0.32	0.03

[*] Adjusted for other two variables in the model

[†] Population-level estimates

Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics, State and Local Area Integrated Telephone Survey, National Survey of Children with Special Health Care Needs, 2001.

Although the results for North Carolina are better than for the nation as a whole (40%),[10] more than half of CSHCN do not receive effective care coordination in North Carolina.

The American Academy of Pediatrics recognizes the importance of care coordination in the care of CSHCN and provides recommendations for care coordination for this population.[19] Policy development and program planning for CSHCN should emphasize improving care coordination for CSHCN in North Carolina. Family-centered care is another feature of access to services where North Carolina's performance should be improved. Similar to observations at the national level,[2,10] we found disparities associated with race/ethnicity and functional status of CSHCN in the receipt of family-centered care. It is possible that cultural or language differences accounted for the differences in family-centered care among racial/ethnic groups. The caregivers of CSHCN with functional status limitations report greater problems with referral to specialists. One could speculate that the referral needs of CSHCN with severe functional status limitations are much higher and likely result in problems in obtaining referrals to specialists. The association of functional status with referral problems and family-centered care needs further exploration.

It is important to note that there are differences in the association of socio-demographic factors and the five components of a medical home. For example, mother's education is an important factor in access to a source of care and not important for the other components of a medical home. Individual components of the medical home should be examined separately. The relationship between socio-demographic factors and having a medical home must be understood in order to monitor and evaluate their implementation.

Limitations

Although the National Survey of CSHCN was designed to make it possible to conduct state-level analyses, in-depth analysis could not be performed because the sample size for North Carolina was small. For this reason, specific categories among the socio-demographic factors could not be examined. Another important limitation involves the measure of having a medical home in this study. The National Survey contains information that can be used to measure the medical home concept. However, it does not fully operationalize all of its characteristics. If a different set of items were used to measure having a medical home, the results may be different. Hence, the results of this study can be compared only with other studies that use the same items to measure the medical home concept. This point is important when comparing studies across the United States and studies across different points in time. The lower response rate for the survey could have resulted in non-response bias. Since this study is exploratory in nature, multiple comparisons were made without correction, among socio-demographic factors and the components of the medical home. This could have resulted in a Type I error and in spurious associations. Hence, the associations between socio-demographic factors and the components of the medical home warrant further evaluation. Finally, because of the cross-sectional nature of this study, a causal relationship between the socio-demographic factors and the presence of medical home cannot be established.

Conclusions

Our study provides comprehensive information about the characteristics of CSHCN in North Carolina and the experience of these children and their families with a medical home. This information will be useful for North Carolina Title V needs assessment reports to the MCHB. Children with special healthcare needs belonging to specific minority groups and CSHCN whose conditions cause some or severe limitation of their activities were identified as at-risk for problems accessing a medical home. Disparities in access to a medical home should be considered in setting goals and in planning programs for CSHCN using the medical home model. The data in this study can be used to compare the health access situation for CSHCN in North Carolina with other states and to evaluate state performance in the future.

Each component of the medical home model must continue to be investigated. Since the lack of effective care coordination is the most common problem identified by families of CSHCN in North Carolina, strategies to improve performance in this area should be pursued. While efforts are made to provide certain components of a medical home, such as a usual source of care, there is a need to work toward increasing the effectiveness of care coordination and family-centered care to achieve the *Healthy People 2010* objective of providing a medical home to all CSHCN in North Carolina. **NCMedJ**

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ARTICLE

Implantable Left Ventricular Assist Devices:

New Hope for Patients with End-Stage Heart Failure

Carmelo A. Milano, MD, Andrew J. Lodge, MD, Laura J. Blue, RN, Peter K. Smith, MD, G. Michael Felker, MD, Adrian F. Hernandez, MD, Paul B. Rosenberg, MD, and Joseph G. Rogers, MD

Abstract

Introduction: *Recently, the Food and Drug Administration approved implantable left ventricular assist devices (LVAD) as destination therapy (DT) for end-stage heart failure patients who are ineligible for cardiac transplantation.*

Objective and Study Design: *This is a case series that describes the early results with DT LVAD at Duke University Medical Center (DUMC). An additional objective is to provide general information to a broad group of caregivers on this LVAD therapy, which is a new and developing treatment option.*

Data Source/Collection Methods: *Pretreatment clinical condition and outcomes data were collected retrospectively on this cohort of patients through chart review. Outcomes in our patients are compared to data from prior studies and established databases.*

Principal Findings: *Since approval of this therapy two years ago, 18 patients have been treated with implantable LVAD as DT at DUMC. The primary reason for ineligibility for transplant was advanced age (median age was 66). Nearly all of the patients (89%) were confined to the hospital requiring continuous inotropic infusions or temporary mechanical support (e.g., intra-aortic balloon pump) prior to LVAD. The 30-day survival following LVAD implantation was 94.5%; one-year survival was 60%. Eighty-nine percent of patients were successfully discharged to independent living. Operative mortality is similar to that of other cardiac surgery procedures performed on patients with advanced heart failure, while duration of intensive care stay and hospitalization remain considerably longer.*

Principal Limitations: *The principal limitation of this review is the absence of a control group of patients with end-stage heart failure who received conventional therapies. For this reason, the DT LVAD outcomes are compared to prior studies and database results.*

Conclusion: *Implantable LVAD therapy provides new hope for end-stage heart failure patients who do not qualify for cardiac transplantation.*

Introduction

Heart failure (HF) remains a major public health problem in developed nations. It is estimated that five million individuals in the United States suffer from HF with over 550,000 new cases diagnosed annually.[1] Roughly 100,000 patients have end-stage HF, which is characterized by the presence of symptoms at rest, refractory to standard oral medical therapies.[2] Treatment options for these patients remain limited and include inotropic infusions and cardiac transplantation.[2] Treatment with inotropes is associated with transient improvement in symptoms, but reduced survival. In a study of patients with end-stage HF treated with continuous outpatient inotropic infusions (COSI trial), one-year survival was only 6%.[3] Heart transplant represents an effective treatment, but only about 2,000 transplants are performed annually in this country; this number does not appear to be increasing despite efforts to use marginal donor organs. Thus, while heart transplant provides tremendous rewards for a select group, it remains epidemiologically insignificant.

Given the limited options for these end-stage patients, mechanical pumps have been in development for more than three decades to replace the function of the failing heart. The total artificial heart has been the most publicized mechanical option. Unfortunately, the total artificial heart (TAH), which requires removal of the native organ and provides replacement

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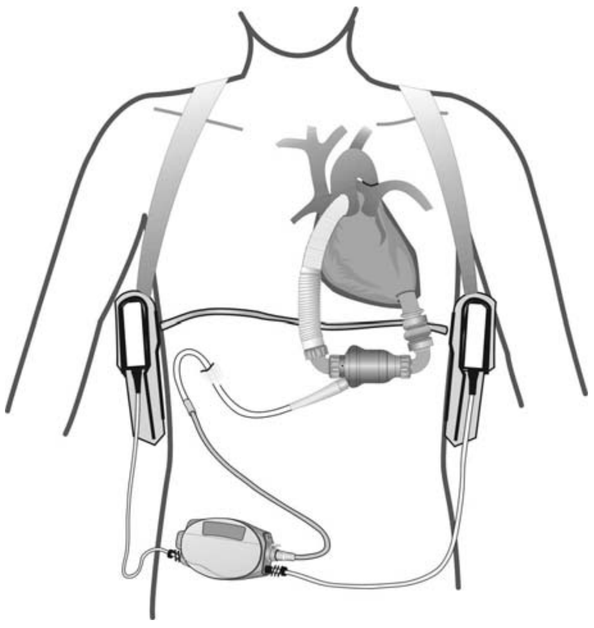
of both the right and left heart, has achieved limited application. Approximately 200 patients have been supported in investigational studies with these devices. There are two currently utilized TAH products: the CardioWest™ device has been Food and Drug Administration (FDA)-approved as a bridge to support patients who have deterioration of native heart function and are awaiting heart transplantation. Patients with this device are tethered to a large external driver that operates the pump, making discharge from the hospital difficult. The other TAH is the AbioCor® device (ABIOMED, Inc.), which recently failed to achieve FDA panel approval.[4] Major limitations for these products have consisted of thromboembolic complication and infection.

A more positive experience has occurred with implantable LVADs. Relative to the TAH, these devices attach more simply to the native heart; the left ventricular apex is cannulated for drainage of blood to the pump, and blood is pumped into an outflow graft, attached to the ascending aorta (see Figure 1). Development and testing of implantable LVADs has been ongoing for several decades. More than 10,000 patients have been supported with LVAD devices predominately as a bridge to transplantation. Extensive experience with patients who have been bridged to transplant suggested that these devices can restore normal hemodynamics even in the setting of biventricular failure. Home discharge and even return to employment has been possible for patients with implantable LVADs.[5] This positive experience led to the Randomized Evaluation of Mechanical Assistance for the Treatment of Congestive Heart Failure (REMATCH) trial in which end-stage HF patients who were not candidates for transplantation were randomized to optimal medical management versus implantable LVAD.[6] The Heartmate® I device (Thoratec, Inc.) was utilized exclusively in this trial. Patient's treated with LVADs experienced significant improvement in one- and two-year survival as well as improved quality of life relative to optimal medical management.[6] This trial led to FDA approval of the Heartmate® I as a destination therapy for patients with end-stage HF who fail to meet criteria for transplantation. Destination therapy refers to utilization of these devices as primary and final therapy rather than as a bridge therapy to support patients until transplantation is possible. Subsequently, the Centers for Medicare and Medicaid Services (CMS) have approved designated destination therapy (DT) LVAD centers. Duke University Medical Center has been designated as a CMS-approved DT LVAD center. In this paper we review, our early experience with implantable LVAD as primary treatment for end-stage HF.

Figure 1.
Implantable Ventricular Assist Devices



The Heartmate® II LVAD system is shown. The pump drains from the left ventricle via an apical cannula. Blood is pumped into the ascending aorta via an outflow graft. The Heartmate® II provides an axial flow with an Archimedes screw design. It is valveless and currently being tested as a DT LVAD.

Methods

From July 2003 to July 2005, 32 patients were referred for evaluation for DT LVAD at Duke University Medical Center (DUMC). Fourteen patients were excluded from treatment due to a variety of factors: (1) heart failure was not sufficiently advanced, (2) patient refused LVAD treatment, or (3) patient had inadequate financial resources. From this larger group, a subset of 18 consecutive patients underwent DT LVAD treatment at DUMC. The institutional review board of the Duke University Medical Center approved prospective collection of patient data and outcomes. Outcomes are reported as either early post-operative events occurring within the first 30 days of the LVAD implantation surgery, or late events occurring more than 30 days from the time of implant. Outcomes are reported as means for normally distributed events and medians for skewed distributions; range and standard deviations are provided where appropriate.

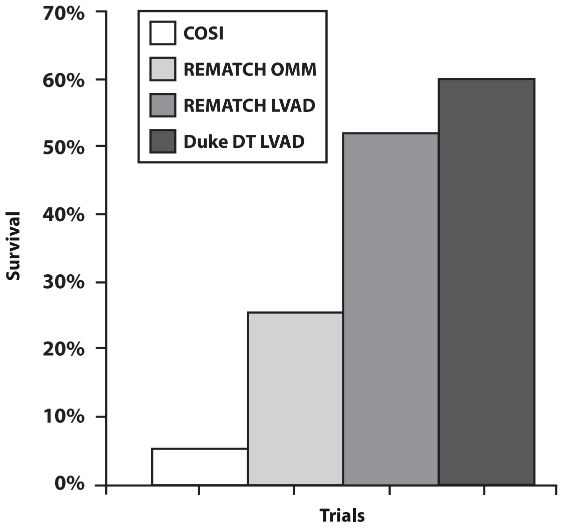
All patients were felt to be poor candidates for cardiac transplantation and did not meet traditional transplant criteria at the time of LVAD implant. Patients were ineligible for transplant due to: advanced age (n = 6), obesity (n = 5), renal insufficiency (n = 2), compliance issues (n = 2), malignancy (n = 2), and pulmonary insufficiency (n = 1). The most common reasons that patients were turned down for transplant were advanced age and obesity.

Results from the Duke DT LVAD cohort are compared to results from established cardiac surgery procedures performed on heart failure patients. Society of Thoracic Surgery data are shown for cardiac transplantation (n = 1,683 cases) and LV aneurysm resection (n = 277 cases) from 2000-2004.[13] In addition, results are compared to published data from the REMATCH and COSI trials (see Figure 2).

Results

Median age for the Duke DT LVAD group was 66 and ranged between 39 and 75; a disproportionate number were

Figure 2.
One-Year Survival for Patients with End-Stage Heart Failure



One year survival is shown for four groups of patients who had end-stage HF. The results of the REMATCH trial are shown for both the optimal medical management (OMM) group as well as the LVAD group. There was significant survival benefit to LVAD treatment compared with OMM in REMATCH. Relative to these results, the survival for 36 end stage HF patients treated by continuous outpatient support with inotropes (COSI trial) is also shown. Finally, the Duke DT LVAD (N = 18 patients) survival is shown.

older than age 65 because this is a common age cut-off for transplant surgery. One third (33%) were females. Fifty percent suffered from non-ischemic cardiomyopathy. All patients had end-stage heart failure with symptoms at rest despite standard medical treatments. Sixty-one percent of the patients were maintained on inotropic infusions preoperatively for clinical and/or hemodynamic evidence of cardiogenic shock. Preoperative mechanical support with intra-aortic balloon pump or temporary LVAD, in addition to inotropic infusions, was present in 28% of the patients (see Table 1). The HeartMate® I pulsatile LVAD was used in 16 of the 18 patients, while two smaller patients received the Heartmate® II axial flow device as part of a prospective FDA-sponsored trial (see Figure 1).

Table 1.
Preoperative Destination LVAD Patient Characteristics (N = 18)

Mean age	66
Sex (% male)	67%
Non-ischemic cardiomyopathy	50%
Mean LV ejection fraction	15% ± 5%
Inotropes	61%
Mechanical support	28%
Mean creatinine	1.5 ± 0.6

Thirty-Day Post-Operative Outcomes (see Table 2). Early death occurred in one of 18 patients (5.5%), which compares favorably to 30-day mortality in the Society of Thoracic Surgeons (STS) national cardiac surgery database of 3% for heart transplant and 7% for left ventricular aneurysm repair.[13] This patient expired due to pulmonary embolism. Most patients had an elevated preoperative creatinine, and many patients experienced elevation in post-operative serum creatinine, but none of the patients progressed to require dialysis during the post-operative period (see Tables 1, 2). There was one peri-operative stroke, which resulted in only a mild motor deficit. The incidence of serious post-operative bleeding that required patients to return to the operating room was 11%. There were no serious mediastinal or pump pocket infections during the early post-operative period. Median duration of hospitalization was 21 days, and median duration of initial intensive care unit (ICU) stay was six days (see Table 2). Discharge to independent living was achieved in 16/18 patients.

Table 2.
Post-Operative (30-day) Outcomes (N = 18)

30-day mortality	5.5%
Median ICU stay	6 days (range 1-76 days)
Median hospital stay	21 days (range 14-111 days)
Major infection	0%
Need for dialysis	0%
Take back for bleeding	11%
Embolic stroke	5.5%

Late Outcomes (see Table 3). The vast majority of patients were discharged to independent living (89%); all of these patients were ambulatory without significant neurological deficits or mental status impairment. None of the patients required permanent placement in a nursing home or chronic care facility. Overall, one-year survival was 60%, which compares favorably to survival rates (52%) for patients receiving an LVAD in the REMATCH trial. In addition to the one post-operative death, there have been a total of five additional deaths in this group. The causes of these late deaths were progression of malignancy (1), intracranial hemorrhage (2), sudden device failure (1), and overwhelming LVAD infection (1). One of the two intracranial hemorrhage deaths occurred in a patient with severe hypertension and was not thought to be attributable to LVAD therapy. Both episodes of intracranial hemorrhage occurred in patients anticoagulated with Coumadin® (one for atrial fibrillation and the other for deep venous thrombosis). Notably, the post-operative protocol for the HeartMate® I device, which was utilized in the majority of these cases, is for aspirin alone. Readmission during the first year after device implantation was 50%. Late embolic stroke occurred in two patients and neither experienced a persistent or disabling deficit. One of these embolic strokes occurred in the setting of LVAD endocarditis; this patient represented the only major LVAD infection in our cohort. A need for device replacement

Table 3.
Late Outcomes (N = 18)

Discharged to independent living	89%
Readmission	50%
Overall embolic stroke	16.5%
Major device infection	5.5%
Device replacement	16.5%
One-year survival	60%

occurred in three late survivors; two of the three replacement procedures were accomplished successfully. Reevaluation for transplantation occurred in four patients with two of these being accepted for transplant listing and ultimately receiving transplants. One patient achieved significant weight loss during LVAD support, enabling transplantation; the other patient maintained smoking cessation, allowing for transplantation.

Discussion

The preoperative status of this DT LVAD group reflects end-stage heart failure with the majority of patients requiring inotropic support or even some form of mechanical support. Most commonly pre-LVAD mechanical support consisted of intra-aortic balloon pump in patients with ischemic cardiomyopathy. Some degree of end-organ compromise existed in this group manifested by elevated serum creatinine. Despite the compromised preoperative status, post-operative survival (30-day) compares favorably to that of more conventional cardiac surgery, which is performed in HF patients. The 30-day Duke DT LVAD survival was slightly better than that reported for LV aneurysm repair, a commonly performed procedure in HF patients. The Duke DT LVAD 30-day survival is slightly less than cardiac transplant survival.

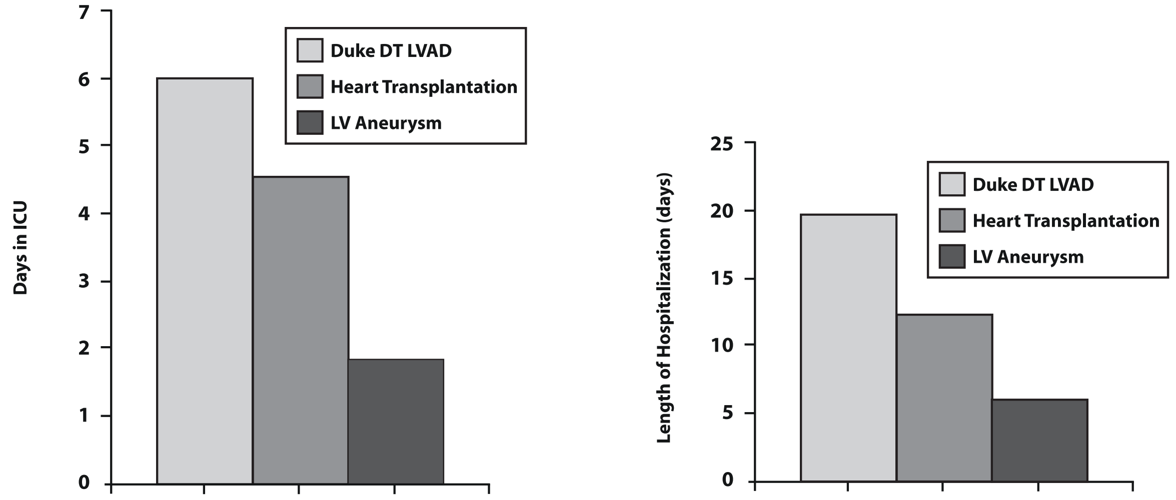
The encouraging 30-day survival rate in this population reflects increased experience with LVAD patients and perhaps improved perioperative strategies to control bleeding and right heart dysfunction.[5] Only 11% of patients returned to the operating room for bleeding, and none of the patients required mechanical support for right heart failure. All 18 patients were supported with inhaled nitric oxide and milrinone during the immediate post-operative period to prevent significant right ventricle dysfunction.

Post-operative length of hospital stay (21 days) and ICU stay (six days) for the Duke DT LVAD cohort remain high and represent an important area for future improvement. Relative to other cardiac procedures performed on HF patients, length of ICU stay and total hospitalization are markedly increased for DT LVAD (see Figure 3). These prolonged stays are important relative to patient quality of life and the economic feasibility of this therapy. The longer stays, in part, reflect the newer technology of LVADs. Furthermore, recovery of nutritional status, restoration of skeletal muscle function, and management of depression and psychological issues are additional factors inherent to this very sick cohort of patients, which prolong the post-operative hospital stay. Anticipation of these problems and a systematic treatment strategy may yield improved results.

Length of ICU stay and duration of hospitalization for surgical procedures on advanced HF patients.

The majority of patients in this series have now survived beyond the first year. Comparison of the Duke DT LVAD group to the REMATCH LVAD group suggests a trend toward improved outcomes at one year.[6] Indeed, the post-approval DT

Figure 3.
Length of ICU Stay/Hospitalization for Surgical Procedures on Advanced HF Patients



The ICU length of stay (in days) during post-operative recovery is shown for the Duke DT LVAD group (N = 18) relative to ICU length of stay for cardiac transplant and left ventricular aneurysm repair (STS national cardiac surgery database 2001-2004). Median values are shown. The total length of post-operative stay (in days) is shown for the Duke DT LVAD group (N = 18) relative to that for cardiac transplantation and left ventricular aneurysm repair (STS national cardiac surgery database 2001-2004). Median values are shown.

LVAD practice at large volume centers has shown trends toward improved one-year survival relative to REMATCH LVAD.[7,9] Relative to groups of patients with end-stage HF, who have been managed solely with infusions of inotropes, survival at one year is markedly improved with DT LVAD treatment. In fact, relative to the COSI trial, the one-year survival for the Duke DT LVAD group is an order of magnitude better (6% versus 60%) (see Figure 2). These results argue strongly that inotrope-dependent HF patients who are not eligible for transplant should be offered the option of DT LVAD.

Embolic stroke historically has represented an important limitation to mechanical heart support, but in this small series of patients, only three patients suffered documented embolic stroke. None of these events led to significant permanent deficits. These three patients remained ambulatory, did not require nursing home placement, and maintained an independent life style. One of these events occurred in a patient who also suffered LVAD endocarditis and, ultimately, died from sepsis. This favorable rate of embolic stroke is probably device-specific and reflects the low thromboembolic risk for the HeartMate® I device, which was used in the majority of cases. The HeartMate® I features a textured blood contacting surface, which allows for "neointimal deposition" and low thromboembolic rates. Most patients were maintained on aspirin as the only form of anticoagulation.

Three out of the 16 patients treated with the HeartMate® I device experienced major device wear with one patient experiencing rapid hemodynamic deterioration and death. Fortunately, device replacement has been successful at our center. Multiple modifications have been made to the HeartMate® I design to reduce valve and bearing wear and improve durability.[8] Furthermore, current destination LVAD trials including the RELIANT (Randomized Evaluation of Novacor LVAS In A Non-Transplant population) trial and the HeartMate® II trial hope to document greater durability with newer pump designs (see Figure 1).

This small series also illustrates how DT LVAD treatment may, in certain patients, enable reconsideration for transplantation. Of the 18 patients implanted, four were re-evaluated for transplant. Two patients were deemed suitable for transplant listing: one experienced substantial weight loss and achieved a specified weight goal, while the other patient achieved sustained abstinence from smoking. Many of the criteria for transplant listing represent variables that may change over time. Therefore, it is expected that some DT LVAD patients may become eligible for transplant listing after a period of extended support. Another example of this scenario is the group of patients who may have severely elevated pulmonary vascular resistance associated with advanced heart failure. Traditionally, these patients are ineligible for transplant because of the risks of right heart failure post-transplantation. Management of these patients with chronic LVAD support may restore more normal pulmonary vascular resistance enabling re-consideration for transplant.

An important limitation to this report is that it is a case series without a formal control group. Furthermore, while a variety of outcomes are reported, quantitative measures of quality of life were not performed for the Duke DT LVAD cohort. Lastly, the current cost of an implantable LVAD is approximately $70,000. Therefore, cost is a limiting factor. This increased cost may be reduced as additional types of LVADs achieve FDA approval.

In summary, implantable LVAD treatment is now a viable option for patients with end-stage HF, who do not qualify for cardiac transplantation. The appropriate population for LVAD therapy includes patients with recurrent decompensation despite optimal medical therapy. Patients who require continuous infusion of inotropic agents have very limited survival and should be offered DT LVAD. The REMATCH trial demonstrated that implantable LVAD treatment offers both a survival and a quality of life advantage for these end-stage HF patients.[6] Operative mortality for the Duke DT LVAD cohort compares favorably to that of other surgical procedures performed for advanced HF. Furthermore, trends are toward improved long-term outcomes, and newer LVAD devices, which offer greater durability (see Figure 1), are now being tested. **NCMedJ**

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EDITORIAL

The Price of Progress:

Destination Left Ventricular Assist Device Therapy for Terminal Heart Failure

Craig H. Selzman, MD, and Jonathan Oberlander, PhD

Heart failure (HF) is a growing epidemic in the United States. Nearly five million patients suffer from this disease, with 400,000-600,000 new cases identified each year. Within this population exists a subset of individuals, estimated between 50,000-150,000, who has a severe form of HF. These patients in New York Heart Association III/IV or class D[a] heart failure are symptomatic despite excellent medical therapy, require frequent hospitalizations, and carry a mortality rate that rivals metastatic malignancies.[1] Although heart transplant remains a viable option for these desperately ill patients, the availability of donor organs limits our use of this therapy to roughly 2,000 each year. Mechanical circulatory devices—ranging from intra-aortic balloon pumps to the total artificial heart—have been utilized to help many of these patients. Over the last decade, widespread use of left ventricular assist devices (LVAD) has significantly impacted the natural history of end-stage HF. Three conceptual paradigms exist for the use of LVADs: bridging a patient until heart function recovers, bridging until a suitable organ for transplantation is available, and implantation as end-of-life therapy in lieu of transplantation—often referred to as Destination Therapy (DT).

As observed in the seminal Randomized Evaluation of Mechanical Assistance for the Treatment of Congestive Heart Failure (REMATCH) trial, which randomized class IV HF patients who were ineligible for heart transplantation to best medical therapy versus LVAD implantation, this disease is aggressive.[2] Compared to optimal medical managements, patients receiving LVADs had an increased one-year (52% versus 26%) and two-year (28% versus 8%) survival rate, as well as an improved quality of life.[2] In late 2003, the Centers for Medicare and Medicaid Services designated more than 50 centers nationwide as implant DT centers. Importantly, for the readers of the *North Carolina Medical Journal*, only two centers in North Carolina, South Carolina, Georgia, southern Virginia, and eastern Tennessee have been given this designation: Duke University Medical Center and the University of North Carolina at Chapel Hill.

In this issue of the *North Carolina Medical Journal*, the HF surgeons and cardiologists from Duke University Medical Center present their early series of patients over the last two years who have received LVADs for destination therapy.[3] Dr. Milano and his team should be commended for their impressive results in this challenging and severely ill group of patients. Eighteen patients deemed ineligible for heart transplant (secondary to age, obesity, renal failure, malignancy, compliance issues, or respiratory insufficiency) with end-stage HF (61% on intravenous inotropes and 28% with intraaortic balloon pumps) received the Heartmate® LVAD. Compared to the REMATCH cohort, the Duke investigators had lower operative mortality, lower stroke rate (well below the nearly 40% neurologic event rate noted in REMATCH), less perioperative bleeding, and preserved right ventricular function. Their infection rate was also markedly lower than the REMATCH group. These technical proficiencies translated to relatively low intensive care unit and hospital length of stays. At one year, 60% patients were alive with the majority living independently; again, better than the REMATCH group.

Others have reported post-REMATCH improved outcomes with DT.[4] Although the reported results are indeed admirable, the technology with pump refinement as well as new, innovative, and smaller axial flow pumps will likely make short- and long-term results for LVAD even better. Unfortunately, these therapies come with great cost. The authors spend little time discussing the economic and health policy issues intrinsic to such expensive device therapy. Although they mention the current cost of the

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[a] Heart failure is frequently classified by the severity of symptoms. The New York Heart Association (NYHA) classified heart failure into Class I, II, III or IV. Classes III and IV are moderate and severe, respectively. The ACC/AHA have created guidelines that complement the NYHA classification.

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LVAD at $70,000, that only buys the actual device at the time of surgery. For this particular device, nearly $35,000 is needed to purchase components to allow their discharge from the hospital. In addition, hospital and intensive care stays are typically quite high for these patients, such that total implant costs are typically more than $200,000.

Consequently, all hospitals offering LVAD therapy as destination therapy, including Duke and UNC, as well as public and private insurers, must confront a host of ethical and economic dilemmas as use of such devices becomes more widespread. Is this a just and efficient use of medical care resources? Who should have priority to receive such treatments? Do the benefits of LVADs as DT justify their high costs at a time when healthcare inflation is pricing millions of Americans out of the health insurance market? How much money should cash-strapped state Medicaid programs spend on this technology given other competing demands? And what are the implications for a Medicare program, which already faces substantial fiscal pressures in coming years as the baby boomers retire?

These questions will not be easily resolved. Preliminary assessments of LVAD's cost effectiveness have not been favorable.[5] Clear assessment of cost-effectiveness ratios are difficult to calculate, ranging from $37,000 per quality-adjusted life year (QALY)[6] to $802,700/QALY.[7] These costs must be weighed in the context of other valuable therapies, including cholesterol testing ($330/QALY) and home hemodialysis ($25,000/QALY). Yet, given the scarcity of available transplants, the life-saving difference they make for some HF patients, and the prior contribution of medical technologies to improving cardiovascular health outcomes,[8] LVAD's promise cannot be easily dismissed. This is a rapidly changing area of medicine, and as pump technology evolves, so too will calculations of costs and benefits. That is, the cost effectiveness of LVADs is likely to improve with further technological developments and clinical experience. Conversely, even if LVAD costs decline, total spending on this technology will rise considerably if it is utilized more widely and indications broaden. Studies such as those reported in this issue of the *North Carolina Medical Journal* indeed show both the feasibility and utility of LVAD therapy as end-of-life therapy for HF patients. As LVAD therapy continues to evolve, attention to clinical effectiveness should also be accompanied by awareness of the compelling ethical and economic implications raised by widespread implementation of this innovative therapy. **NCMedJ**

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POLICY FORUM

Prostate Cancer: Screening, Diagnosis, Treatment, and Follow-Up Care

Introduction
Gordon H. DeFriese, PhD

Issue Brief:
Carcinoma of the Prostate: Overview of the Most Common Malignancy in Men
Culley C. Carson III, MD

> *"...some North Carolina counties have the highest incidence of and death from prostate cancer in the world, irrespective of race."*

COMMENTARIES

Confronting Prostate Cancer: A Personal Reflection
Senator David W. Hoyle

Racial Differences in Prostate Cancer
Kris E. Gaston, MD, and Raj S. Pruthi, MD

Screening for Prostate Cancer in 2006: PSA in the 21st Century
Paul D. Maroni, MD, and E. David Crawford, MD

The Role of the Pathologist in Diagnosing Prostate Cancer and Guiding Therapy
Michael H. Weinstein, MD, PhD

Treatment for Localized Prostate Cancer: Surgical Approaches
Eric M. Wallen, MD

Radiation Therapy for Prostate Cancer: External Beam, Brachytherapy, and Salvage
Scott L. Sailer, MD

Systemic Therapy for Prostate Cancer
William R. Berry, MD

The Economic Impact of Prostate Cancer Screening and Treatment
Rachael L. DiSantostefano, PhD, and John P. Lavelle, MB, BCh, FRCSI

INTRODUCTION

Policy Forum:
Prostate Cancer: Screening, Diagnosis, Treatment, and Follow-Up Care

In this issue of the *North Carolina Medical Journal*, we focus on one of the most common cancers among men in our nation—a cancer for which there are excellent technologies for early detection and definitive diagnosis, as well as several options for treatment. It is a disease where North Carolina's adult male population seems to exhibit an incidence greater than for the nation as a whole, with African American men being diagnosed with the disease more frequently than whites. Similar findings have been observed with regard to mortality from prostate cancer as well, with dramatic disparities between United States men and North Carolina men, as well as between African American and white men. Such data raise questions about disparities in access to (or participation in) proper screening for the disease, and also about the accessibility of treatment options and possible biological differences among racial groups in susceptibility to the disease itself.

Prostate cancer is a condition for which there should be fairly low mortality if screening and definitive diagnosis occur early, when the disease is localized to the prostate. Yet, it remains the second leading cancer-related cause of death among men in this country. Educational campaigns about this disease, the availability of both screening and treatment facilities, and efforts to dispel the widespread fear of the consequences of treatment (such as incontinence and/or sexual dysfunction) have not had the desired effect.

In this issue of the Journal, Dr. Culley Carson, Chief of the Division of Urology at the University of North Carolina (UNC) School of Medicine, has written an Issue Brief summarizing the overall situation with regard to the screening for and detection, diagnosis, and treatment of prostate cancer. Dr. Carson's overview is followed by North Carolina Senator David Hoyle's personal reflections on being diagnosed and treated for prostate cancer. Those who have gone through the various steps toward surgery will find familiarity in his commentary. These two papers provide both a contemporary overview of the medical science and available treatments for this condition, as well as an appreciation for how the disease can affect an individual faced with this diagnosis.

We have included commentaries by a number of experts from North Carolina and elsewhere dealing with the diagnosis and treatment, as well as the epidemiology, of this disease. Drs. Gaston and Pruthi of UNC offer a detailed discussion of the disparities among white and African American men in the experience of prostate cancer, its natural progression, and response to treatment. Similar data are reported in a succinct way by Dr. Deborah Porterfield of the North Carolina Division of Public Health in our regular "Running the Numbers" section.

Drs. Paul Maroni and David Crawford of the University of Colorado provide a detailed discussion of contemporary methods and programs for screening adult men for this disease. We invited Dr. Michael Weinstein of Director of WakeMed's Department of Clinical

Laboratories to discuss how the clinical pathologist deals with the diagnosis of prostate cancer, as well as new technologies for the assessment of laboratory specimens in reaching a definitive clinical diagnosis. Dr. Eric Wallen from the UNC Department of Surgery describes contemporary surgical approaches to the treatment of prostate cancer. Dr. Scott Sailer from Wake Radiology Associates describes current approaches from the perspective of radiation oncology. Dr. William Berry from the Cancer Centers of North Carolina provides a detailed description of endocrine and chemotherapeutic interventional options and their appropriateness for the treatment of this disease.

Following this rather comprehensive array of clinical commentaries, we are fortunate that Drs. Rachael DiSantostefano and John Lavelle of UNC-Chapel Hill have been willing to discuss the economic aspects of prostate cancer, including the implications of policies related to screening, diagnosis, and treatment.

We are grateful to our colleagues for summarizing the latest in available technologies for screening, diagnosis, treatment, and after-care and for making this information available to our extensive readership. We know there are controversial aspects to some prostate cancer approaches and unknown implications of some recently developed therapies, but this is one area of contemporary medical science and practice where considerable progress has been made. It is our view that understanding this forward movement cannot take place without an appreciation of the many clinical disciplines involved in both the diagnosis and the treatment of this disease.

As always, we welcome the comments and observations of our readers on these and other contributions to the Journal.

Gordon H. DeFriese, PhD
Editor-in-Chief

Carcinoma of the Prostate:
Overview of the Most Common Malignancy in Men

Culley C. Carson III, MD

In the United States and North Carolina carcinoma of the prostate is the most common non-cutaneous malignant process and second most common cause of cancer death among United States men. Since carcinoma of the prostate strikes middle-aged and elderly men and usually has a prolonged progression, the controversy regarding the health effects, treatment, survival, and, most importantly, screening continues throughout the medical literature. Because of this prolonged course and the difficulty with identifying the most indolent tumors, it has been widely suggested that prostate cancer is over diagnosed, as many men may live with prostate cancer with no effect on either their quality of life or ultimate longevity.

More than 230,000 men are diagnosed with prostate cancer in the United States annually. Of these, more than 30,000 die of their disease. Mortality from prostate cancer is, therefore, second only to lung cancer for men in the United States.[1] The possibility of an American man acquiring prostate cancer during his lifetime is approximately 15%. Of great importance, however, is the fall in prostate cancer mortality witnessed since 1994. Similarly, the incidence of prostate cancer in all populations has begun to decline, with the initial decline beginning in 1993. This decline is observed in both white and black patients.[1] While the etiology of carcinoma of the prostate remains elusive, some associated risk factors have been identified.

> *"...it has been suggested that the PSA threshold for biopsy of 4.0 ng/ml should be lowered. Such lowering, however, will increase the number of biopsies performed..."*

Risk Factors

Genetic influences may determine the risk of carcinoma of the prostate in some men. Indeed men with first-degree male relatives with prostate cancer have more than a two-fold increase in their incidence of prostate cancer, and men with two or three first-degree relatives with carcinoma of the prostate may have as high as a five-to-ten fold increased risk. Approximately 10-12% of prostate cancer cases are genetically influenced, and these most often manifest as prostate cancer in patients under age 60. This genetic increase is most marked in African American men. The highest risk for prostate cancer for African American men is seen in eastern North Carolina.[2] The reason for the high prevalence of prostate cancer remains controversial. Men living in Africa have one of the lowest prevalences of prostate cancer in the world. Diet may have an influence, as diets high in saturated fat have been associated with increased risk for prostate cancer, while antioxidants, such as selenium, lycopenes, and vitamin E, have been reported to decrease risk.

Indeed, the lifestyle trait in United States men that is most highly associated with both the incidence and mortality of prostate cancer is diet. Diets high in meat with high animal fat and low levels of fruits and vegetables appear to be associated with higher risks and mortality from prostate cancer.[3] A prospective study of more than 50,000 men reporting diet and associated risk of prostate cancer demonstrated that red meat consumption was highly associated with carcinoma of the prostate.[3,4] Studies have also demonstrated decreased prostate cancer among men consuming the antioxidant, selenium, and vitamin E.[4] A current, ongoing study (SELECT) further elucidates this association.[5] Because of the many basic science and epidemiologic studies that suggest there is decreased prostate cancer prevalence with the intake of antioxidants, it appears that oxidative stresses may contribute to the genesis of prostate

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cancer. These oxidants, in addition to diet, may be produced by environmental exposures and inflammation. Indeed androgens (steroid hormones, such as testosterone) associated with prostate cancer may increase oxidant effects in prostate cancer cells.[6]

Increasing evidence suggests that chronic inflammatory processes may have an etiologic role in human cancers, including prostate cancer.[7] While the symptoms of inflammation or infection in the prostate are uncommon preceding the diagnosis of prostate cancer, radical prostatectomy specimens often demonstrate evidence for chronic inflammatory conditions. Although the association of these prostatic conditions continues to strengthen, no specific etiology has been defined. Inhibition of GSTP1 gene expression, which encodes glutathione S-transferase capable of cell damage from oxidant stress, and is frequently found in prostate cancer cells. Lesions of proliferative, inflammatory atrophy with activated inflammatory and epithelial cells may be precursors to prostatic carcinoma.[7] Clinically, other non-specific inflammatory markers, such as C-reactive protein also have been associated with rising PSA levels and prostate cancer.[8]

Prostate Cancer Prevention

The fact that prostate cancer occurs in such high numbers of men and later in life in addition to evidence suggesting environmental influences in its etiology, chemoprevention has long been discussed and investigated. Prostate cancer prevention, if simple and well tolerated, would significantly limit the financial costs of screening and treatment, as well as, the psychological cost and morbidity and, ultimately, the mortality from prostate cancer of a large portion of the 30,000 or more men who die each year from this difficult disease. Because it is well known that males with low androgen levels have a decreased prevalence for prostate cancer (and eunuchs rarely are afflicted with prostate cancer), androgen manipulation is a natural target for prostate cancer prevention.

Certain Pharmaceuticals May Help Prevent Prostate Cancer

The Prostate Cancer Prevention Trial (PCPT) was the first large population-based trial to test chemoprevention in men with carcinoma of the prostate.[9] This study, begun in 1993, accrued more than 18,000 men over age 55 with normal digital rectal examination (DRE) and prostate-specific antigen (PSA) values of less than or equal to 3.0 ng/ml. Because men with congenital deficiency of Type II, 5 alpha reductase[a] do not suffer from either benign prostatic hyperplasia (BPH)—enlargement of the prostate or prostate cancer, Finasteride (a pharmacologic agent designed to block Type II, 5 alpha reductase) was used in this trial. Men were randomized into two groups: (1) a placebo group or (2) a treatment group that took 5 mg of Finasteride each day for seven years. Subject's in both groups received a biopsy during the study if any of the following three indications occurred: (1) PSA level exceeded 4.0 ng/ml, (2) digital rectal examination was abnormal, or (3) PSA values rose significantly with Finasteride. Subjects who completed the seven-year study without indication received an end-of-study biopsy. Because the National Institutes of Health (NIH) Data Safety and Monitoring Committee identified a substantial reduction in risk among subjects taking Finasteride, the study was concluded 15 months prior to its scheduled end date. Once analyzed, data from this study demonstrated a reduction in the prevalence of prostate cancer by 24.8% in patients randomized to Finasteride. However, a larger percentage of subjects treated with Finasteride (6.4%) were found to have more severe malignant tumors (Gleason scores[b] of 7-10) than subjects in the placebo group (5.1%). While sexual side effects were experienced by patients in the Finasteride arm, urinary symptoms (lower urinary tract symptoms) were more common in the placebo group. Although researchers found that a reduction in prostate cancer risk among patients treated with Finasteride was present in subjects who received biopsies due to the three indications and to those who completed the study without indication, there were equal numbers of deaths due to prostate cancer in each group. While this study continues to be controversial, and the increased incidence of higher-grade cancers in the Finasteride-treated men appears to be explained by changes in prostate size and tumor interpretation, the PCPT trial is the first convincing demonstration that prostate cancer can be prevented by a tolerable oral medication without significant adverse events.

Prostate Cancer Screening

Because prostate cancer rarely causes early symptoms, the diagnosis of prostate cancer is best performed by physical examination and laboratory testing. Digital rectal examination (DRE) has long been the cornerstone for the diagnosis of carcinoma of the prostate. Areas of palpable induration (hardness), firmness, and asymmetry of the prostate gland strongly suggest the presence of carcinoma. While BPH produces prostate enlargement, induration of the posterior prostatic lobe strongly suggests a diagnosis of prostate cancer. However, cancers found on DRE are more often of advanced pathologic stage; a diagnosis before nodules are formed improves prognosis.[10] DRE alone may miss as many as 45% of cancers subsequently identified by prostate biopsy following observation of rising PSA.[11] Abnormal DRE appears to

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[a] Type II, 5 alpha reductase is an enzyme responsible for regulating the conversion of testosterone to dihydrotestosterone (DHT) in the liver.

[b] The Gleason scoring system grades prostate cancer patterns from 1 (well differentiated malignancy) to 5 (poorly differentiated malignancy). The Gleason combined score or grade is then computed by adding the most abundant Gleason grade pattern to the second most abundant Gleason grade pattern to obtain a Gleason sum. This score from 2 to 10 has been demonstrated to be accurate in predicting patient outcomes. Gleason scores of 2 to 6 respond best to primary treatment with significantly lower recurrence rates than Gleason scores of 8 to 10. In a group of more than 8,000 men diagnosed between 1989 and 2001, men with low-risk histories rose from 29.8% to 45.3%.[27]

be dependent upon PSA level, patient race, and age. There is a higher predictive value for DRE in African American men, older men, and men with higher PSA levels.[12]

PSA testing has significantly changed the diagnosis of prostate cancer since its introduction in the early 1990s. PSA is an enzyme (human kallikrein serine protease) that is encoded by the genes of chromosome 19. PSA is produced predominantly by the columnar secretory cells of the prostate and is present in high levels in the ejaculate. PSA first becomes detectable in the serum during puberty when steroid hormone levels increase. As patients age, their PSAs continue to rise, and there is an age-associated PSA value. Similarly, PSA rises with prostate volume and can be used as a surrogate marker for prostate size. Baseline PSAs in patients without prostatic malignancies are higher in African American men than in white men.[13]

Produced by the prostate in both benign and malignant conditions, PSA is a more accurate *prostate marker* than a *prostate cancer marker*. Any condition that produces prostate inflammation or disrupts prostate tissue will produce an elevation in PSA. This includes benign conditions such as BPH, prostatitis, urinary retention, prostatic infarction, prostate biopsy, and vigorous prostatic massage. While these inflammatory and surgical conditions produce changes in PSA, studies of ejaculation prior to PSA determination have not demonstrated convincingly a change in PSA level.[14] The 5 alpha reductase inhibitors, such as Finasteride and Dutasteride, reduce PSA levels to approximately 50% of baseline by six to 12 months following treatment.[15] While the use of PSA screening in identifying prostate cancer continues to be controversial, there are many studies that have demonstrated the importance of PSA testing to diagnose prostate cancer. Because PSA is more sensitive and specific than DRE alone, the detection of prostate cancer with a combination of PSA and DRE has a significantly higher predictive value than either study alone. In fact, PSA values in screening populations have the highest predictive value.[11] Longitudinal follow-up population studies using banked serum samples have reported a five-year lead time of prostate cancer diagnosis from PSA levels with 4.0 ng/ml as initial cutoffs.[16] Because PSA can be elevated by benign conditions, and elevations in PSA trigger prostate biopsies, efforts have been made to improve the accuracy of PSA determinations. Newer tests, such as the free and total PSA ratio,[c] prostate specific membrane antigen (PSMA),[d] complexed PSA,[e] and others, are under investigation for improving PSA accuracy. Current practice, however, can employ *PSA density*, an adjustment in PSA level to account for prostate volume. Adjusting the PSA level for prostate volume permits increased accuracy. More commonly, however, *PSA velocity* is used. PSA velocity measures changes in serum PSA values over time.[17]

> *"Because a single PSA value may be less accurate, PSA velocity, rise in PSA over time, may be a better indicator for prostate biopsy."*

PSA Threshold for Prostate Biopsy

Controversy continues regarding the interpretation of PSA values and the threshold for which a biopsy is required. The ideal PSA value for differentiating prostate cancer from benign prostates remains elusive. The standard PSA value differentiating normal from abnormal prostates of 4.0 ng/ml was established in 1990.[18] Because many prostate cancers can be present and even significant at PSA levels below 4.0 ng/ml, investigation has focused on the percentage of cancers missed at levels below 4.0. In the PCPT trial, end-of-study biopsies were correlated to PSA levels. Of 2,950 men biopsied, 449 (15.2%) were found to have prostate cancer with PSA levels less than 4.0. Of those men with PSAs between 3.1 and 4.0, 26.9% had positive biopsies, of which 25% were high-grade malignancies. Even among patients with PSA levels less than 0.5 ng/ml, 6.6% had positive biopsies at end-of-study. These data strongly suggest that PSA is better when focused on *density* or, more conveniently, *velocity* to differentiate those patients at high risk for prostate cancer and positive biopsies.[19] Based on this study, it has been suggested that the PSA threshold for biopsy of 4.0 ng/ml should be lowered. Such lowering, however, will increase the number of biopsies performed. The controversy continues.

PSA velocity appears to be more helpful in a clinical setting. Outcome studies have demonstrated that PSA velocity of greater than 2.0 ng/ml per year is associated with significantly higher death rates from prostate cancer when compared with lower PSA velocities.[20,21] Thus, annual PSAs in patients at risk are important for the identification and treatment of carcinoma of the prostate. Because a single PSA value may be less accurate, PSA velocity, rise in PSA over time, may be a better indicator for prostate biopsy. In a prospective screening study, a velocity threshold of 0.75 ng/ml per year was used to differentiate patients. Using this threshold of velocity, 47% of men with velocities greater than 0.75 ng/dl were diagnosed with prostate cancer compared with only 11% of those with velocities less than 0.75 ng/ml.[22] In a European study where men were followed for four years, PSA velocity was 0.62 ng/dl per year for men with prostate cancer compared with

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[c] The free and total PSA ratios are used to measure the percentage of free PSA relative to the total amount of PSA in a patient's blood sample.

[d] Prostate specific membrane antigen is a PSA produced by the membrane of prostate cancer cells.

[e] Complexed PSA is a test that measures the level of PSA, which has been complexed or bound with a certain protein (alpha-1-antichymotrypsin) in a patient's blood sample.

0.46 ng/dl per year for those without cancer. PSA doubling time was 5.1 years with prostate cancer and 6.1 years with negative biopsies.[23] In men with low PSAs, however, PSA velocity appears to be less accurate in selecting men for prostate biopsy.[24] Thus, PSA change over time appears to be more valuable than static values in selecting which men will require prostate biopsy.

Biopsy

Once a suspicious PSA has been identified by value, density, or velocity, a transrectal, ultrasound-guided prostate biopsy is the most accurate technique for identifying prostate cancer. This outpatient procedure is usually performed using local anesthetic injection of the periprostatic nerves and can be done in an office setting. Although transrectal ultrasound typically does not demonstrate specific areas of suspicion, the procedure permits prostate targeting, which allows accurate sampling of all portions of the prostate. For repeat biopsies where initial malignancy is not identified and PSA continues to rise, careful sampling of the transition zone is important to eliminate less common foci of prostate malignancy.

Biopsies of the prostate are safe and have a low incidence of morbidity. In a series of more than 5,800 prostate biopsies, fewer than 0.5% of men required hospitalization; however, only 2.6% of men reported self-limiting hematuria (blood in urine) and occasional 50.4% hematospermia (blood in semen) early following biopsy.[25]

The diagnosis of prostate cancer, once made through transrectal needle biopsy of the prostate, is graded by histopathology using the previously mentioned Gleason grading system.[26] Staging of prostate cancer is performed using the standard TNM system (see Table 1). TNM describes the extent of the primary *tumor* (T stage), the absence or presence of spread to nearby lymph *nodes* (N stage), and the absence or presence of distant spread, or *metastasis* (M stage). Staging can be performed pre- and post-treatment, and the most definitive staging occurs following radical prostatectomy. With the advent of PSA testing, there has been a dramatic shift to diagnoses at lower stages and, thus, more likelihood of organ-confined cancer.[27] While imaging studies can be helpful in patients with extensive carcinoma of the prostate, further staging assistance using cross sectional imaging of the pelvis by computerized tomography or magnetic resonance imaging have not added to the accuracy of cancer staging.

Treatment of Localized Prostate Cancer

Treatment of localized prostate cancer requires significant discussion with patients regarding outcomes, morbidity, mortality, and requirement for treatment. Choices include: watchful waiting, radical prostatectomy, interstitial brachytherapy (radioactive seed implantation), and external beam radiation therapy. Choice of treatment alternative is based upon the individual, his family, and prognostic factors, such as stage, grade, and the patient's general physical condition. Over the past decade with the use of PSA, treatment of prostate cancer patients has decreased in average patient age and average stage. During this same time, surgery and radiation therapy for prostate cancer has significantly improved. Radiation therapy applied with conformal external beam techniques or the implantation of small radioactive seeds using brachytherapy has improved the efficacy of cancer control and decreased treatment morbidity. The combination of these treatment modalities with androgen deprivation therapy using luteinizing hormone-releasing hormone (LHRH) agonist[f] treatment has further improved outcomes.[28]

Radical prostatectomy has likewise improved markedly over the past two decades. The introduction of the bilateral nerve sparing radical prostatectomy in the early 1990s has improved continence levels and potency post-radical prostatectomy, while preserving cancer control rates and limiting positive margin rates. The introduction of laparoscopy and robot-assisted laparoscopic prostatectomy has further improved the morbidity from radical prostatectomy. With these inventions, the hospitalization time of patients undergoing modern robotic-assisted laparoscopic prostatectomy has declined from more than seven days in the mid 1990s to one day or less in the 21st century.

Table 1.
Clinical TNM Staging of Prostate Cancer

T1	Cancer is clinically inapparent, not palpable or visible by imaging
T1a	Incidental histologic finding, less than or equal to 5% of resected tissue
T1b	Incidental histologic finding, greater than 5% of resected tissue
T1c	Tumor indetified by needle biopsy, for any reason (e.g., elevated PSA)
T2	Palpable or visible tumor, confined within the prostate
T2a	Less than or equal to one half of one lobe
T2b	One lobe
T2c	Both lobes
T3	Tumor extends through the capsule
T3a	Extracapsular extension, unilateral or bilateral
T3b	Seminal vesicle involvement
T4	Tumor is fixed or invades adjacent structures
T4a	Tumor invades bladder neck, external sphincter or rectum
T4b	Tumor Invades to the floor and/or the wall of the pelvis

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[f] Luteinizing hormone-releasing hormone is a naturally occurring hormone that controls sex hormones in both men and women. LHRH agonist is a compound similar to LHRH (luteinizing hormone-releasing hormone) that serves in a manner similar to LHRH to control the same sex hormones.

This decreased hospitalization time has been accompanied with improved potency and continence rates, decreased blood loss, and decreased mortality rates. In a landmark randomized study comparing radical prostatectomy with watchful waiting with median 8.2 year follow-up, there was a 44% decrease in cancer death, 40% decrease in metastatic disease, and 67% decrease in disease progression.[29] Thus, radical prostatectomy appears to reduce disease-specific mortality, overall mortality, and risks of metastases and local progression.

Because prostate cancer is associated with slow progression and few deaths within ten years of diagnosis, men with life expectancies of less than ten years or significant comorbidities may be safely and effectively managed with a watchful waiting program. Watchful waiting generally consists of follow-up with regular PSA, monitoring PSA velocity, symptomatic treatment for obstructive uropathy and lower urinary tract symptoms (LUTS), and repeat biopsy if necessary.[30]

Systemic treatment of progressive prostate cancer continues to evolve and improve. The association of prostate cancer control with castrate levels[g] of testosterone was first identified by Huggins et al. in the 1940s.[31] The use of physical castration was widely used until the introduction and wide acceptance of luteinizing hormone releasing hormone agonist (LHRH). These agents, which rapidly produce castrate levels of testosterone, are associated with prostate cancer suppression. Androgen deprivation therapy, therefore, appears efficacious irrespective of method of treatment. Current depo preparations allow LHRH agonist to be administered monthly, or every three or four months. Implantable devices permit yearly changes of LHRH implants. While androgen deprivation therapy is associated with the side effects of castration including: hot flashes, osteoporosis, loss of libido, and decreased muscle mass and strength, prostate cancer control is quite satisfactory. In fact, survival can be increased by many years (average 3.5 years). Timing of initiation of androgen deprivation therapy, however, has been controversial. Since recent studies have demonstrated a prolongation of survival, many feel that androgen deprivation therapy should be initiated with initial detections of PSA rise.[32] Due to the significant morbidity, including an increase in osteoporosis and fracture risk, however, patients and physicians may chose to delay androgen deprivation therapy to preserve sexual function, muscle mass, and bone health.[33]

Newer concepts in LHRH agonist therapy with intermittent therapy are being utilized and investigated throughout the world. With this technique, testosterone is decreased using an LHRH agonist to castrate levels and until PSA response is observed. LHRH agonists are then withdrawn until the PSA value again climbs. Survival outcomes and effectiveness of treatment of this approach remain controversial.

Other methods for treatment of advanced prostate cancer have now progressed to agents beyond androgen deprivation. Newer chemotherapeutic agents, such as mitoxantrone and paclitaxel, have improved the outcomes of systemic chemotherapy.[34] These agents, which are currently reserved for patients with systemic malignancy unresponsive to androgen deprivation, provide some promise for improving survivals and prostate cancer control in patients with advanced disease.

Future Directions

Over the past decade, PSA testing, screening, and evaluation has revolutionized the diagnosis and treatment of prostate cancer. Indeed, urologists in clinical practice in the United States have observed a significant shift in stage of disease at diagnosis with few patients presenting in the 21st century with locally advanced or metastatic prostate cancer. This "stage shift" has permitted better diagnosis and more effective treatment of those patients at risk. Unfortunately, however, PSA as a prostate marker and prostate-specific marker is an imperfect screening tool. Current research on newer, more specific markers continues; however, PSA with modified use that incorporates measures of PSA density and velocity remain the mainstay for diagnosis. Newer imaging modalities are being developed to localize prostate cancers with the goal of localized treatment. Treatment of localized prostate cancer continues to be best carried out with radiation therapy or radical prostatectomy.

Modifications in radical prostatectomy over the past two decades, to include nerve sparing, laparoscopic approaches, and robotically assisted laparoscopic approaches, have improved morbidity, mortality, and outcomes. The United States' decrease in prostate cancer mortality over the past decade may, arguably, be a result of this improved diagnosis and treatment. Better serum diagnostic testing and imaging studies are being investigated in an effort to improve the specificity of diagnosis. Similarly, studies to identify tumors that are biologically aggressive and important, versus those that are more indolent, are ongoing. Identification of biologically less active and more indolent tumors may increase the number of men eligible for safe watchful waiting and active surveillance. Active investigation into gene and vaccine therapy may assist in the treatment of men with locally advanced or metastatic cancer. Similarly, this sub-categorization of prostate malignancies may assist in identifying patients most in need of early androgen deprivation therapy. With the advances in systemic chemotherapy and post-operative radiation therapy, more patients with aggressive, advanced prostate malignancies can be effectively treated with expected increased survival and decreased morbidity. **NCMedJ**

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[g] Castrate-level occurs when the levels of the body's testosterone drop 90-95%, which is consistent with the loss of the testicles.

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COMMENTARY

Confronting Prostate Cancer:
A Personal Reflection

Senator David W. Hoyle

Editorial Note: Because prostate cancer, its early detection and treatment, raise so many issues of personal concern, we considered it important to include a discussion of some of these matters from a personal perspective. We are fortunate that one of our state's leading public policy makers, Senator David Hoyle of Gaston County, was willing to share his own experience with all phases of the process from detection and diagnosis to surgical intervention and post-operative care. We hope that this narrative will help bring clear focus to many of the issues raised by the authors in this issue of the Journal and encourage men who are not regularly screened at appropriate ages to raise these issues with their personal physicians.

No one likes the sound of the word "cancer," especially when it applies to you. In this respect, I was just like everyone else.

But, I had heard from many that "most of us [men] have this condition, whether we know it or not, and that we may all die from this disease if we live long enough. Although most of us die from something else long before symptoms of prostate cancer appear." The fact that the disease is slow-growing (in most) and more prevalent in older men makes many feel less concerned at younger ages. I was one of those, although I had been having prostate-related problems for many years, since my mid-40s. Off and on, I had experienced problems with discomfort, inflammation, and something my doctors referred to as prostatitis. My PSA levels had been slowly rising (from around 2, then 3, then 4, and eventually to 6; the so-called "velocity" of change was notable, but still failed to raise the concern of my physician).

Finally, my primary care physician, who had been taking care of me for years, after a usual digital rectal examination as part of a normal physical, noted a lump or hard spot on my prostate. My doctor thought it would be good for me to see a urologist for a consultation visit.

This preliminary unusual finding from a regular primary care visit began a long and convoluted series of events that caused no small amount of anxiety for me and my family.

Importance of Follow-Up to Preliminary Findings

Right away, my physician helped me get an appointment at the University of North Carolina Hospital (UNC) in Chapel Hill. A biopsy was performed and laboratory results came back with the unwelcome news that I did have cancer of the prostate, with a Gleason score of "6." My urologist at UNC explained several (surgical and non-surgical) options, but recommended that I consider surgery to remove the prostate.

I consulted a number of friends, including friends in the field of surgery and urology, about my situation and asked several of them: "If you had this condition, where would you go to have the surgery performed." A physician friend, with whom I had often played golf, recommended a surgeon at Johns Hopkins University in Baltimore. On his recommendation, I contacted that surgeon and arranged an appointment to be seen in his clinic. He recommended surgery within two weeks of that appointment.

The "Ups and Downs" of Good and Not-So-Good News

Then, a startling thing happened. A week later, after I returned to my regular work at the North Carolina General Assembly, I was summoned from a committee meeting by my secretary who said the surgeon from Baltimore was trying to reach me rather urgently. I rushed from the room and spent a nervous 20 minutes or so trying to page the surgeon. I had all sorts of images racing through my mind. Were the results of my laboratory tests found to be even more serious than they first appeared to be? Was it necessary for surgery to take place even sooner for some reason? What could it be?

When my surgeon and I managed to speak, he explained that when the pathologists at Johns Hopkins looked at the slides I brought with me from North Carolina, they concluded that I did not have prostate cancer after all! My surgeon was

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calling to tell me that he had cancelled my scheduled surgery for the next week.

Even though there was a certain sense of "relief" in this news, my surgeon followed his announcement of these results with the request that I try to have an immediate second biopsy done here in North Carolina. He felt that was necessary to confirm the Hopkins pathologist's opinion that no disease existed, and then we would re-evaluate further options.

So, a few days later, I was scheduled for a second biopsy. This time, different from my first experience, the procedure was less painful and more extensive. Instead of six "punches," they did 12. But this time, I was more psychologically prepared and knew what to expect.

Two days later, the results were disappointing in that they confirmed the initial diagnosis: I did have prostate cancer. Surgery was scheduled for a second time, just before Christmas, after my prostate had time to heal from the extensive biopsy procedure. I got out of the hospital after surgery two days before Christmas and checked into a Baltimore hotel to rest for a few days before traveling home. The Hopkins surgeons wanted to make certain that I had no post-operative complications.

> *"No one likes the sound of the word "cancer," especially when it applies to you. In this respect, I was just like everyone else."*

After the surgery, I had a catheter to assist with bladder issues, which I kept in place for 20 days when it was removed by my own physician in Gastonia. I also wore paper diapers to make certain that I did not have a problem with incontinence. Thankfully, these were necessary for only a few days. I had no problems with urination or anything else after that.

I was relieved to learn that the surgical margins of my disease were contained (localized) within the prostate, and the disease had not spread to other parts of my body. Therefore, I had no post-surgical radiation. I am now followed on a regular basis (every six months) by a urologist in Charlotte, and my PSA has dropped to "zero." Several other tests have been done, such as a bone scan in Chapel Hill, to make certain that the disease was not transmitted to other parts of the body. In every respect, this has been a complete success, and I am pleased to have been disease-free for the seven-to-eight years since the surgery was performed.

Lessons Learned

This experience provides a number of "lessons" that I would pass along to others who may yet have to confront this same set of circumstances. First, it is important to have a regular primary care physician who knows you and your health situation well. It was important that my physician who had been seeing me off and on for many years was able to note the appearance of a "hard spot" on my prostate during a routine examination. Were it not for that finding, one might have concluded that an elevated PSA level alone, which had remained high for many years, was simply benign prostatic hypertrophy (BPH) and no cause for concern. I have a family history of prostate cancer, so I knew that this was something that might likely develop in my case.

Second, once I followed-up this initial finding with a more thorough urological examination and biopsy, and once I had a definitive diagnosis, I asked lots of questions of my doctors and my friends who had gone through this before. I read everything I could get my hands on about this condition, so I would know what courses of action were available to me, and what the likely (or possible) outcomes might be of any given course of action. One of my friends, who had considered the option of the implantation of radiological "seeds" instead of surgery, had worried (before taking that route) about problems with both incontinence and impotence. Neither of these problems resulted in his case. But, I learned that once radiation is chosen as an option, surgery is no longer an option.

Third, it is important to realize that medicine is not "perfect." Mistakes do happen, and test results are often inaccurate. It is important, especially with diseases like cancer, to double check test results and, if possible, with a different laboratory or clinical setting. I was fortunate that my Hopkins physicians recommended that I have another biopsy performed here in North Carolina. That second set of biopsy results confirmed the findings of the first biopsy—I did, in fact, have cancer and needed surgery. I've tried many times to figure out how the Hopkins pathologists could have been so certain that I didn't have cancer. My only explanation is that somehow the slides I brought with me from Chapel Hill were either the wrong slides, or they got mixed up in some way in the lab at Hopkins. In any event, a second set of biopsy results were necessary to actually detect the disease.

Finally, the combination of early diagnosis and immediate follow-through with a detailed diagnostic workup and consultation can lead to better treatment outcomes. Also, although there are risks of post-operative complications, for large numbers of men who undergo these procedures, results are similar to mine. In this day and age, there is really no reason for men to die from prostate cancer if they follow these recommended procedures for clinical examination and testing.

I am one of those grateful patients who has been well-served by many healthcare professionals here in North Carolina and elsewhere, as my family and I have confronted what, for some, is a very unnerving diagnosis. **NCMedJ**

COMMENTARY

Racial Differences in Prostate Cancer

Kris E. Gaston, MD, and Raj S. Pruthi, MD

Prostate cancer is the most common non-cutaneous cancer diagnosed in American men and the second leading cause of male cancer deaths.[1] African American men suffer disproportionately with almost double the incidence of and death from prostate cancer. Many sociologic and biologic theories have been applied to solve this conundrum; however, there is still great contention over what the isolated causes of these racially divided outcomes are.

Epidemiology

United States Statistics

In 2006, it is estimated that 234,460 men will be diagnosed, and 27,350 men will die from prostate cancer.[1] Data from the Surveillance, Epidemiology, and End Results (SEER) database 1998-2002 revealed the median age at diagnosis for prostate cancer was 69 years of age. Approximately 0.0% were diagnosed under age 34; 0.5% between 35 and 44; 8.0% between 45 and 54; 26.1% between 55 and 64; 37.5% between 65 and 74; 23.2% between 75 and 84; and 4.7% at 85 years of age or greater.[2] The age-adjusted incidence rate from 1998-2002 was 173.8 per 100,000 men per year. SEER data from 1998-2002 also revealed the median age at death from prostate cancer was 79 years of age. Approximately 0.0% died under age 34; 0.1% between 35 and 44; 1.2% between 45 and 54; 6.3% between 55 and 64; 22.1% between 65 and 74; 42.3% between 75 and 84; and 27.9% at 85 years of age or greater. The age-adjusted death rate was 30.3 per 100,000 men per year.[2]

African Americans suffer a disproportionately high incidence of and mortality from prostate cancer compared to whites. Relative to whites, African Americans suffer from a 1.6 times higher incidence of prostate cancer. According to SEER 13 registries from 1998-2002, whites were diagnosed with prostate cancer at a rate of 169.0 per 100,000 men compared to African Americans diagnosed at a rate of 272.0 per 100,000 men.[2] African Americans compared to whites also suffer from a 2.5 times greater mortality from prostate cancer. Whites died with prostate cancer at a rate of 27.7 per 100,000 men compared to African Americans who died at a rate of 68.1 per 100,000 men.[2]

North Carolina Statistics

In 2006, it is estimated that 7,120 men will be diagnosed and 830 men will die from prostate cancer in North Carolina.[1] The age-adjusted incidence rate for all races from 1999-2001 in North Carolina was 159.4 per 100,000 (United States 161.2 per 100,000).[2] The age-adjusted death rate from 1999-2001 for all races in North Carolina was 35.6 per 100,000 (United States 30.3 per 100,000).[2] More alarmingly, some North Carolina counties have the highest incidence of and death from prostate cancer in the world, irrespective of race (see Table 1 and 2). The etiology for such high prostate cancer incidence remains unknown.

Racial differences in the incidence of and death from prostate cancer persist when examined at the state-specific level. SEER data from North Carolina from 1999-2001 showed that whites had an incidence rate of 143.6 per 100,000 (United States white incidence in 2001 was 144 per 100,000) compared to African Americans who had an incidence rate of 238.5 per 100,000 (United States African American incidence in 2001 was 234.1 per 100,000).[2] During a similar time period (1998-2002),

> *"African Americans should be screened aggressively and early (after age 40) if any survival benefit from treatment is to be shown."*

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Table 1.
Ten Counties with the Highest Incidence of Prostate Cancer (per 100,000)
(United States White Incidence 144 per 100,000/African American Incidence 234.1 per 100,000)

	All		White		African American
Lenoir County	262.7	***Lenoir County***	213.6	***Onslow County***	464.7
Onslow County	247.8	***Onslow County***	212.4	***Perquimans County***	419.3
Perquimans County	245.2	***Craven County***	212.0	***Lenoir County***	376.2
Hertford County	243.0	***Perquimans County***	199.3	***Craven County***	334.7
Craven County	233.1	***Hertford County***	194.1	Burke County	319.0
Pamlico County	231.5	Pamlico County	192.0	***Alamance County***	316.8
Pasquotank County	216.7	Transylvania County	189.4	Catawba County	313.9
Camden County	212.8	***Alamance County***	187.1	Cleveland County	309.6
Alamance County	206.7	Pasquotank County	186.4	***Hertford County***	303.9
Northampton County	204.3	Alleghany County	186.3	Chowan County	298.9

Bold italic indicates counties with the highest incidence of prostate cancer shared by African Americans and whites.

Table 2.
Ten Counties with the Highest Mortality from Prostate Cancer (per 100,000)
(United States White Mortality 27.7 per 100,000/African American Incidence 68.1 per 100,000)

	All		White		African American
Caswell County	62	***Pender County***	49.3	Richmond County	143.8
Warren County	61.1	Franklin County	41.8	Catawba County	141.6
Pender County	60.7	Watauga County	39.4	Sampson County	120.0
Perquimans County	58.9	Lenoir County	38.5	Cleveland County	115.8
Granville County	58.8	Montgomery County	38.5	***Pender County***	108.2
Hoke County	57.2	Yancey County	37.7	Wayne County	103.6
Halifax County	55.8	Craven County	36	Duplin County	99.8
Richmond County	55.2	Carteret County	35.9	Caswell County	98.9
Northampton County	55.1	Granville County	35.9	Gaston County	97.7
Vance County	55.1	Halifax County	35.9	Northampton County	97.1

Bold italic indicates counties with the highest incidence of prostate cancer shared by African Americans and whites.

whites in North Carolina had a mortality rate of 27.9 per 100,000 (United States white mortality rates 1998-2002 were 27.7 per 100,000) compared to African Americans who had a death rate of 79.3 per 100,000 (United States African American mortality rates 1998-2002 were 68.1 per 100,000).[2] African Americans in North Carolina suffer a 1.6 times greater incidence of and 2.8 times greater mortality from prostate cancer compared to whites. These differences are similar to differences seen on a national level.

Possible Explanantions for Prostate Cancer Differences

Access and Allocation of Healthcare

Many studies have shown that minorities do not receive the same allocations of procedures as do whites who have the same disease processes.[3-5] Peterson et al. showed in a Veteran Affairs study of 33,641 men that African Americans with an acute myocardial infarction were 33% less likely than whites to undergo cardiac catheterization, 42% less likely to receive coronary angioplasty, and 54% less likely to receive coronary bypass surgery.[3] Similar outcomes were demonstrated by Ayanian et al. who studied a retrospective cohort of 27,485 men and women from various hospital systems who underwent inpatient angiography for coronary heart disease in 1987.[4] Results showed that whites are more likely than African Americans to receive revascularization procedures after coronary angiography. With regard to cancer care, Armstrong et al. studied 408 women with a family history of breast or ovarian cancer, of whom 217 underwent genetic counseling for breast cancer (BRCA1/2) testing (cases), and 191 women did not (controls).[5] Results showed that African Americans were significantly less likely to undergo genetic counseling for BRCA1/2 testing than were white women.

Access to and allocation of healthcare alone cannot explain the racial differences in prostate cancer outcomes. Robbins et al. studied men insured within the Kaiser Permanente organization and found that African American men presented with higher stages and worse survival from prostate cancer compared to white men.[6] This study showed that even in an equal access system, racial differences in prostate cancer outcomes still remained. In contradiction to the Kaiser study, Freedland et al. found an equal percentage of African American and white men presenting with clinically localized and metastatic prostate cancer in the Veterans Affairs system.[7] No differences were found in patient age or clinical stage of prostate cancer between black and white men at the time of diagnosis, but African American men presented with higher median serum prostate-specific antigen (PSA) values (14.2 versus 9.4 ng/mL, p = 0.0001) and slightly higher median Gleason scores (6.2 versus 5.9, p = 0.025).[7] More recent studies have shown that African Americans and whites, when matched by pathologic stage and grade after radical prostatectomy, have similar disease outcomes.[8] Eastham et al. demonstrated that African American and white men with clinical T1c[a] prostate cancer (diagnosed by PSA alone) have similar pathologic outcomes and PSA recurrence rates after radical prostatectomy, which further illustrates that in the modern era of PSA testing, stage for stage/grade for grade, African Americans and whites have similar outcomes.[9] These data re-enforce the argument that African Americans should be screened aggressively and early (after age 40) if any survival benefit from treatment is to be shown.

Prostate Cancer Screening Participation

The frequency of incidental prostate cancer detection in African Americans and whites appears similar;[10] however, African Americans are more frequently diagnosed with higher tumor volumes,[11] more advanced tumor stages,[12] more diffuse and greater volumes of high-grade prostatic intraepithelial neoplasia (HGPIN),[13,14] higher Gleason grades,[15,16] and higher PSA levels[11,14,16,17] compared to whites. Several studies have shown that when African Americans and whites are matched for stage and grade and undergo radical prostatectomy, there are no differences in PSA recurrence or risk of death from prostate cancer. [18-20] In light of the disparity in the incidence and mortality statistics, it would be reasonable to think that African American men would participate in more prostate cancer screening when offered. Unfortunately, several studies have shown quite the contrary. Ashford et al. evaluated 404 African American men in Harlem, New York and analyzed those who received prostate cancer screening.[21] Results showed that the prevalence of self-reported PSA screening in Central Harlem was lower than that reported for other populations, with only 24% of men 50-74 years of age ever having had a PSA test.

Choice of Definitive Therapy

Many studies have shown that African Americans compared to whites choose radical prostatectomy less often. Hoffman et al. studied 1,144 African American and white men with clinically localized prostate cancer and found that among men with more aggressive cancers (PSA greater than or equal to 20 ng/mL or Gleason score greater than or equal to 8), African Americans were less likely to undergo radical prostatectomy than whites (35.2% versus 52.0%), but more likely to receive conservative management (38.9% versus 16.3%, p = 0.003).[22] Treatment differences may reflect the greater likelihood for African Americans to present with pathologically advanced disease. Yan et al. analyzed men that underwent PSA screening and followed outcomes of therapy in men subsequently detected to have prostate cancer.[23] Non-African American patients had a greater than four times likelihood of selecting radical prostatectomy versus watchful waiting compared to African Americans. In an analysis of SEER data from 1995-1999, Denberg et al. showed that African Americans received equal amounts of definitive therapy for curative intent; however, African Americans compared to whites were significantly more likely to choose radiotherapy versus radical prostatectomy.[24]

Biologic Explanations for Prostate Cancer Differences

Androgen Axis:
Steroids

In studies that would later win the Nobel Prize in Medicine, Charles Huggins and Clarence Hodges demonstrated that withdrawal of testosterone causes prostate cancer to go into remission, but that it is almost certainly to recur in its testosterone-insensitive form.[25] Since prostate cancer is an androgen-stimulated cancer, could racial differences in prostate cancer be attributable to differences in androgen levels? In a study by Ross et al., male college students (mean age 20 years) living in southern California had testosterone levels measured. Total testosterone and free testosterone levels were 15% and 13% higher, respectively, in African Americans compared to whites.[26] Ellis et al. also measured androgen levels in over 4,000 male Army veterans ranging from 31-50 years of age (mean 38 years), but found that African Americans had only a 3.3% higher mean testosterone level compared to whites.[27] Kubricht et al. reported serum testosterone levels were similar between 189 African American and 264 white men undergoing biopsy for prostate cancer.[28] Beyond 40 years of age, African Americans and whites appear to have similar testosterone levels. If there are any differences in androgen levels, it occurs earlier in life and not in the prostate cancer-risk group after age 40.

Dihydrotestosterone (DHT) binds to the androgen receptor with affinity similar to testosterone, but DHT reduces androgen receptor degradation rates more than testosterone because of its slower dissociation.[29,30] Small racial differences in DHT or 5-alpha

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[a] Prostate cancer with a T1c stage is traditionally characterized as being early-stage disease and having the best prognosis.

reductase, which catalyzes the conversion of testosterone to DHT, may increase androgen receptor protein levels in African Americans compared to whites. Accordingly, Ross et al. studied serum DHT metabolites in 100 university students and 54 Japanese medical students.[31] African Americans and whites, respectively, had 25% and 31% higher levels of the DHT metabolite A-diol-glucuronide compared to Japanese students. Four recent studies have reported serum levels of DHT, and none found differences between cases and controls; however, in each of these studies, African Americans were either not included or race was unspecified.[32-35]

The aforementioned studies measured serum androgens that may not accurately reflect the true androgenic environment within the prostate. Mohler et al. analyzed steroid hormones that were extracted from snap frozen prostate tissue obtained intraoperatively from radical prostatectomy specimens of 36 African Americans and 59 whites.[36] Although tissue levels of testosterone and DHT did not differ by race, African American men had higher tissue androstenedione (ASD) and sex hormone-binding globulin (SHBG) than white men.

Androgen Receptor Expression

Lubahn et al. at the University of North Carolina at Chapel Hill (UNC-Chapel Hill) was the first to isolate the androgen receptor in 1988.[37] Extensive androgen receptor research continues at UNC-Chapel Hill. Recently, Gaston et al. performed a study looking at archived radical prostatectomy specimens obtained from 25 white and 25 African American men who had androgen receptor protein antigen retrieved and immunostained.[38] Androgen receptor protein expression was 22% higher in the benign prostates and 81% higher in the cancerous prostates of African American men when compared with white men. Similar results were found in a study by Olapade-Olaopa et al. The Olapade-Olaopa study compared androgen receptor expression in benign prostatic hyperplasia (BPH) and prostate cancer tissue of non-American blacks and non-American whites and found a similar increased expression of androgen receptor in blacks compared to whites.[39] Accordingly, prostate cancer may occur at a younger age and progress more rapidly in African American men compared to white men due to racial differences in androgenic stimulation of the receptor.

Racial differences in androgen receptor gene polymorphisms have also been described in the literature. African Americans, compared to whites, have been shown to express more androgen receptor polymorphisms, which may increase the risk of developing prostate cancer.

Racial Polymorphisms in the 5-alpha Reductase

Reichard et al. described genetic polymorphisms in the gene encoding the 5-alpha-reductase type II enzyme and compared allelic frequencies between three major United States populations—African Americans, whites, and Asian Americans. The authors found three different allelic families [containing 87 base pairs (bp), 103-107 bp, and 121-131 bp].[40] Whereas 18% of African Americans exhibited the 121-131 bp alleles, these alleles were not found in white or Asian Americans. Consequently, this 5-alpha-reductase type II enzyme polymorphism may result in more efficient conversion of testosterone to DHT within the prostate, and thereby may have a role in carcinogenesis.

Diet and Nutrition

Genetic differences cannot be the sole basis for difference of prostate cancer incidence. Epidemiological studies have demonstrated that as populations migrate from geographic areas with a low-incidence rate of prostate cancer to areas with higher-incidence rate, the migrating population begins to exhibit higher-incidence rates of prostate cancer. The incidence of prostate cancer varies throughout the world, yet African Americans have the highest incidence of prostate cancer in the world. The highest incidence of prostate cancer is in the United States, and the lowest is in Asia (as low as 0.5 per 100,000 in Qidong, China).[41] Asia also has a low consumption of saturated animal fat and a high consumption of fiber and soy protein.[41] Soy protein is abundant in the Asian diet, but is rarely consumed in the American diet. Soy has long been thought to have broad anti-neoplastic effects.[42] There are two broad isoflavonoid components found in soy—genistein and daidzein, both of which may have mild estrogenic effects, which may cause apoptosis (cell death) of prostate cancer cells.[42-44]

Dietary fat intake is thought to be a major factor involved with the increased incidence of prostate cancer in the United States.[45-48] Omega-6 fatty acids are thought to act as promoters of prostate cancer.[49] It is thought that at the cellular level, these fatty acids influence cellular proliferation, the immune system, and the potential for the tumor to invade locally and metastasize.[49] It is also thought that Omega-6 fatty acids (found in cereals, eggs, poultry, most vegetable oils, etc.) affect prostaglandin synthesis.[49] It has been shown that increased levels of prostaglandin E_2 increases oncogene Bcl-2 expression leading to carcinogenesis.[50] On the other hand, Omega-3 fatty acids found in fish oils, appear to be protective against prostate cancer.[49] These Omega-3 fatty acids are consumed in high amounts in Asia, whereas Omega-6 fatty acids are consumed in low amounts. The opposite occurs in the United States where Omega-3 fatty acids are consumed in low amounts and Omega-6 fatty acids are consumed at high amounts. Subsequent studies have shown that the African American diet contains the highest overall saturated fat and Omega-6 fatty acid content in the world.[47,48]

Obesity may be an independent factor of prostate cancer progression. Amling et al. examined the relationship between obesity and race in predicting adverse pathological variables in patients undergoing radical prostatectomy.[51] This was a multi-institutional retrospective analysis of the clinical and pathologic parameters on 860 patients with prostate cancer undergoing radical prostatectomy between 1992 and 1998. Obesity was defined as a Body Mass Index (BMI) greater than 30 kilograms/meter^2 (kg/m^2). Obese patients presented with prostate cancer at younger ages, higher Gleason grades, and more advanced pathologic stages. These data suggest a racial correlate of prostate cancer because African Americans tend to have higher grade prostate cancer and significantly higher average BMI compared to whites.

Insulin Growth Factor Pathways

Insulin-like Growth Factor 1 (IGF-1) stimulates cellular proliferation and inhibits apoptosis.[52] IGF-1 is a stimulator prostate cancer growth factor and 95% circulates bound to specific high-affinity IGF binding proteins (IGFBPs 1–6).[53] Blood levels of IGFs in each individual are relatively constant with no apparent diurnal or circadian variation. Studies have shown that African Americans have low IGFBP-3 compared to whites.[54] This may allow for more free IGF-1 to stimulate neoplastic growth of the prostate. Abdominal obesity and hyperinsulinemia are associated with decreased serum levels of sex hormone-binding globulin, with a resultant increase in testosterone, lower serum levels of IGFBP-1, increased serum levels of IGF-1, and estrogenic compounds.[55-58] Since African Americans have the highest BMI in the world, one can assume these IGF pathways may directly affect carcinogenesis of the prostate.

Vitamin D

Vitamin D may have protective benefits against prostate cancer. Vitamin D is believed to decrease bcl-2 expression increasing apoptotic cell death.[59] Some have suggested that endogenous Vitamin D synthesis may be impaired in African Americans because of the darker skin pigmentation.[60]

Conclusion

Striking differences in the incidence of and mortality from prostate cancer between African Americans and whites have persisted even after the advent of PSA testing. African Americans do not appear to fair worse than whites when matched by cancer stage and grade. More must be done to target this population for early and aggressive screening. **NCMedJ**

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Screening for Prostate Cancer in 2006:
PSA in the 21st Century

Paul D. Maroni, MD, and E. David Crawford, MD

Few issues in urologic oncology seem so intrinsically correct, but empirically unproven as the utility of screening for prostate cancer. For a predominantly asymptomatic disease until an incurable stage, preemptive diagnosis at a time when intervention might be curative seems intuitively beneficial. As treating physicians, we have patients with clear elements of biologically aggressive disease found through screening and cured with local therapy, who otherwise should have succumbed to the disease. We attribute this "cure" to the screening process, and this serves as anecdote for future patients facing the decision of whether to screen or not. We also have patients with low-volume, low-grade cancers detected through screening and experiencing chronic mental or physical debilitation as a result of their cancer diagnosis or treatment, which may serve as anecdote as well, especially considering the potential that the disease may have followed a benign course.

Critics of screening typically cite concerns related to overdiagnosis and the attendant overtreatment, diagnosis at a time when cure is not possible, economic issues, and the morbidity of screening. Autopsy studies demonstrate that about 35% of men in their fifties have prostate cancer, yet only 15% of men are diagnosed and 3-4% die from it.[1] This contributes to the idea that "men die *with* prostate cancer, not *from* it." Others worry that prostate cancer screening could potentially misuse important resources with initial estimates of about $25 billion per year for screening men between ages 50 and 70. Critics also raise the issue of patient morbidity with the anxiety and discomfort associated with the biopsy, the complications of treatment, and the potential for disease recurrence. Additionally, the heterogeneous behavior of prostate cancer allows a relatively narrow window for screening to be effective in the men most likely to benefit from it. The diagnosis and treatment of incurable, but asymptomatic disease is debatable for some when diagnosis and treatment upon symptomatic progression might have avoided emotional morbidity. One might argue that prostate-specific antigen (PSA) screening is more efficient at identifying the less important, slow-growing tumors and, therefore, contributes to overdiagnosis. These seemingly potent arguments cast doubt on the overall utility of screening and leave the internist or general practitioner wondering what to do since the burden of complaints among patients with low-volume, low-grade cancers primarily falls on them.

> *"While screening might not benefit certain individuals, taken as a whole, screening appears to decrease morbidity and mortality.*

While an issue of reasonable contention, overdiagnosis tends to not burden men that typically proceed to surgical therapy. In analyses of radical prostatectomy series, less than 10% of tumors removed are considered "insignificant" as generally judged by pathologic stage, grade, and size.[2] Over-diagnosis has not been overlooked by oncology care providers, and most men diagnosed with prostate cancer will have a care plan considering comorbidities, the benefits/side effects of treatment, and the likelihood of disease progression. While broad screening could potentially incur high costs, as a matter of resource allocation, the cost of prostate cancer screening would be between $9,000 and $145,000 (best and worst case scenarios, respectively) per quality-adjusted life year (QALY) saved.[3] This is on par

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with using hydrochlorothiazide or captopril for treating hypertension and much less expensive than mammography screening ($232,000/QALY gained). There are other ways to make screening more cost effective. Early data from the Prostate, Lung, Colorectal, and Ovarian (PLCO) trial suggests that men with PSA values between 1 and 2 ng/mL might only require screening every two years, while men with PSA levels less than 1 ng/mL might be screened every five years.[4] This alone would still detect 99% of men eventually progressing to a PSA greater than 4 ng/mL and would result in savings up to $1 billion per year. Morbidity reduction and management are well-developed areas of prostate cancer treatment. Prostate biopsies are much more tolerable with local anesthesia, and pathology results are typically available within a week. The competition of local therapies has enticed providers to pursue and achieve real decreases in rates of side effects. Also, our understanding of what constitutes aggressive cancer has advanced, allowing for active surveillance trials in patients with low-risk disease. While screening might not benefit certain individuals, taken as a whole, screening appears to decrease morbidity and mortality.

Most of the data supporting screening has been inferential by analyzing trends in morbidity and mortality before and after the addition of the PSA blood test. Analysis of the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) database has demonstrated a 20% reduction in prostate cancer mortality between 1991 and 1999.[5] Over a similar time period, men in Mexico have experienced a small increase in mortality presumably due to the lack of screening available.[6] These inferences are complicated by the fact that improvements in treatments, including the massive expansion of androgen-deprivation therapies, may have affected prostate cancer survival and the development of metastasis. In Tyrol, Austria, men over 50 years old were offered screening while men in other regions were not. Tyrol men have experienced greater than a 40% decrease in mortality from prostate cancer, which has not been experienced in other regions in Austria.[7] Numerous large randomized trials are currently underway regarding prostate cancer screening, including the PLCO Cancer Screening and the European Randomized Screening for Prostate Cancer (ERSPC) trials that have collectively accrued over 230,000 men. Results from these trials will not be available for several years and are eagerly awaited. Currently, most expert organizations recommend some form of cancer screening using PSA and/or digital rectal exam beginning at the age of 50 in men with a life expectancy of more than ten years with informed decision making. The United States Preventive Services Task Force does not recommend prostate cancer screening with the absence of supportive Level 1 evidence.

Informed Consent and Ethical Concerns

Along with this lack of Level 1 evidence and the need for informed consent are numerous ethical concerns. Unfortunately, most PSA screening performed today does not involve a thorough consent process. The "required" discussion is an impediment to PSA screening, as internists might forego the discussion and, thus, the test, focusing instead on other prudent medical issues. Given time constraints in today's practice environment, this lengthy discussion cannot happen in a practical manner without some sort of supplemental material in the form of videos or pamphlets that would ideally be reviewed prior to the office visit. Many institutions have constructed these sorts of materials (see Table 1). Even with results of randomized trials, some level of informed consent would still be beneficial prior to including PSA in a general lab panel. Maybe prostate cancer screening is not for "everyone." Patients may forgo diagnostic procedures based on individual utilities of sexual and urinary function. Our philosophical approach is that "knowledge is power," and patients may make educated decisions about treatment choice (including active surveillance) after diagnosis.

Several years ago, enthusiasm was building for the next round of PSA-related markers, such as free, complexed, and pro-PSA. The use of these markers has been examined, but has not realized wide acceptance. While their use results in increases in sensitivity and specificity of diagnostic testing, the benefits are incrementally small, and the complexity of interpreting results is often an intellectual endeavor. Newer diagnostic tests using advanced laboratory techniques are also in development. The addition of these tests also creates a logistic and systemic problem. Some combination of tests may be optimal, but how can this be prospectively studied in a randomized fashion when these types of trials are time-consuming and potentially obsolete when results are available? At this point, PSA velocities have proven more clinically valuable. Recent studies have demonstrated a link between prostate cancer mortality and pre-treatment PSA velocity. Generally, an increase of PSA greater than 0.75 ng/mL in a year would support prostate biopsy, while an increase of greater than 2 ng/mL in a year carries a worse prognosis.[8,9] The threshold for PSA screening has also decreased, with some authorities recommending biopsies in patients with age-specific

Table 1.
Informational Resources for Prostate Cancer Screening

Resources for Prostate Cancer Screening
Prostate Cancer Screening: A Decision Guide *www.cdc.gov/cancer/prostate/decisionguide/index.htm*
Screening for Prostate Cancer: Sharing the Decision *www.cdc.gov/cancer/prostate/screening/index.htm*
Leaflet from the Centre for Reviews and Dissemination *www.york.ac.uk/inst/crd/em22b.htm*
Link from UpToDate® Patient Information *http://patients.uptodate.com/topic.asp?file=cancer/6435*
Patient Guide from the American Urologic Association *www.auanet.org/timssnet/products/guidelines/patient_guides/prostate_awareness.pdf*

PSA values as low as 2.0 ng/mL. This approach can diagnose a number of potentially aggressive cancers at a more curable stage.

Screening techniques for other malignancies, such as cervical, breast, and colon cancer, tend to be much more invasive than a blood test or digital rectal exam (DRE). Yields of these exams vary widely based on risk group, age, etc., but tend to be less than 10% for the detection of a malignancy (pre-malignant lesions not included). By logical extension, a prostate biopsy could almost be considered as a screening device as the degree of invasiveness is on par with other screening exams, and the yields are universally greater than 10% in men over the age of 62 regardless of age or rectal exam.[10] Improvements in ultrasound probes, biopsy devices (smaller, spring-loaded needles), and local anesthetic techniques have made a diagnostic prostate biopsy fast and tolerable for most men. This approach is not accepted, considered, or even being examined with large trials in regard to prostate cancer screening. Clearly, the approach to prostate cancer is different largely due to estimates of over-diagnosis of up to 50%. The above diseases are universally more fatal in a shorter period of time. Additionally, the social consequences of local prostate therapy tend to be more personally destructive. As a requirement of expanding the indication of prostate biopsy to a screening instrument, we would need to have a better understanding of morbidity and lethality after diagnosis, more accurate staging tools, and embrace an active surveillance approach, initiating treatment at a time prior to the development of advanced disease. Ongoing active surveillance trials and the use of molecular markers hold much promise in this area.

One of the problems with screening trials is the approach to treatment after diagnosis. While treatment of other malignancies tends to follow a step-wise course based on evidence, in the prostate cancer literature, there is only one randomized trial that demonstrates that local treatment of prostate cancer will extend life (prostatectomy versus no treatment) and one other comparison trial with only 100 patients.[11,12] Numerous impediments limit academic production in this area and accruals in head-to-head treatment trials have historically been dismal, resulting in early abandonment. Most sources accept that treatment choice probably does not substantially affect mortality in a seven-to-ten-year window, but time periods beyond this, parenthetically the most important, are subject to speculation and debate. Hopefully, retrospective analysis of treatment choice in the larger screening studies will contain homogenous groups of the different treatment modalities, but these results could be decades away. Unfortunately, questions in this area may never be fully answered through randomized trials without an acceptable short-term end-point that is a surrogate for death from prostate cancer.

Conclusion

On speculation, the future for prostate cancer screening will likely consist of: (1) occasional PSA (or other unspecified blood or urine molecular marker) checks at long intervals based on risk group in the fifth decade, (2) PSA/molecular marker checks based on level after the sixth decade, and (3) 12-core prostate biopsy with local anesthesia and digital rectal exam at intervals based on risk group after the sixth decade. Screening will probably be discontinued when a patient has a negative prostate biopsy and a functional index score that would predict an eight-to-ten year life expectancy. Using this hypothetical algorithm for experiment generation, simultaneous advances would need to occur for more sensitive screening instruments, individual risk assessment (including genetic susceptibility testing pre/post-diagnosis), and screening interval modification.

As physicians who treat prostate cancer, we have an enormous problem with expectation management related to imperfect predictive modeling and unique nuances increasing the complexity of patient discussion. Our patients reasonably expect that we will recommend care that will extend the quality and the quantity of their lives. Clearly, not all prostate cancer behaves the same; however, the connotations of a cancer diagnosis from a patient's perspective are usually different from the clinical reality. Actuarial estimates of average gain from prostate cancer treatment are between zero and three years of additional "quality-adjusted life years" per patient.[13] True or perceived effects of treatment on urinary and sexual function appropriately guide many men's choice of treatment, but results of treatment (e.g., potency after prostatectomy) are not universally reproducible. The empathetic physician thoroughly reviews these and other issues and generally receives reward in conscience only. The wise physician recommends directed patient research and deliberate decision making, while the unwise recommends urgent and narrow treatment options. Walking hand-in-hand with better knowledge about PSA screening will be improvements in treatment, morbidity reduction, and other technological advances in detection. In theory, a negative PSA screening study may not be valid considering this dynamic process. The face of prostate cancer screening might change substantially in the future and may no longer even involve PSA blood testing. **NCMedJ**

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COMMENTARY

The Role of the Pathologist in Diagnosing Prostate Cancer and Guiding Therapy

Michael H. Weinstein, MD, PhD

Introduction

The recognition that serum prostate-specific antigen (PSA) concentration is a marker for adenocarcinoma of the prostate and the ability to measure PSA concentration represent major watersheds in the treatment of prostate cancer. Prior to these advancements in the 1980s, enlargement of the prostate gland detected by digital rectal exam, local symptoms, or sequelae of metastatic disease were the usual means of discovery of prostate cancer. In this pre-PSA era, prostate cancers were usually incurable at the time of diagnosis. PSA screening has lead to earlier detection and, although interpretation of recent epidemiologic data is still being debated, there is good evidence that PSA screening, prostate biopsy, and therapy with curative intent have lead to decreased morbidity and mortality from this disease.[1]

Also during the 1980s, refinements in the surgical technique for radical prostatectomy, which is potentially curative, yielded significant advancement in the treatment of prostate cancer by reducing the risk of morbidity associated with the surgery. These refinements hinged on two discoveries. First, elucidation of the venous plexus in the region of the prostate allowed operation in a "bloodless" field. This led to more accurate dissection, especially at the prostatic apex and, thus, greater preservation of urinary continence. Second, understanding the anatomy and function of the network of nerves around the prostate allowed "nerve-sparing" surgery and greater preservation of sexual function following radical prostatectomy.

These advancements required better means of screening and definitive diagnosis. PSA measurement and the thin-needle biopsy technique and equipment, although not perfect, are powerful tools for these purposes. Thin-needle biopsies cause less morbidity than open biopsy or biopsy with larger needles. As the pieces of tissue obtained by biopsy became much smaller, pathologists had to develop new techniques and expertise in interpreting these very thin biopsies.

PSA measurement has limitations, primarily in specificity, making this non-invasive test most useful as a first-line or screening detection method. While a few patients with prostate cancer have a normal serum PSA concentration, there are a significant number of men without cancer who have an abnormal concentration for whom therapy would not be warranted.

Thin-needle biopsy, by contrast, has essentially 100% specificity. The sensitivity of this test is estimated to be at least 75%, meaning that it will accurately detect three-out-of-four true cancers. Although more than one set of biopsies may be required for diagnosis, the morbidity associated with thin-needle biopsy is very low.

> *"PSA screening has lead to earlier detection, and... there is good evidence that PSA screening, prostate biopsy, and therapy with curative intent have lead to decreased morbidity and mortality from this disease."*

Pathologists have played a crucial role in the accumulation of the data upon which modern therapy is based, and they continue to provide essential information upon which medical oncologists, radiation oncologists, surgeons, and patients base their therapeutic and management decisions. This commentary is meant to outline the ways in which the clinical pathology laboratory and the work of pathologists serve as crucial components of the clinical decision-making process.

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PSA Testing

Prostate-specific antigen (PSA) is a serine protease enzyme secreted by the glandular epithelium of the prostate into the ducts of the gland. It ultimately contributes to the composition of the seminal fluid. Its normal function is thought to be liquefaction of semen. Much lower concentrations are typically found in the blood, where the majority of PSA is protein-bound. Measurement of PSA concentration is based upon binding of a PSA-specific antibody to the substance. Multiple tests have been developed using different antibodies, and there is a variation in results between laboratories of up to 25% or more in the range of 0-6.0 ng/ml.[2] Moreover, some methods show greater precision than others. PSA testing has two principal uses. It is widely used to screen for prostate cancer and to monitor individual patients, either following therapy or during a "watchful-waiting" period. The variation between laboratories is of less significance when PSA testing is used for screening purposes than when following an individual patient. In the latter circumstance, it may be helpful to use a single, reliable laboratory for serial testing.

PSA Screening

The "normal" PSA concentration in men has been given as less than 4.0 ng/ml, although there is considerable disagreement over the threshold value that should prompt additional testing for prostate cancer. More recently, age-specific ranges have been given, including an upper limit of 2.5 ng/ml for men under the age of 50.[3,4] Elevated serum PSA concentration is associated with multiple pathological processes and some situations in which there is no disease. Benign prostatic hyperplasia (BPH), prostatitis, and prostate cancer are the main pathologic states in which increased serum PSA is often seen. Prostate biopsy itself, ejaculation, and, possibly, exercise may also lead to an increase in the PSA.

It is the association of elevated PSA concentration with prostate cancer that has lead to its utility in screening. The test is non-invasive (requiring only a blood sample through venipuncture) and is relatively inexpensive. Unfortunately, the range of PSA concentrations seen in patients with prostate cancer overlaps with the range seen in benign processes. The essential limitation is that there is no single value separating men with cancer from those without.

The *sensitivity* of a test is defined as the fraction of individuals with a specific disease for whom the test will yield a positive result. The *specificity* of a test is defined as the fraction of all abnormal results that represent individuals who do have the disease for which they are being tested. Decreasing the maximum PSA value that is considered "normal" increases the sensitivity of the test in detecting prostate cancer. However, this also leads to an increase in the number of men who are labeled "abnormal" who do not have this disease (decreased specificity). Thus, while measurement of serum PSA concentration has proved to be a powerful tool in the ability to detect prostate cancer, appreciation of its limitations is critical for maximization of its utility. In fact, average PSA concentration in men without prostate cancer increases with age. This is largely due to BPH, which increases in incidence and severity. In truth, the PSA test is best used to estimate the chance that an individual has carcinoma of the prostate. PSA testing cannot be used to render a definitive diagnosis.

In an effort to increase sensitivity and specificity, derivative PSA tests have been developed. These include measurement of free PSA and calculation of the ratio of free/total PSA. These methods have yielded some increase in sensitivity and specificity with increased cost, but still suffer from an overlap in ranges in the populations of men with and without prostate cancer.[5,6] They may provide additional guidance in difficult circumstances, such as when PSA levels are significantly elevated, multiple sets of biopsies have been negative, and no other explanation for the elevation in PSA level is apparent.

The ratio of free/bound PSA is considered abnormal by many when it falls below 25%. This cutoff is associated with sensitivity and specificity of approximately 90% and 25%, respectively, for the detection of prostate cancer.

PSA velocity is the rate at which the serum PSA concentration rises over time. This calculation is of some use in men with borderline elevated PSA.[7] A PSA velocity greater than or equal to 0.75 ng/ml per year with measurements spanning at least 18 months has sensitivity and specificity of approximately 70% and 90%, respectively. Specific measurement of bound PSA has not been demonstrated to offer a significant improvement in detection.

PSA density, which is defined as the serum PSA concentration divided by the volume of the prostate as measured by transrectal ultrasound, has proven to have limited value.

Other tests potentially on the horizon include pro-PSA and human kallikrein-2, but these are not ready for routine clinical use in screening for prostate cancer.

PSA Monitoring

Serum PSA concentration is also useful for monitoring patients for progression of disease. Until late in the disease when the tumor may become so poorly differentiated that its ability to produce PSA protein becomes impaired, increasing PSA concentration is associated with advancing disease. Thus, the serum PSA typically falls to near zero following prostatectomy, since all of the prostate tissue, both benign and malignant has usually been removed. Minute amounts of tumor that may have spread beyond the prostate prior to surgery may not produce enough PSA to be detected until they grow, at which time the PSA concentration begins to rise.

The PSA often does not fall to zero in patients who have received radiation therapy without surgery. However, the PSA does fall for months following the treatments. In fact, the lower the nadir (lowest concentration detected) in PSA, the greater the chance of cure or long-term remission. Moreover, the longer the time it takes to reach the PSA nadir, the better the prognosis.[8]

Some patients with proven prostate cancer choose "watchful waiting" over therapy in order to avoid the morbidity associated with prostatectomy, radiation therapy, and hormonal therapy. A significant rise in serum PSA concentration may prompt physicians to recommend therapy to avoid morbidity and mortality associated with progression of the disease.

Prostate Biopsy

The thin-core needle biopsy technique and equipment allow multiple biopsies to be performed in the doctor's office with minimal morbidity (significant complications less than 0.5%) and provide material for definitive diagnosis of prostate cancer. The sensitivity of this procedure is very difficult to gauge. In the absence of metastatic disease, there is no way to tell with certainty whether a man has prostate cancer without pathologic examination of the entire prostate gland, which requires removal. Moreover, the sensitivity likely varies with the prevalence and type (i.e., grade, stage) of prostate cancer in the population being studied. However, based on data that do exist, a reasonable estimate for the sensitivity of needle biopsy of the prostate in patients with elevated PSA is at least 75%, if cancers detected on a second or later set of biopsies are included.

There is little debate about which areas of the prostate to biopsy, at least on the initial attempt to demonstrate tumor. However, the optimal number of biopsies to perform is not clear. The sextant biopsy technique (six biopsies) was considered adequate and was, by far, the most commonly used technique for approximately a decade. In recent years, it has become clear that performing more biopsies improves the chances of detecting cancer on the first attempt.[9] This is especially true when the prostate is markedly enlarged due to BPH. However, more biopsies are associated with greater discomfort, a greater chance of complications, and greater cost. Moreover, the incremental increase in sensitivity with each additional biopsy diminishes progressively. At the present time, there is no agreement on how many biopsies more than six should be performed.

In addition to identifying the presence of cancer, the pathologist interpreting the biopsies routinely provides other indispensable information regarding the tumor. The following diagnostic categories should be included in the pathologist's report. The clinical significance of each is summarized in Table 1.

Tumor Grade

Tumor grade is probably the single most important tumor characteristic assessed on needle biopsy of the prostate. The Gleason grade, also termed Gleason score or Gleason sum, is very useful in predicting the behavior of a given patient's tumor. Thus, it is used in planning therapy and estimating prognosis. Although the grade of the tumor in the biopsies is not a perfect predictor of the grade of the tumor in the prostate as a whole, the correlation is good. The lack of perfect correlation is not surprising, since the volume contained in an entire set of biopsies usually comprises less than one thousandth of the volume of the entire prostate gland.

It is worth noting that each type of cancer specific to an organ in the body has its own histopathologic (microscopic) grading scheme. The Gleason grading scheme is very unusual in that it ignores the appearance of the individual cancer cells and concentrates purely on the patterns of growth of the malignant prostate glands. The method takes into account the common occurrence of multiple glandular patterns of cancer being present in a single patient's tumor. Numerals 1-5 have been assigned to recognized categories of tumor patterns, and, traditionally, the two most prevalent pattern types are given as well as the numeric sum. Thus, a Gleason grade of 3+4 = 7 might be reported, where "3" represents the tumor pattern most prevalent in a specimen and "4" represents the second most prevalent pattern. The Gleason score of a homogeneous tumor will simply have the same number repeated in the sum (e.g., 3+3 = 6). A consensus of genitourinary pathologists has recommended long-overdue modifications to the original scheme, which was devised around 1970, but the essential concepts remain unchanged. It is now recommended that small amounts of high-grade tumor (i.e., Gleason pattern 4 or 5) be reported even when they represent neither the first nor second most prevalent pattern, as this finding correlates with more aggressive tumor behavior.[10]

The combination of PSA concentration, findings from digital

Table 1.
Pathologic Parameters Assessed on Thin-Needle Core Biopsy of the Prostate and the Clinical Significance of Each Parameter.

Parameter	Clinical Importance
Tumor Grade	Used to predict aggressiveness of tumor, stage, response to non-surgical therapy, and chance of cure with various types of therapy.
Location and Extent of Tumor in Biopsy Cores	Used to predict stage and response to some types of therapy (e.g., radiation therapy).
Perineural Invasion	May be used to plan extent of surgery (e.g., whether to sacrifice neurovascular bundle).
Atypical Glands	Re-biopsy should be performed—indicate ~50% chance of finding cancer on re-biopsy.
High-Grade Prostatic Intraepithelial Neoplasia (HGPIN)	~30% or less chance of finding cancer on re-biopsy, depending on how many biopsies originally performed. HGPIN may represent a precursor of prostate cancer.
Tumor Characteristics Following Therapy: Grade of tumor and whether therapy effect is present.	Used to assess prognosis and predict whether additional therapy is likely to be of benefit.

rectal exam, and biopsy Gleason grade has been used to estimate the stage of the tumor. The likelihood that the tumor is confined to the prostate, the chance of local spread into the surrounding fibroadipose tissue, the chance of invasion into the seminal vesicles, and the chance of local lymph node metastases can be estimated. These data have been compiled in the "Partin Tables,"[11] providing useful summary information to help each patient and his physician to make sensible decisions regarding choice of therapy.

Location and Extent of Tumor

The pathologist should report the amount of cancer present in the biopsy core(s) originating from each biopsy site. This information can be useful in estimating stage and predicting long-term outcome following therapy (e.g., prostatectomy, radiation therapy), especially when combined with other parameters, such as PSA concentration and tumor grade.[12,13]

Perineural Invasion

The presence of invasion of small nerves in the biopsy cores by the cancer is predictive of spread beyond the prostate when viewed in univariate analyses.[14] The reasoning behind these initial studies stemmed from the hypothesis, which is still accepted, that one of the main routes of tumor escape from the prostate is by tracking along nerves that traverse the surface of the prostate and comprise a portion of the periprostatic neurovascular bundles. However, most of the predictive power of the finding of perineural invasion on needle biopsy disappears in multivariate analyses when other variables, such as Gleason grade, are taken into account. Still, it may provide marginal additional information and may play a role in deciding whether or not to sacrifice one or both neurovascular bundles during surgery.

Atypical Glands

Unfortunately, a significant minority (≈5%) of prostate biopsies are neither definitively benign nor definitively diagnostic of carcinoma. The term often used in this situation is "atypical," sometimes in the phrase "atypical small acinar proliferation" (ASAP). The frequency of this occurrence is somewhat dependent on the experience of the pathologist interpreting the biopsies. Special studies (e.g., immunohistochemical staining) can occasionally lead to a more definitive diagnosis, but diagnosis usually hinges on tried and true ordinary techniques (i.e., H&E staining). The finding of atypical glands suspicious for carcinoma without other, definitively diagnostic areas warrants repeat biopsy.[15,16] In fact, the chance of finding prostate cancer on subsequent re-biopsy (one or more sets) is approximately 50%. Should re-biopsy prove inconclusive, other factors, such as total PSA concentration, free/total PSA ratio, clinical findings, and patient desire, provide guidance in choosing a course for repeat re-biopsy or longer-term follow-up with measurement of PSA velocity.

It should be noted that it is important for each biopsy to be separately labeled to designate the area of the prostate from which it originated. One reason for this is that 90% of all cancers discovered following an initial atypical, non-definitively diagnostic biopsy are identified in the same region or an area adjacent to the one from which the atypical biopsy originated. Thus, these areas are preferentially sampled on re-biopsy in order to maximize the sensitivity of the procedure in detecting tumor.

High-Grade Prostatic Intraepithelial Neoplasia (HGPIN)

Other findings that may increase the suspicion of cancer in the absence of definitively diagnostic biopsy material include the presence of high-grade prostatic intraepithelial neoplasia (HGPIN). Early studies indicated that the risk of unsampled carcinoma in the prostate gland associated with the isolated finding of HGPIN on needle biopsy was approximately 30%.[16,17] At the time, re-biopsy was required. However, if no carcinoma was detected on two sets of re-biopsies, additional biopsies were unlikely to contain tumor. More recent data, especially in the case of more than six biopsies to a set, suggest that the increased risk associated with this circumstance may be less than originally estimated, and the significance of this finding is somewhat diminished.

Since HGPIN is thought by many to represent a precursor of prostate cancer, it is postulated that potential chemopreventive agents may help to prevent prostate cancer in men who have been diagnosed with isolated HGPIN.

Other Clues to Tumor Behavior

Needle biopsy may provide other clues to tumor behavior. For example, prostate cancer clearly identifiable within fat at one end of a core biopsy is indicative of extraprostatic tumor spread. Clearly such information must be factored into therapeutic decisions.

Biopsy Following Therapy

Biopsy following therapy for prostate cancer is useful in a limited set of circumstances and poses challenges for the pathologist interpreting the biopsy. Therapy often alters the microscopic appearance of the tumor, sometimes making recognition of the malignant prostate tissue difficult. It can also alter the appearance of the tumor in ways that abolish the correlation between microscopic pattern and biologic behavior, so that Gleason grading of tumor following therapy is not meaningful in some circumstances.

A rising PSA following therapy is indicative of growing tumor. However, it does not indicate whether the tumor is growing at the primary site (i.e., in the prostate or in the prostatic bed after prostatectomy) or at a metastatic site. Radiographic studies (e.g., x-ray studies or computerized tomography scans) can be used to detect metastases. In the absence of detectable metastatic disease, biopsy of the prostate or prostatic bed may be performed to assess for local tumor growth. As with initial biopsy, skill is required on the part of the pathologist to properly interpret the changes due to therapy and to give an accurate assessment of the presence of cancer and, sometimes, whether it shows effects of therapy.

Pathologic Assessment of Prostatectomy Specimens

Pathologic review of the prostate after it has been removed for cancer also provides important information regarding prognosis and whether further therapy (e.g., radiation therapy) might be of benefit. The main pathologic parameters evaluated are tumor grade, stage (extent of cancer), and whether there is cancer at the surface of the specimen, which might indicate that not all of the tumor was removed. Other parameters may also have prognostic impact.

Tumor Grade

As with prostate biopsy, the recently modified Gleason grading system is used to grade prostate cancer in the prostatectomy specimen. Tumor grade is a powerful predictor of outcome, including risk of recurrence and time to recurrence. Minor discrepancies between the grade assigned on biopsy and the grade obtained from the whole prostate specimen are common. This is typically due to the fact that prostate cancers are usually heterogeneous. Only about one thousandth of the prostate is sampled even with multiple thin-needle core biopsies, and the tissue obtained may not be perfectly representative of the entire tumor.

Lymphvascular Invasion

Careful microscopic examination of the prostatectomy specimen may reveal the presence of tumor within minute lymphatic or blood vessels. It is a significant factor indicative of a poorer prognosis. This finding is rarely discernable on biopsy.

Tumor Stage

Tumor stage is crucial in determining whether adjuvant therapy is likely to be of benefit. Staging is performed according to the American Joint Committee on Cancer (AJCC) guidelines.[18] For example, invasion of the tumor into the adjacent fibroadipose tissue is designated stage T3a. Tumor invasion into either or both of the seminal vesicles is designated T3b, which supercedes T3a, and invasion into surrounding organs, such as the bladder, is designated T4. The absence or presence of metastatic spread into local lymph nodes (i.e., pelvic lymph nodes) is noted as N0 or N1, respectively, and the absence or presence of metastatic spread beyond this is designated M0 or M1. Thus, one might have a patient with staging "T3b N0 M1" if tumor has spread to the seminal vesicles and the spine, but is absent from the pelvic lymph nodes.

Margin Status

The final feature that must be assessed on the prostatectomy specimen is whether prostate cancer is present at the surface of the specimen. This is termed margin positivity and may, especially if it is present in more than a small area, be indicative of local tumor that could not be excised at the time of surgery. The pathologist should report the extent and location of tumor present at the margins. Like tumor stage, this information is needed to make decisions regarding subsequent adjuvant therapy.

Summary

In summary, the role of the pathologist has proven indispensable in diagnosing prostate cancer, planning initial therapy,

Table 2.
Utilities of Various Pathologic Parameters in Detecting Prostate Cancer and in Guiding Therapy.

	Determining need for biopsy/ re-biopsy	Planning initial therapy/ prognosis	Assessing likelihood of benefit from adjuvant therapy	Assessing for recurrance/ progression
PSA				
PSA Concentration	X	X	X	X
PSA Velocity	X			
PSA Density	X			
Free/Total PSA	X			
Biopsy				X
Tumor Grade		X	X	
Location/Extent of Tumor		X		
Perineural Invasion		X		
Atypical Glands	X			
HGPIN	X			
Prostatectomy				
Tumor Grade		X	X	
Stage		X	X	
Lymphvascular Invasion		X	X	
Margin Status		X	X	

assessing prognosis, estimating the likely benefit of adjuvant therapy following prostatectomy or radiation therapy, and in following patients for possible recurrent disease. Moreover, the work of pathologists has been pivotal in the research that has lead to our present understanding of the natural history of prostate cancer and the present methods for estimating the likelihood of benefit from various therapies. Such work continues to be integral to scientific advancement in these areas. **NCMedJ**

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Treatment for Localized Prostate Cancer:
Surgical Approaches

Eric M. Wallen, MD

Men who are diagnosed with prostate cancer face a dizzying and growing array of treatment options. These include watchful waiting, two forms of radiation, and three types of surgery. In addition, ever more therapies are entering the field of prostate cancer treatment, such as cryosurgery and high-frequency ultrasound therapy.

Each option comes with a set of risks, including inadequate treatment of the cancer, rectal problems, urinary incontinence, and erectile dysfunction. In the medical field, a great deal of controversy exists regarding the treatment of prostate cancer, and the patient is faced with a great deal of uncertainty when considering his treatment options. The patient's urologist and his primary care physician play crucial advisory roles in the patient's treatment decision. Ultimately each patient must navigate this complex process and make the decision himself.

Most, if not all, urologists are trained to be capable of discussing three major pathways for patients to consider once the diagnosis of prostate cancer is made. These are watchful waiting, radiation therapy, and surgery. Unlike many medical diagnoses, there is not an absolutely correct treatment for prostate cancer, and given this uncertainty, the patient (and his spouse or partner) must participate in the decision-making process. Notably, research has shown that most patients are comfortable in this role.[1]

> *"Unlike many medical diagnoses, there is not an absolutely correct treatment for prostate cancer, and given this uncertainty, the patient (and his spouse or partner) must participate in the decision-making process."*

Watchful Waiting

Watchful waiting is an important option for urologists to discuss with patients and for patients to seriously consider. The rationale for watchful waiting is based on the high incidence but low mortality of prostate cancer in the United States. As of 2005, a man in the United States has a one in six chance of being diagnosed with prostate cancer during his lifetime.[2] However, due to the biologic nature of prostate cancer, most men are destined to die from other causes before they die from prostate cancer—the likelihood of a man dying from prostate cancer is approximately one in 34.[2] More than ever, it is becoming clear that many men do not need to undergo treatment for prostate cancer. Given the risks and the costs of treatment, watchful waiting is an important option to consider, both as a patient and for healthcare systems.

Watchful waiting requires that patients have semi-annual examinations and testing for changes in the prostate-specific antigen (PSA) blood test. In addition, watchful waiting in healthy patients mandates that the patient undergo a repeat prostate biopsy to assess for changes in cancer grade and volume. This should be performed approximately one year after the initial biopsy.

Radiation or Surgical Treatment?

The next level of discussion regarding treatment for prostate cancer involves consideration of intervention in the form of radiation or surgery (i.e., local radical treatment in an attempt to cure what is expected to be organ-confined disease). Both radiation and surgery in all forms generally confer a disease-

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specific survival of at least ten years. Of course, disease-specific survival varies greatly based on the individual patient's disease biology. Most patients with screen-detected prostate cancer have a disease with slow biological progression and can expect little, if any, impact on their lives for 15-20 years. A smaller proportion of patients have more aggressive disease as identified by PSA levels found in their blood and Gleason[a] parameters and may indeed, succumb to the cancer.

Urologists are familiar with the efficacy and side effects of both radiation and surgical treatment, and they can discuss both with patients. Ideally, the radiation modality should be discussed with a radiation oncologist familiar with both brachytherapy (permanent or temporary implantation of the prostate with radioactive seeds) and external beam radiation therapy, so the patient may obtain a balanced view of his treatment options. It is well known that urologists, as surgeons, and radiation oncologists each favor their own treatment modality, and the best way for a patient to navigate this complexity is to discuss treatment with both specialists. However, many urologists perform brachytherapy and can discuss this treatment with the patient in terms of disease control and the potential side effects of lower urinary tract symptoms and erectile dysfunction.

Dr. Wallen controls the robotic instruments using sophisticated joysticks.

At the robotic console, the surgeon views the operation through a 3-D viewfinder and controls the instruments.

Surgical Options

Radical Retropubic Prostatectomy

The discussion of surgery for prostate cancer has become more complex in the past five years, as laparoscopic approaches to surgery have increased the number of surgical techniques available to the patient. The current standard of care, radical retropubic prostatectomy (RRP), has been performed and refined for several decades. This technique, also known as "open surgery," is performed through a vertical incision made below the umbilicus. Data on disease control and the two major functional outcomes, erectile dysfunction and urinary continence, are well known, and these complications are much less common than even ten years ago.[3] Research into healthcare quality is also well defined and indicates that outcomes are better and complications are fewer at medical centers where many RRPs are performed.[4] Similar findings have also been demonstrated when looking at individual surgeons. In the community setting, this information may be difficult for the patient to obtain. Patients who research their treatment options usually learn that an important question to ask their urologist is how many RRPs he or she has performed and how often.

Laparoscopic Radical Prostatectomy

Laparoscopic techniques for performing radical prostatectomy have become more common since the start of the new millennium. Laparoscopy has supplanted open surgery for many surgical procedures, including gall bladder removal, appendectomy, adrenal surgery, Nissen fundoplication (a procedure to alleviate gastroesphageal reflux), and some gynecologic surgeries. Laparoscopic surgery is performed through buttonhole-sized incisions with the aid of a scope placed internally to visualize the operation. The major driving force for laparoscopic surgery is decreased pain and faster recovery; additional benefits are improved visualization of anatomic structures and cosmetic outcomes.

Initially, laparoscopic radical prostatectomy (LRP) was developed as a standardized series of steps by surgeons in France. Adoption of this technique worldwide was limited due to the difficulty in learning this procedure, and it was

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[a] The Gleason scoring system grades prostate cancer patterns from 1 (well-differentiated malignancy) to 5 (poorly differentiated malignancy). For more information see page 123 of Dr. Culley Carson's article in this issue of the Journal.

abandoned by many urologists after their initial efforts. At a small number of medical centers, however, the technique for LRP has been mastered and is the standard surgical treatment offered to patients. Data evaluating outcomes for cancer control, complications, continence, and erectile function show that LRP is equivalent to RRP in experienced, capable hands.[3]

Robotic-Assisted Radical Prostatectomy

Robotics came to the field at approximately the same time that laparoscopic prostatectomy was being attempted around the world. Surgical robotics was developed over the past two decades by the military, and private companies brought these instruments to the bedside in the late 1990s. Only one surgical robotic platform, the da Vinci® Surgical System, is in widespread use today, with approximately 300 of these systems in place around the United States. The major benefit of this instrument is that it makes LRP feasible for many more surgeons, by virtue of creating a three dimensional (3-D), immersive environment for the surgeon and providing instruments with superior manipulation. The downside of this tool is its cost—more than $1 million—to individual hospitals and to the healthcare system in general.

Due to widespread purchase and use of the da Vinci® Surgical System, robotic-assisted radical prostatectomy (RARP) is rapidly becoming a new standard of care in the surgical treatment of prostate cancer. Access to the prostate is very similar to LRP, in the sense that small incisions are made to permit scope and instrument placement. However, the instruments used to perform the operation are controlled by a surgeon who sits away from the patient at a console. There, the surgeon looks into a viewfinder that provides 3-D visualization of the surgical field, and controls the instruments with sophisticated joysticks and foot pedals. Compared to traditional laparoscopic instruments, the robotic-controlled instruments have more flexibility to perform the delicate nerve sparing and sewing parts of the procedure. In addition, the robot eliminates tremor, thereby steadying the surgeon's hands.

Results from RARP appear to be at least as good as RRP and LRP, and some studies have claimed that oncologic and functional outcomes are even better.[5,6] Compared to RRP, LRP and RARP have shorter hospitalizations and lower rates of blood transfusion.[7] The results of RARP, as with the other techniques, are best at medical centers where many of the procedures are performed.[8] Indeed, patients undergoing surgery for prostate cancer by an experienced surgeon can expect to have an excellent chance for recovery of urinary control and baseline sexual function, regardless of the technique. Currently, the field of urology is witnessing patient migration to centers where RARP is performed, based on good results and effective marketing of the robot. I expect that over the next decade, robotic-assisted laparoscopic radical prostatectomies will become the most common surgery performed for patients with prostate cancer.

Conclusion

Prostate cancer as a disease entity is rife with controversy. As common as it is, it certainly does not warrant aggressive treatment in many patients. This is a difficult concept for physicians and patients alike to understand. Over and beyond the next decade, the option of watchful waiting will be further explored by researchers and recommended for more and more patients, spurred by the recognition that most prostate cancer is not lethal. The presence of newer surgical techniques should not obscure this, and urologists, as well as other physicians must recognize this.

At the same time, surgery for prostate cancer is in a state of evolution. The emergence of RARP as a less invasive option has encouraged more physicians and patients to consider surgical treatment. So how are patients supposed to make sense of these developments? Urologists play a crucial role in facilitating patient education through discussion, providing or recommending written material, and directing them to appropriate Internet resources. Patients should be made aware of all options, including watchful waiting, and should understand that the slow pace of the disease process allows them time to carefully consider these options. Patients should advocate for their healthcare by inquiring about the experience of their potential surgeon, investigating outcomes through prostate cancer support groups, becoming educated via media resources, and discussing options with their partner and other family members. At the conclusion of this process a patient is empowered to make a choice with which he is comfortable. **NCMedJ**

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COMMENTARY

Radiation Therapy for Prostate Cancer:
External Beam, Brachytherapy, and Salvage

Scott L. Sailer, MD

Radiation is a viable curative treatment option for localized prostate carcinoma. It can be used as primary therapy and can also be used to cure patients who have failed surgery or are at high risk of recurrence after prostatectomy. For locally advanced tumors, radiation is the preferred treatment and, based on randomized trials, should be combined with hormonal therapy for optimal results. Watchful waiting is another option for patients with low-risk disease.

Radiation as Primary Therapy

Radiation can be delivered using external beam radiation therapy, brachytherapy (permanent or temporary implantation of the prostate with radioactive seeds), or a combination of these methods. There are no randomized trials comparing the various radiation techniques to each other or to radical prostatectomy, so comparisons of outcomes after various treatments is based on retrospective reviews. Risk groups have been developed to categorize the aggressiveness of prostate carcinomas so that patient cohorts who have similar prostate cancers can be compared. One of the more popular risk-group categorizations has been developed by D'Amico et al.[1,2] (see Table 1).

Table 1.
Risk Groups for Clinically Localized Prostate Carcinoma[1,2]

Risk Group	Characteristics	Expected ten-year PSA failure-free survival
Low	PSA < 10 and Gleason score < 6 and 1992 AJCC stage T1c, T2a	80-85%
Intermediate	PSA > 10 and < 20 or Gleason score = 7 or 1992 AJCC stage T2b	50-60%
High	PSA > 20 or Gleason score > 8 or 1992 AJCC stage T2c, T3	30-40%

American Joint Committee on Cancer (AJCC).

These risk groups can be used to compare patients treated at different institutions with different techniques, but as always, there are pitfalls with retrospective reviews arising from patient selection and unknown bias. Patients treated with radiation tend to be older, have more advanced local disease, have higher prostate-specific antigen (PSA) levels, and have higher Gleason scores.[a] Because of this bias, outcomes after radiation will be inferior to surgery unless there is an attempt to compare patients with similar prostate cancers. Risk-group stratification is a simple way to adjust for this bias, but is obviously not as rigorous as randomized trial data. Another difficulty that limits retrospective comparisons is that both surgical and radiation techniques have improved over the past ten-to-15 years, so there is no long-term follow-up of prostate cancer patients treated with modern techniques.

Nevertheless, retrospective comparisons using appropriate risk groups are the best datasets available during patient counseling. Kupelian et al.[3] reported results for 2,507 patients treated with external beam radiation (greater than or equal to 72 Gy), surgery, brachytherapy, or a combination of brachytherapy and external beam from 1990 to 1998 (see Table 2). The data are not "clean" in that a fraction of patients in each treatment group also received hormonal therapy. For some patients receiving radiation, hormonal therapy can improve survival, but at a minimum, patients treated with hormonal therapy will have a delay in PSA recurrence. Hormone use was limited to six months in this study, so the impact of hormonal therapy should be minimal. The patients in the intermediate- and high-risk

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[a] The Gleason scoring system grades prostate cancer patterns from 1 (well-differentiated malignancy) to 5 (poorly differentiated malignancy). For more information see page 123 of Dr. Culley Carson's article in this issue of the Journal.

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group were primarily intermediate risk. There were no T3 patients (patients with tumors that had spread outside the prostate capsule), 27% of patients had a PSA level greater than 20, and 19% had a Gleason score greater than 7. D'Amico has also reported outcomes for surgery and radiation based on risk groups.[1] No patients received hormonal therapy (see Table 3). These retrospective series show that the results after surgery and radiation are similar at five years. There is also little difference between brachytherapy and external beam radiation. Of note, even within the same risk group, the outcome after surgery is better at the Hospital of the University of Pennsylvania in Philadelphia than it is at Brigham and Women's Hospital in Boston (see Table 3), implying selection of more favorable patients at the University of Pennsylvania even within similar risk groups (assuming surgery is equivalent at the two institutions). While some patients in these series have been followed for ten years, the number of patients followed for ten years is too small to provide reliable data. With additional follow-up, long-term comparisons within these databases will be possible.

> *"...both surgical and radiation techniques have improved over the past ten-to-15 years, so there is no long-term follow-up of prostate cancer patients treated with modern techniques."*

For patients with intermediate- and high-risk prostate cancers, however, comparing surgery to radiation alone no longer reflects clinical practice. There are randomized data that support the use of hormonal therapy in patients with intermediate- and high-risk prostate carcinoma who are treated with radiation.[4-6] Several studies have shown a statistically significant survival advantage from the addition of hormonal therapy to radiation (see Table 4). Patients in the D'Amico et al. study[5] had slightly less severe prostate cancer compared to the other two studies, although many of the patients would still be considered high risk. The optimal duration of hormonal therapy when combined with radiation is not known, but higher-risk patients are probably best treated with two-to-three years of hormonal therapy.

Table 2.
PSA Failure-Free Survival for Stage T1-T2 Prostate Carcinomas at the Cleveland Clinic and Memorial Sloan Kettering at Mercy Hospital, 2003[3]

	Five-year PSA failure-free survival			
Treatment	Number	Low risk	Intermediate and high risk	Percent with hormonal therapy (duration < 6 months)
Radical Prostatectomy	1,034	90%	70%+	17%
External Beam Radiation (> 72 Gy)	301	92%	75%*	39%
Permanent Implant	950	90%	75%++	24%
External Beam and Implant	222	92%	75%**	36%

+ 21% Gleason score > 7, 26% PSA > 20

++ 12% Gleason score > 7, 21% PSA > 20

* 22% Gleason score > 7, 35% PSA > 20

** 22% Gleason score > 7, 35% PSA >20

Table 3.
PSA Failure-Free Survival after Surgery or Radiation[1]

		Five-year PSA failure-free survival		
Treatment	Number	Low risk	Intermediate risk	High risk
Radical Prostatectomy*	1027	90%	71%	40%
Radical Prostatectomy+	1100	85%	55%	30%
External Beam Radiation^	473	90%	61%	42%

* Hospital of the University of Pennsylvania, Philadelphia

\+ Brigham and Women's Hospital, Boston

^ Joint Center for Radiation Therapy, Boston

Over a five-to-ten-year time frame, the outcome after radiation or surgery is similar, based on the above retrospective reviews of patients stratified by risk groups. Outcome beyond ten years is less certain. On theoretical grounds, surgery should have a slight advantage over radiation because, if a prostate cancer is truly localized to the prostate gland (without extracapsular spread or occult distant metastasis), surgical removal of the gland should be permanently curative. Surgery is not always successful in clinically localized, low-risk tumors, however, because of inadequate surgical technique or tumor biology, which often leads to early dissemination or extracapsular spread. If the "horse is out of the barn," no local therapy is curative, although radiation probably has an advantage if there is only local

Table 4.
Randomized Trials Evaluating Hormonal Therapy in Intermediate and High-Risk Prostate Carcinoma

			Five-year survival	
Study	Number	Duration of hormones	Radiation alone	Radiation and hormones
D'Amico[5]	206	6 months	78%	88%
Hanks[6*]	361	2 years	71%	81%
Bolla[4]	415	3 years	62%	78%

* Gleason score 8-10 only

extension of disease, since radiation delivers a margin of effective dose around the prostate gland and seminal vesicles.

In contrast, the long-term efficacy of radiation, if a cancer is truly localized to the gland, is less certain based on a number of theoretical arguments. Although atrophied, the prostate is still present after radiation, and new cancers may develop ten-to-20 years after initial treatment. Second, there is variability in the sensitivity of prostate cancer cells to radiation. Finally, radiation kills clonogenic (replicating) cells in a random fashion. A given dose of radiation theoretically kills a fixed fraction of clonogenic cells, and with repeated doses of radiation, the fraction of surviving cells approaches, but never reaches, zero:

$$\text{survival fraction} = e^{-\text{(constant * radiation dose)}}$$

For a given survival fraction, the chance of cure is mathematically described by the tumor control probability. If the surviving fraction is 0, the tumor control probability is 100%:

$$\text{tumor control probability} = e^{-\text{(surviving fraction*number of clonogens)}}$$

Although the above is supported by laboratory work, tumor control probability *in vivo* is also dependent on host factors that are not well characterized. Radiation can definitely cure many prostate cancers, but if a large number of similar, truly localized tumors are radiated, there will likely be a few that are not cured because of the random nature of radiation killing, variability in radiation sensitivity, and variability in host factors. These tumors would have been cured with adequate surgical resection.

Based on these theoretical arguments and the lack of long-term randomized or retrospective data, I usually recommend radical prostatectomy for patients with low- and intermediate-risk cancers who are healthy and have a greater than ten-year life expectancy. For patients in poor health or older than 70 years, I will usually recommend radiation, since I am fairly confident that the ten-year results are similar to surgery. The patient with high-risk, localized prostate cancer, however, may be better treated with radiation and hormonal therapy, regardless of age, although there may be a role for surgery and adjuvant radiation in the younger patient.

Radiation Modality

For patients choosing brachytherapy, the most important consideration is the experience of the brachytherapy center. The quality of the prostate implant as judged by dosimetric parameters increases with the number of implants performed. If appropriately proctored, however, treatment is likely satisfactory at less-experienced centers.

For external beam radiation, newer techniques that allow greater doses of radiation to be delivered safely should be used. At a minimum, this should include three-dimensional (3D) conformal therapy, which allows more accurate targeting of the prostate and seminal vesicles while avoiding the rectum and bladder. Intensity-modulated radiation therapy (IMRT) should also be considered in patients with intermediate- and high-risk disease. IMRT is an extension of 3D, which modulates the intensity of each radiation beam in a way that allows for dose escalation while minimizing dose to sensitive normal structures. A similar dose escalation with standard 3D techniques results in excess late rectal toxicity.

Image-guided radiation therapy (IGRT) is another new technology that is being introduced into the clinic. Using a variety of techniques, IGRT increases the daily accuracy of tumor localization, which results in lower doses to surrounding normal tissue by allowing a decrease in the margin from the tumor to the edge of the radiation beam.

The choice of radiation modality is partially based on disease characteristics. Treatment with brachytherapy alone is best for patients with low-risk disease as long as the prostate is not too large (greater than 60-70 cc) or too small (less than 30 cc). Hormonal therapy is occasionally used with brachytherapy to decrease the size of the prostate prior to the implant. External beam radiation is used alone for low-risk disease and is combined with hormonal therapy for intermediate- and high-risk disease. Some centers will combine external beam radiation, hormonal therapy, and brachytherapy for patients with intermediate- or high-risk disease. As briefly reviewed above, there are no data to support one type of radiation over another for appropriate patients.

Patient preference and expected side effects also influence treatment choice. Brachytherapy as sole therapy has the distinct advantage of being completed in a single appointment although it requires general or spinal anesthesia, and treatment effects are felt for several months after the implant. External beam radiation typically involves daily treatments for seven-to-eight weeks (35-to-40 treatments). During treatment, brachytherapy tends to result in more urinary symptoms (frequency, burning, and urgency), and external beam radiation tends to cause more rectal symptoms (tenesmus, increased bowel frequency, hemorrhoid discomfort, and diarrhea), although both treatments can result in urinary and rectal symptoms. A small percentage of brachytherapy patients require bladder catheterization during the first few months after implantation, while this rarely occurs during or after external beam radiation. Both techniques can result in rectal injury, which manifests as rectal bleeding several months to years after treatment. Urinary incontinence is rare with both treatments, although it is more likely following brachytherapy. Sexual dysfunction is probably more frequent after external beam radiation compared to brachytherapy.

Radiation after Radical Prostatectomy

After prostatectomy, the PSA should become undetectable. If the PSA fails to fall to zero or becomes detectable after initially falling to zero, radiation is often used in a curative attempt to "salvage" the failure. As a local modality, radiation will only be effective if residual disease is confined to the prostate bed or pelvic nodes, although pelvic (nodal) radiation is less frequently used than prostate bed radiation after prostatectomy. Post-prostatectomy radiation is more effective with lower post-prostatectomy PSAs, an initially undetected PSA after surgery, a long disease-free interval prior to PSA failure, and adverse pathologic features, which predict residual local disease (extracapsular extension or positive margin). If a patient's PSA does not initially decline to zero, he likely had occult metastatic disease at diagnosis and would not benefit from localized radiation, unless the source of the residual PSA is a positive margin and the Gleason score less than 8. A ProstaScint® scan[b] is often used to confirm a prostate bed recurrence or, at least, attempt to rule out distant disease, but the low sensitivity and specificity of this examination limits its usefulness. The PSA disease-free survival after salvage radiation for all patients is approximately 25-40% at five-to-ten years after radiation.[7,8] Favorable patients (PSA less than 2.0, Gleason score less than 8, positive surgical margins) may experience PSA disease-free survivals of 60-70%.[8]

Adjuvant radiation for high-risk prostate cancer after radical prostatectomy is rarely used. Adjuvant refers to a situation where all clinically detectable disease has been removed. Most urologists will follow patients with high-risk prostate cancer and only consider radiation if the PSA does not fall to zero or if it becomes detectable, at which time the treatment is considered salvage therapy. The rationale for this "wait-and-see" approach is that not all high-risk patients are destined to fail, failures can be picked up "early" with PSA, and many patients are spared the toxicity of unneeded radiation. Arguments pointing out that PSA becomes detectable only after a million cells are present[9] have not increased the use of adjuvant radiation. Theoretically, radiation is most effective when the tumor burden is smallest. A randomized study of adjuvant radiation showed that the biochemical relapse was reduced from 47% to 26% at five years with the use of radiation.[10]

Watchful Waiting

For the older patient with low-risk prostate carcinoma, watchful waiting is a reasonable option. This is especially true if the patient has multiple co-morbidities or the Gleason score is less than 6. A group of patients identified from the Connecticut Tumor Registry had data extracted from chart review. For patients with Gleason 2-5 carcinomas who were not treated with local therapy, only 4-11% died from prostate carcinoma.[11] D'Amico showed that for low-risk prostate carcinoma, the risk of dying from prostate cancer after radiation or surgery was 1-2% at ten years, while the risk of dying from other causes was ten-to-30%.[12]

Most radiation oncologists are comfortable following patients without treatment, although this is usually done in conjunction with an urologist. Ideally, these patients should be enrolled in a study so outcomes of watchful waiting can be determined, but this is not usually possible in a community setting. A reasonable approach to watchful waiting is to monitor PSA every three months and consider treatment if the PSA doubling time (velocity) is less than 12 months. If the PSA is fairly stable after one-to-two years, monitoring can be decreased to every six months. While patients initially agree to watchful waiting, many elect to proceed with treatment as their anxiety rises with the rise in their PSA, even if the doubling time is greater than 12 months.

Summary

Radiation is a curative treatment for prostate cancer that is most appropriate for the older patient or the patient with significant co-morbidities. Younger patients with a greater than ten-year survival are probably best treated with surgery unless the disease is high risk. For all patients, high-risk disease is best treated with hormones and radiation. The long-term superiority of surgery over radiation, however, has not been demonstrated in randomized or retrospective studies, and the recommendation for surgery in the younger, healthy patient with favorable local disease is largely based on theoretical considerations. If chosen for appropriate indications and delivered with appropriate techniques, radiation can be delivered using external beam or brachytherapy with equal efficacy. The choice of radiation treatment is based on tumor characteristics and patient preference. Radiation can be used after prostatectomy to cure patients who are not cured with surgery. Watchful waiting may be appropriate for patients with low-risk disease. **NCMedJ**

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[b] ProstaScint® scan involves injecting a small amount of radioactive material into the body to determine if and where any prostate cancer cells may be.

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Systemic Therapy for Prostate Cancer

William R. Berry, MD

Systemic therapy plays an important role in the management of prostate cancer. Since the pioneering work of Dr. Charles Huggins in the 1930s, medical science has known that prostate cancer cells were, to some extent, dependent on the presence of androgens (steroid hormones) for their growth and survival.[1] Hormonal therapy, with various forms of androgen manipulation and androgen receptor interaction, has been the primary form of systemic therapy for prostate cancer since that time. In recent years, a role has been proven for systemic chemotherapy as well. Clinical research trials are now investigating the role of new biologic agents and immunotherapy. This commentary will review the current status of the systemic therapy for prostate cancer.

Hormonal Therapy: General Principles

The androgen receptor is the primary driver of cell growth for prostate cancer.[2] Stimulation of the androgen receptor can be reduced by depletion of circulating androgens, blocking the binding of androgens to the androgen receptor, or a combination of the two methods.

Depletion of androgens can be accomplished directly by bilateral orchiectomy (castration) or indirectly by administration of estrogens or luteinizing hormone releasing hormone (LHRH) analogues.[3] Both of these classes of drugs exert their effect indirectly via reduction of the production of luteinizing hormone by the pituitary, with subsequent loss of luteinizing hormone signal to the testicles to produce testosterone. Both classes of drugs are capable of reducing serum testosterone levels to levels equivalent to orchiectomy.

Blocking the binding of androgens to the androgen receptor can be accomplished with anti-androgens. Anti-androgens accomplish inhibition of prostate cancer cell growth by competitive binding to the androgen receptor versus androgens. Anti-androgens administered to a patient with functional testes do not decrease testosterone levels, but actually cause some increase.

A third means of manipulation of the androgen and androgen receptor interaction could have a role in the management of prostate cancer, but has not been well studied. Medications approved only for the treatment of benign prostatic hypertrophy, such as 5-alpha reductase inhibitors, block the conversion of testosterone to dihydrotestosterone (DHT).[3] DHT binds more strongly to the androgen receptor than testosterone, and theoretically, blocking the conversion of testosterone to DHT could diminish prostate cancer cell growth.

Roles of Hormonal Therapy

Hormonal therapy has been used to treat various states of prostate cancer, including metastatic disease, disease manifest only by a rising prostate-specific antigen (PSA) after primary therapy, as adjuvant therapy[a] post primary therapy, as neoadjuvant therapy[b] prior to and/or with primary therapy, and as a primary therapy for localized disease.

Metastatic Disease

The role of hormonal therapy in metastatic disease is well accepted as first-line therapy. All of the three methods of testosterone depletion, (e.g., orchiectomy estrogens, or LHRH analogues) are equally effective.[3] LHRH analogues, although expensive, are the primary therapy used in most patients. Many patients prefer injections to orchiectomy, and estrogens can be associated with significant thrombo-embolic cardiovascular risk. Between 70-90% of patients will respond initially with a decrease in PSA and clinical improvement in symptoms. Median duration of response to this therapy is about 18

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[a] Adjuvant therapy is treatment, such as chemotherapy, radiation therapy or hormone therapy, given to a patient after the primary treatment to increase the chances for a cure.

[b] Neoadjuvant therapies are similar to adjuvant therapies except they are given prior to the primary treatment.

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months. There is controversy over whether treatment should begin when metastatic disease is diagnosed or only at the onset of symptoms. A review of the randomized clinical trials suggests that there is a benefit with higher rates of one- and five-year disease-free progression and ten-year survival among those who receive immediate versus deferred therapy.[4]

Anti-androgens in standard doses as monotherapy have been demonstrated to be inferior to testosterone depletion.[5] Their use as single agents in general should be restricted to patients who refuse testosterone depletion because of concern over loss of sexual function.

Combined androgen blockade (CAB), the addition of anti-androgen to testosterone depletion, is also controversial. Randomized trials have produced mixed results. Three meta-analyses of the data have all suggested a small improvement in five-year survival as opposed to simple testosterone depletion with orchiectomy or LHRH analogues.[6,7,8,9] There are some minor side effects with anti-androgens (e.g., diarrhea, gynecomastia, etc.), but the biggest objection to the addition of anti-androgens is the significant monetary cost of these drugs as compared to marginal survival benefit. It should be determined by each patient and his physician whether the potential benefit of CAB is worth the cost.

> *"Since the pioneering work of Dr. Charles Huggins in the 1930s, medical science has known that prostate cancer cells were, to some extent, dependent on the presence of androgens (steroid hormones) for their growth and survival."*

PSA Recurrence as the Only Sign of Disease

It has become common clinical practice in the PSA era to treat patients who have a PSA level that begins to rise but have no evidence of metastases, at some point after primary surgery or radiation therapy. The rationale is to prevent or delay the onset of overt metastatic disease. Not all patients who have a PSA recurrence die of prostate cancer. Recent studies have demonstrated that several factors, including time to PSA recurrence, Gleason score at diagnosis, and PSA doubling time, are all important in determining a patient's risk of dying of prostate cancer when he does have a rising PSA.[10,11,12]

There has also been a trend toward the use of intermittent hormonal therapy in patients with a rising PSA. The rationale for intermittent therapy is to have periods of time away from the side effects (hot flashes, fatigue, etc.) and toxicities (deterioration of bone density, loss of muscle mass, etc.) of testosterone depletion, but also there is speculation that the onset of hormone refractory prostate cancer could be delayed.[13] This method is not yet supported by data from a large randomized clinical trial, but is attractive to many patients and physicians.

Adjuvant Hormone Therapy

There are minimal data on the use of hormone therapy after prostatectomy. In a trial reported by the Eastern Cooperative Oncology Group (ECOG), men who were discovered to have positive lymph nodes when their pathology was reviewed after surgery were given continuous LHRH analogue therapy either immediately post surgery or at the time of recurrence .[14] At ten years there was a dramatic survival benefit (72% versus 49%) for those men who received immediate versus deferred treatment, respectively. This trial has been criticized because there were only 98 men accrued. However, the data are so compelling that one would be hard pressed not to recommend immediate adjuvant hormonal therapy to all men who have positive nodes at the time of prostatectomy.

Neoadjuvant Hormonal Therapy

Neoadjuvant hormonal therapy has been tested in clinical trials prior to surgery and also prior to (as well as concurrent to and after) primary radiation therapy. The neoadjuvant surgical studies have consistently failed to demonstrate any disease-free or overall survival benefit for neoadjuvant hormonal therapy given for anywhere from three-to-eight months pre-surgery.

On the other hand, several large clinical trials have shown a disease-free and, in some, a survival benefit for hormonal therapy administered prior to and continued concurrent with radiation therapy for patients with high-risk prostate cancer. Three of these important trials include RTOG 86-10, the Bolla study from EORTC, and the D'Amico trial.[15,16,17] There are preclinical data to suggest that androgen depletion does make prostate cancer cells more sensitive to radiation, and this phenomenon could explain why neoadjuvant hormonal therapy is beneficial with radiation and not surgery.[18]

Hormonal Therapy as Primary Therapy

Some physicians advocate hormonal therapy as primary therapy for prostate cancer.[19] There are no data to suggest that primary hormonal therapy can be done with curative intent. For that reason, the use of primary hormonal therapy should probably be reserved for those who need treatment, but are unwilling or unable due to co-morbidities or age to pursue a curative primary treatment, such as surgery or radiation.

Hormonal Resistance

As noted previously, the median duration of response to hormonal therapy in patients with metastatic prostate cancer is about 18 months. Virtually all patients develop disease that progresses in spite of this first-line hormonal treatment. This condition has variably been termed androgen-independent prostate cancer or hormone-refractory prostate cancer (HRprostate cancer). Regardless of the terminology, there is evidence to suggest that the androgen receptor is still the predominant driver of prostate cancer cell growth, even in this state of the disease.[20] Therefore, LHRH analogues are usually continued.

Secondary hormonal manipulations may be effective in some patients with HRprostate cancer, with reported response rates of 20-60%.[21] These secondary therapies include the addition of anti-androgen, anti-androgen withdrawal, estrogens, corticosteroids, and suppression of adrenal androgen production with drugs like ketoconazole. There are no clinical trials to suggest a survival benefit from any of these second-line therapies, but in general, they are not especially toxic and are, therefore, useful in selected patients.

Systemic Cytotoxic Chemotherapy

As in other metastatic cancers, clinical trials using chemotherapeutic agents have been undertaken in an attempt to find effective therapy for HRprostate cancer. Early trials were limited by the lack of conspicuously effective agents and the lack of significant numbers of patients with measurable disease. After the discovery of PSA, declines in this serum protein could be used as a marker of disease response to therapy in phase II trials. The PSA Working Group recommended a sustained decline in PSA of 50% or more from baseline as an indicator of response in phase II trials.[22]

In the 1990s, two phase III trials compared mitoxantrone and a corticosteroid to the steroid alone in patients with HRprostate cancer.[23,24] Both of these trials showed a significant benefit in terms of palliation of pain, although there was no survival benefit. Based on this palliative benefit, the combination of mitoxantrone and prednisone was the first chemotherapy regimen to be approved by the Food and Drug Administration (FDA) for the treatment of HRprostate cancer.

The results of these trials led to renewed interest in the use of chemotherapy in HRprostate cancer and a more rigorous preclinical and clinical search for new active agents. Drugs that affected intracellular microtubules, including vinca alkaloids, taxanes, and the combination of either of these classes with estramustine, had enough activity to generate a large number of phase II trials. Docetaxel was the most active of these agents.

The documentation of 50% PSA decline rates in 30-65% of the phase II trials with docetaxel led to the initiation of two large phase III trials using docetaxel in combination with another agent versus the then standard mitoxantrone and prednisone.[25,26] Both of these trials, SWOG 9916 and TAX 327, demonstrated an improvement in overall survival for docetaxel given every three weeks in combination (with estramustine or prednisone, respectively) versus mitoxantrone and prednisone. In addition, patients on docetaxel did better in terms of pain relief and quality of life than those receiving mitoxantrone. These were truly historic studies, which were the first phase III trials to demonstrate that chemotherapy can prolong survival in patients with HRprostate cancer (hazard ratios 0.80 and 0.76). There were increased adverse thromboembolic events in the SWOG 9916 trial, which used estramustine with docetaxel. For that reason, docetaxel every three weeks with daily oral prednisone is now FDA-approved and the standard of care for chemotherapy in HRprostate cancer.

The Next Steps

Now that we have a regimen that can prolong survival in HRprostate cancer, the next steps will be to improve on the first-line therapy of docetaxel and prednisone, develop new agents or regimens for patients who have progressed on docetaxel, explore the role of chemotherapy in the earlier states of prostate cancer, and develop effective biologic and immunotherapy for prostate cancer.

Agents that have been combined with docetaxel include carboplatin;[27] high-dose calcitriol;[28] thalidomide;[29] various small molecule growth factor tyrosine-kinase inhibitors, such as gefitinib and imatinib;[30,31] large molecule antibody-to-cell-surface receptors, such as vascular endothelial growth factor;[32] the endolthelin A receptor antagonist atrasentan;[33] proteosome inhibitors, such as bortezomib;[34] and even vaccines for prostate cancer.[35]

Currently no agents are approved for second-line treatment of HRprostate cancer after failure of initial chemotherapy. A phase III trial of the oral agent satraplatin has recently been completed, and the results are awaited with anticipation.[36]

Systemic chemotherapy, which is effective in an advanced cancer, is often more effective in early states of disease. Two large clinical trials of chemotherapy in combination with androgen depletion in earlier states of prostate cancer are underway as adjuvant therapy post-prostatectomy in patients with high risk for recurrence. An Intergroup United States trial is comparing mitoxantrone and hormone therapy to hormonal adjuvant therapy alone. A large international pharmaceutical company-sponsored trial will test the addition of docetaxel to hormonal therapy in the adjuvant setting. In addition neoadjuvant chemotherapy with docetaxel will be tested in combination with hormonal therapy prior to and concurrent with radiation in patients with high-risk disease. The results of these trials will determine the effectiveness of these chemotherapy strategies in early stage prostate cancer.

Finally, as we learn more about the cancer genome and the immune system, new biologic agents that can be directed at specific targets and new ways to stimulate the host immune system to recognize and destroy prostate cancer cells are being developed and nearing routine use in patients. The progress being made should greatly enhance our ability to alter the course of prostate cancer with systemic therapy. **NCMedJ**

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COMMENTARY

The Economic Impact of Prostate Cancer Screening and Treatment

Rachael L. DiSantostefano, PhD, and John P. Lavelle, MB, BCh, FRCSI

Prostate cancer is a significant public health concern. Because of its high incidence and mortality and a lack of consensus on the recommended frequency of screening and the most appropriate treatments, prostate cancer is also characterized by high costs and uncertainty. As a result, there is perhaps no bigger debate in medicine today as far as whether or not there should be widespread screening for prostate cancer and if and/or how to treat early-detected cases.

> *"Whereas the increase in screening detects cancer early and at a potentially curable stage with aggressive treatment, it has also resulted in the overdiagnosis of latent disease and unnecessary biopsies for men with false-negative screening tests."*

The corresponding economic costs of screening, diagnosis, treatment, and follow-up for prostate cancer are not trivial and are expected to increase with the aging of the population and a larger volume of screening. In 1990, the total annual costs to treat prostate cancer were estimated to range from $1.72 billion to $4.75 billion.[1] With the advent of prostate-specific antigen (PSA) screening in the early 1990s, the costs of treating prostate cancer in the United States likely far exceeded this amount, based on trends toward earlier detection and more aggressive treatment. Based on early estimates, the cost of screening increases prostate cancer expenditures by three-to-ten times.[1] The costs of treating prostate cancer in Sweden have been observed to fall within this range, increasing three-fold between 1991 and 2002 (20 million to 65 million euros).[2]

The exponential increase in the volume of prostate cancer screening adds to healthcare costs via the cost of the screening test, follow-up biopsies for positive tests, and treatment (or long-term monitoring) for confirmed prostate cancers. For example, the use of PSA tests increased seven fold, and radical prostatectomies increased six fold between 1991 and 2002 in Sweden.[2] Radiation therapy increased ten fold from 1997-2002.[2] In the United States, similar trends were likely. Between 1989 and 2002, there was a 234% increase in radical prostatectomy in the United States.[1] In 2003, there were 90,328 hospital discharges with the diagnosis of prostate cancer and associated costs of $673 million.[3] While treatment for prostate cancer is expensive, the overuse and/or inappropriate use of diagnostic tests in a manner inconsistent with treatment guidelines significantly inflates costs for disease management.[2] According to the Medicare Current Beneficiary Survey (2002), nearly two thirds of the 17.6 million Medicare beneficiaries received prostate cancer screening.[4] If all Medicare beneficiaries or all men older than 50 (34.7 million in 2000) sought screening, annual costs for the PSA screening test for

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one year would approach ~$2 billion assuming Medicare reimbursement (~$50 per test).[5] With costs in the range of a few billion dollars per year (screening, treatment, disease management, monitoring, etc.), costs of a population-based screening program, including disease management, could easily exceed $20 billion within five-to-seven years.

The biggest controversy in prostate cancer research is in the lack of consensus on the value of prostate cancer screening given the test's performance at diagnosing cancer and the inconsistent demonstration of effectiveness of early intervention at improving patient outcomes, including reductions in mortality. Although the existing evidence of effectiveness has improved in recent years, and cost-effectiveness analyses have been increasingly performed, uncertainty about the benefits of treatments in improving patient outcomes remains. A recent systematic review demonstrated that it was difficult to draw conclusions without uncertainty on the benefits of treatment alternatives due to lack of randomized clinical trials. Newer technologies, in particular, were hardest to evaluate given a lack of evidence of effectiveness and a lack of comparison with standard treatment alternatives.[6] Although radical prostatectomy and radiation rapidly replaced watchful waiting for early disease detection with the advent of PSA, there was weak and inconsistent evidence regarding any benefits in terms of improved patient outcomes (including mortality) during this period.[2] One recent study demonstrated lower mortality using radical prostatectomy versus watchful waiting in early-stage disease,[7] but evidence is otherwise weak or inconsistent from other trials, including those with long follow-up.

The lack of consistent or compelling evidence about early detection of prostate cancer showing an improvement in survivorship has not stopped numerous treatments from being rapidly diffused, including aggressive treatments in relatively young men. This is problematic in that aggressive treatments themselves have consequences. For example, after 18 months of follow-up, patients receiving radical prostatectomy in one study experienced significant erectile dysfunction (59.9%) and urinary incontinence (8.4%).[8] Other treatment alternatives result in co-morbidities affecting sexual and urinary function. If these patients experience a long survival period, they must face the psychosocial consequences of treatment-related adverse effects that might not have been necessary if their underlying disease was latent or extremely slow in progressing.

Whereas the increase in screening detects cancer early and at a *potentially* curable stage with aggressive treatment, it has also resulted in the overdiagnosis of latent disease and unnecessary biopsies for men with false-negative screening tests.[9] False positive screening has financial and psychological costs, with about half of men with suspicious screening test results and subsequent negative biopsies reporting worrying "a lot" or "some of the time" about prostate cancer.[10] For men with confirmed prostate cancer, those choosing either watchful waiting or aggressive intervention for early-stage disease must address the implications of their choices, which can result in anxiety, decreased activity level, decreased quality-of-life, adverse effects of treatment, etc. [11]

From an economic perspective, the value of a screening test can be determined by estimating the relative costs and benefits, where benefits of screening can be measured in terms of test performance, unnecessary biopsies, and/or formal cost-effectiveness analyses. Studies that evaluate prostate cancer screening focus primarily on the PSA test. One recent study found that complexed PSA (cPSA)[a] (threshold 2.2 ng/ml) was a better test than total PSA (tPSA) (2.5 ng/ml), with higher sensitivity and specificity and fewer unnecessary biopsies.[12] A cost-benefit study looking at five screening strategies found that cPSA (3.8 ng/ml) was dominant (more costly and less effective), with a threshold of 3.0 ng/ml identifying a similar number of cancers with fewer biopsies than tPSA (4.0 ng/ml).[13]

Using simulations including Markov modeling that simulate the progression of disease to determine the most efficient PSA screening algorithm, the benefits of prostate screening vary by age and were not recommended above age 70, where the competing risk of mortality outweighs the benefit.[14,15] In their Markov model, Ross and colleagues conclude that annual PSA screening (4.0 ng/ml threshold) starting at 50 years of age is dominant (i.e., more costly and less effective) by a biennial screening strategy after tests at 40 and 45 years of age.[16] Screening beyond age 70 required more treatments (and significant additional costs) per person-year of life saved.[14] A second computer model supports screening every two years (4.0 ng/ml threshold), which reduces false-positive and overdiagnosis rates sharply, while catching most cases relative to the more traditional annual screening without any age-specific thresholds.[17] Clearly, additional research to determine the best thresholds for PSA measures (tPSA, cPSA, PSA velocity,[b] etc.) and to determine the utility of other biomarkers in detecting aggressive prostate cancer is critical. If future screening tests can better distinguish latent disease from aggressive disease and minimize false positives, they offer great potential to lower unnecessary expenditures for prostate cancer.

The utility of prostate cancer screening and treatment will be debated for the foreseeable future, especially with the advent of new treatments and the absence of randomized clinical trials. The most common treatments, radiation and radical prostatectomy, might never be compared in a randomized trial for a variety or reasons. PSA is the only real biomarker available today to detect prostate cancer, and it is imperfect. Based on the current economic evidence, routine prostate cancer screening using PSA and subsequent treatment for early-stage disease do not appear to be cost-effective until improvement in patient outcomes, including

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[a] Complexed PSA is a test measuring the level of PSA that has been complexed or bound with a certain protein (alpha-1-antichymotrypsin) in a patient's blood sample.

[b] PSA velocity is the rate of change in the PSA level over time.

mortality, have been demonstrated. Methods calculating the expected value of perfect information (EPVI is a measure of the cost of making an incorrect decision due to uncertainty) should also be factored into decisions about prostate cancer screening.[18]

Despite its shortcomings, PSA will continue to be used to detect prostate cancer in the absence of a more accurate biomarker. Furthermore, we will continue to treat early-stage prostate cancer aggressively if a patient prefers this to watchful waiting. However, healthcare administrators might give more scrutiny to screening and treatment programs as costs continue to escalate with the aging of the population. With this increased scrutiny, cost containment might include a prostate cancer screening schedule tailored to individuals based on prognostic factors that are still being identified. **NCMedJ**

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SPECIAL DATA REPORT

Horse-Related Injuries and Deaths in North Carolina, 1995-1999

Doris M. Bixby-Hammett, MD

Nationally, accidents are the leading cause of death for those under 35 years of age and the fifth leading cause of death among all age groups.[1] Injuries are a serious public health problem, which takes a toll on the health of the population and imposes social and economic costs on society. If the medical community is to prevent injuries and deaths, each activity should be individually evaluated.

This data presented here are based on a study is of equestrian accidents in North Carolina resulting in injury or death. North Carolina has a horse population of 256,270 equines,[2] and many North Carolina citizens use horses for recreation and employment. There are an estimated 70,000 horseback riders in North Carolina. This study compared data from three sources for the years 1995 through 1999: the National Electronic Injury Surveillance System (NEISS)[3] (records for North Carolina), North Carolina Trauma Registry (NCTR),[4] and the North Carolina Medical Examiner's Database (NCME).[5] Records in the NCTR were selected with Ecodes indicating injuries caused by animals.

The age group at greatest risk for all injuries (NEISS), severe injuries (NCTR), and deaths (NCME) are equestrians between the ages of 25 and 44 years of age. Equestrians age 45-65 years are the second highest group at risk of injury. The largest percent of injuries among this age group can be seen in the NCME data, with smaller percentages in the NCTR and the NEISS data. It has been suggested that experience would decrease the number of accidents, but one would expect the equestrians age 25-64 years would have more experience in horse-related activities than younger equestrians.

Fractures represent the highest percent of injury type in the NEISS and NCTR data. The second most common injury in NEISS is contusion and abrasion, but in NCTR, it is laceration. Neurological head injury is the most common cause of death, the third most common injury in the NCTR data, and the fourth most common injury in the NEISS data.

Table 1.
Age Groups from NEISS, NCTR, and NCME Databases, 1995-1999

	NEISS (NC subset)		NC Trauma Registry		NC Medical Examiner	
Age	Count	Percent	Count	Percent	Count	Percent
0-4	2	0.5%	16	3.1%	3	12%
5-14	61	16.4%	68	13.3%	1	4%
15-24	59	15.8%	85	16.6%	1	4%
25-44	172	46.1%	211	41.2%	11	44%
45-64	70	18.8%	104	20.3%	7	28%
64+	9	2.4%	28	5.5%	2	8%
Unknown	0	0%	0	0%	0	0%
Total	373	100%	512	100%	25	100%

According to the NEISS data, the extremities are the most commonly injured body parts, while the NCTR and NCME data rank the head as the most commonly injured. The trunk ranks second in all three databases.

Conclusions

The North Carolina data correspond with national medical studies of horse-related activities in that head injury is the leading injury. Head injuries are the most severe of the injuries in North Carolina, causing 56% of all horse-related deaths. Head injuries can be prevented or reduced in severity by wearing properly fitted and secured American Society for Testing and Materials (ASTM) equestrian standard/Safety Equipment Institute (SEI) certification protective headgear. Other factors that can play a role in injury prevention include: horse selection at the level of the rider, horse and rider conditioning for the activity, instruction from a qualified teacher, no use of alcohol while riding, and proper attire for the activity.

Doris M. Bixby-Hammett, MD, is Board of Director emeritus of the American Medical Equestrian Association/Safe Riders Foundation and a past member and chairman of the Safety Committee, United States Pony Clubs. Dr. Bixby-Hammett lives in Asheville, NC and can be reached at dbhammett@yahoo.com or 828-285-2361.

Table 2.
Comparison of Diagnosis Categories from NEISS, NCTR, and NCME Databases, 1995-1999

	NEISS (NC subset)		NC Trauma Registry		NC Medical Examiner	
Injury Type	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**
Fracture	129	34.6%	428	35.5%	2	8.0%
Contusion/Abrasion	118	31.6%	75	6.2%	0	0%
Strain/Sprain	36	9.7%	14	1.2%	0	0%
Laceration	31	8.3%	188	15.6%	0	0%
Neurological Head	31	8.3%	160	13.3%	14	56%
Internal Injury	0	0%	153	12.7%	0	0%
Other	23	6.2%	89	7.4%	6	24%
Spine	0	0%	81	6.7%	2	8.0%
Dislocation	5	1.3%	18	1.5%	0	0%
Perinatal*	0	0%	0	0%	1	4.0%
Total	373	100%	1,206	100%	25	100%

* Mother was kicked by horse resulting in premature delivery and death of baby.

Table 3.
Injured Body Region from NEISS, NCTR, and NCME Databases, 1995-1999

	NEISS (NC subset)		NC Trauma Registry		NC Medical Examiner	
Injured Body Region	**Count**	**Percent**	**Count**	**Percent**	**Count**	**Percent**
Head (including brain and face)	68	18.2%	360	33.6%	14	56%
Trunk	109	29.2%	319	29.8%	6	24%
Extremity	186	49.9%	273	25.5%	0	0%
Spine	0	0.0%	81	7.6%	0	0%
Neck	9	2.4%	0	0	2	8.0%
25-50% of Body	1	0.3%	0	0	2	8.0%
Perinatal	0	0	0	0	1	4.0%
Unspecified	0	0	38	3.5%	0	0%
Total	373	100%	1,206	100%	25	100%

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Running the Numbers

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Recent Trends in Prostate Cancer in North Carolina

Prostate cancer is the most frequently diagnosed cancer in men in North Carolina and in the nation. The objectives of this analysis are to examine recent trends in prostate cancer incidence, mortality, and staging; to examine racial differences in incidence, mortality, and staging; and to compare North Carolina statistics to national data.

North Carolina incidence and mortality data were provided by the State Center for Health Statistics. Incidence rates (cases per 100,000 population) and mortality rates (deaths per 100,000 population) are presented. The rates were age-adjusted to the 2000 United States population by five-year age groups. The incidence and mortality rates were calculated as overlapping three-year rates. For comparison, national incidence (Surveillance Epidemiology and End Results Program, or SEER) and mortality rates (National Center for Health Statistics) are presented.

Figure 1.
Age-Adjusted Incidence Rate (per 100,000)

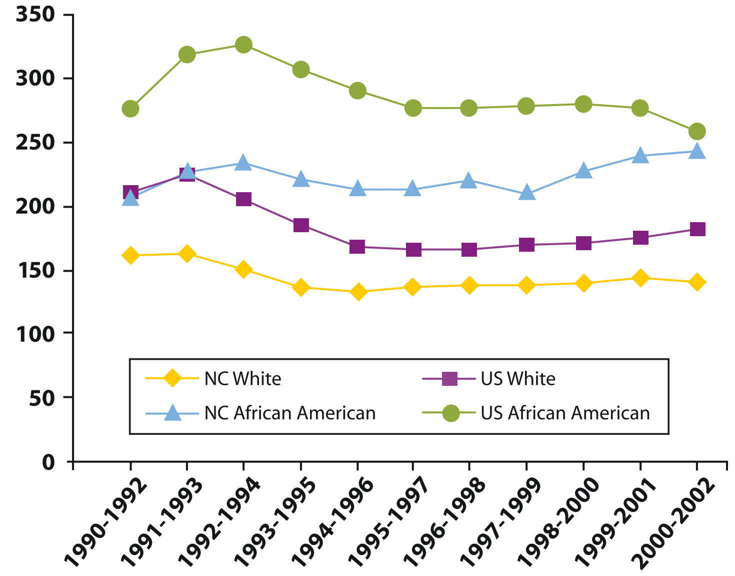
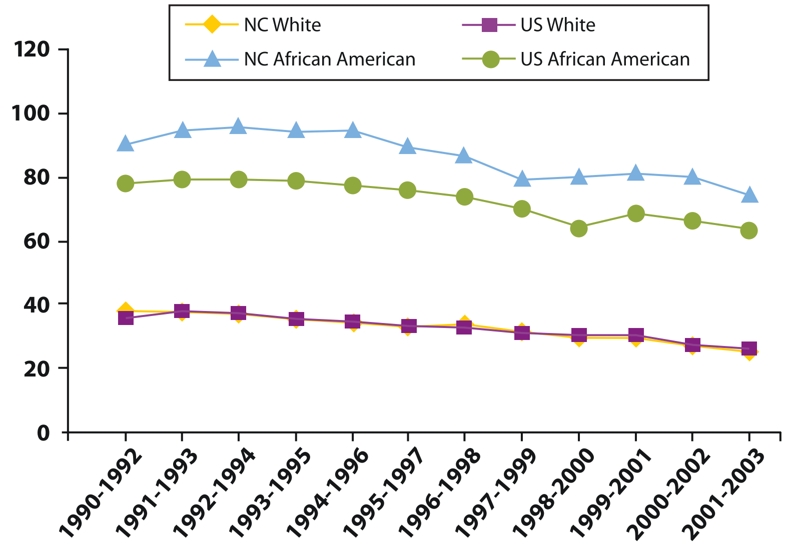


Figure 1 displays trends in prostate cancer incidence. In the last decade, the incidence of prostate cancer in North Carolina has been stable overall. Incidence rates in North Carolina for both whites and African Americans are lower than the SEER national rates. However, according to a second data source, the National Program of Cancer Registries, which includes most of the United States population and, therefore, is more representative of national rates than SEER, in 2002 only North Carolina whites and not North Carolina African Americans had an incidence rate statistically different from the respective national rate. In North Carolina, the incidence for African Americans is approximately 70% higher than for whites (during 2000-2002, 239 per 100,000 versus 139 per 100,000).

Figure 2 displays trends in prostate cancer mortality. In the last decade, North Carolina mortality rates have been declining. Overall, the North Carolina rate is higher than the national rate. Although whites in North Carolina have the same mortality rate as whites in the United States, African Americans in North Carolina have a higher mortality rate than African Americans in the United States. In North Carolina, the mortality rate for African Americans is almost three times as high as that for whites (during 2000-2002, 74 per 100,000 versus 25 per 100,000).

Figure 2.
Age-Adjusted Death Rate (per 100,000)



There are substantial differences in stage at diagnosis between whites and African Americans in North Carolina. Eighty-two percent of white men are diagnosed with local stage disease, compared to 74% of African Americans. These two groups are equally likely to be diagnosed with regional disease (9%), but African Americans are more likely to be diagnosed with distant disease (7% versus 3%) or for the stage to be unstaged or unknown (9% versus 5%). Later diagnosis contributes to higher mortality.

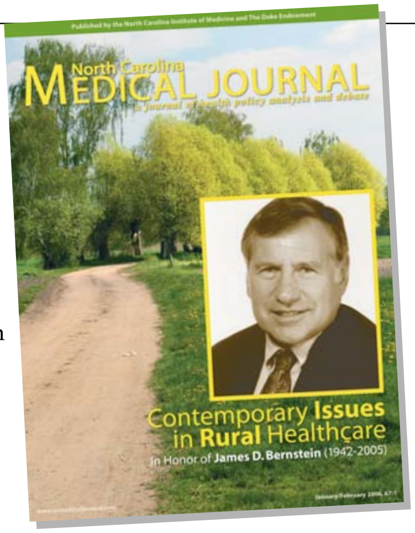
Interpretation of the incidence data is affected by the introduction and dissemination of prostate-specific antigen (PSA) testing. The advent of this diagnostic tool in the 1980s resulted in an overall increase in incidence rates, followed by a period of stability. Future changes in the use of PSA and other methods of diagnosis will impact trends and differences in the incidence data.

North Carolina African Americans have much higher prostate cancer incidence rates than whites, similar to the pattern seen at the national level. It is unlikely that differences in testing for prostate cancer contribute to this racial difference in incidence, since recent data from the Behavioral Risk Factor Surveillance System (BRFSS), a state-based telephone survey, suggest that North Carolina African Americans and whites have similar rates of PSA testing ever or in the last year.

Declining trends in prostate cancer mortality in North Carolina are encouraging and could be related to earlier detection of cancers by PSA testing or improvements in treatment. The three-fold disparity in mortality between whites and African Americans suggests differences in tumor biology, stage at diagnosis, access to healthcare, or treatment. The prostate cancer incidence rates in North Carolina are lower than those for the United States, while the mortality rates in North Carolina are higher overall than for the nation. This pattern could be due to differences between North Carolina and the nation in case reporting, stage at diagnosis, access to healthcare, or treatment.

Contributed by Deborah Porterfield, MD, MPH, Chronic Disease and Injury Section and
Karen Knight, MS, Central Cancer Registry, North Carolina Division of Public Health

Readers' Forum



To The Editor:

I have greatly enjoyed my issues of the *North Carolina Medical Journal*, but none more than the January/February 2006 issue that honored James Bernstein. He was a remarkable man, and I found Donald Madison's article, in particular, both moving and informative.

The mention in Don's article of the Global Community Health Fellows Program, the brainchild of Bill Stewart, MD, when he was serving as Surgeon General of the United States Public Health Service, brought back memories of that remarkable group of individuals who were selected for the program. My closest contacts among the fellows were Steve Joseph, MD, who later became Health Commissioner of New York City, the Dean of the School of Public Health at Minnesota, and the Assistant Secretary of Defense for Health and Medical/Department of Defense; Merve Silverman, MD, who later became Director of Public Health for the City and County of San Francisco and a national and international leader on HIV/AIDS; and Jim Brown, MD, who was the Director of Student Health Services at the University of California Berkley (UC Berkeley) and one of the founders of the Joint Medical Program at UC Berkeley and the University of California San Francisco. All remarkable individuals and contributors as was Jim Bernstein. Jim was what Tom Oliver and others have called "policy entrepreneurs" who could link problems to solutions to the political process, and do it effectively. That is a rare skill.

Leadership is something a lot of people write about, but few practice with the understanding that Jim had for all the elements of leadership. In Don's article, he describes what we might call "Bernstein's principles" on page 35. Very informative.

The January/February 2006 issue was special because of my high regard for Jim and because Don's article triggered so many thoughts about the evolution of rural health service over the past 40 years, including the critical role played by Jim and his colleagues in North Carolina.

Phillip R. Lee, MD
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Editor's Note: Dr. Lee served as Assistant Secretary for Health under both Presidents Lyndon Johnson and Bill Clinton

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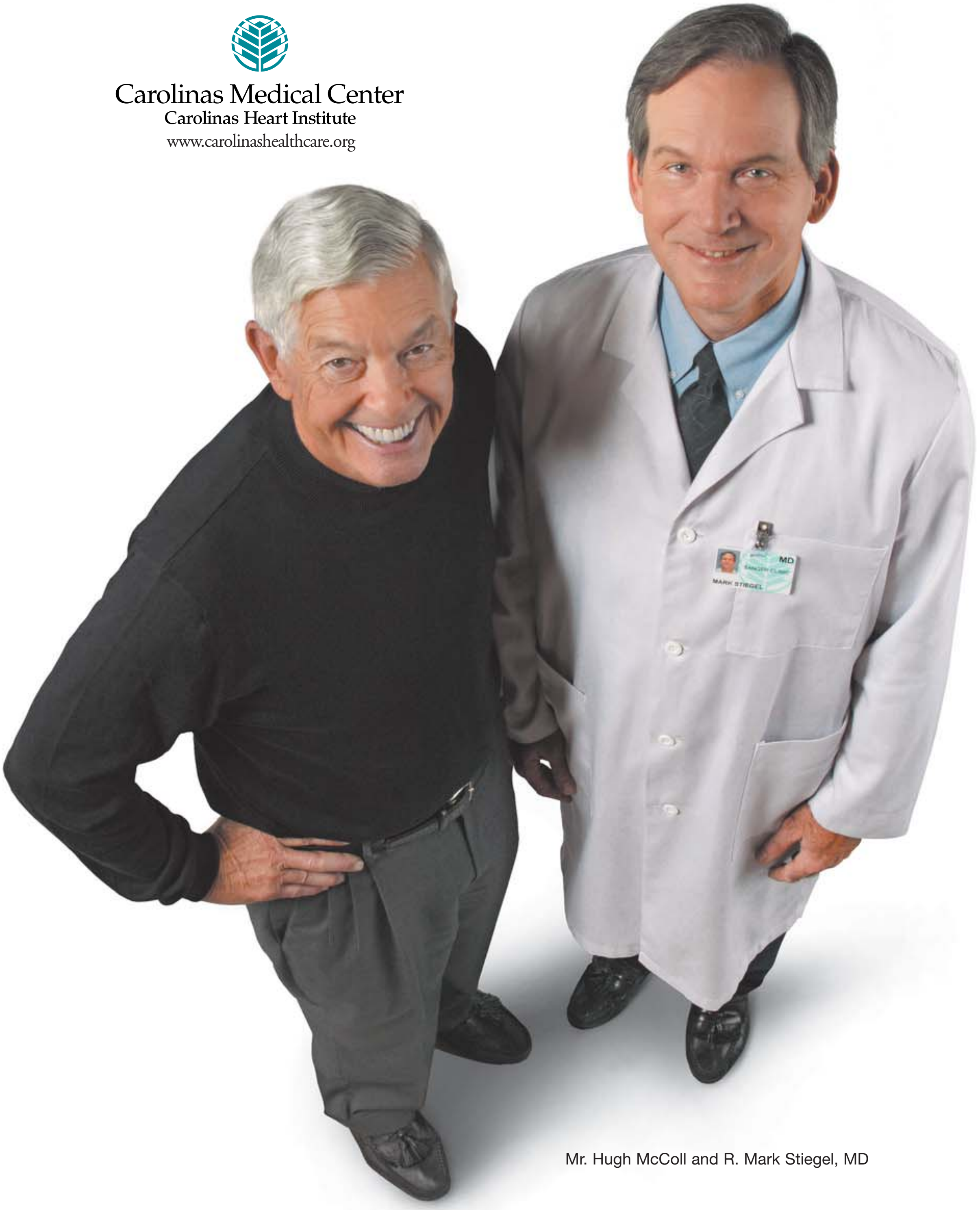

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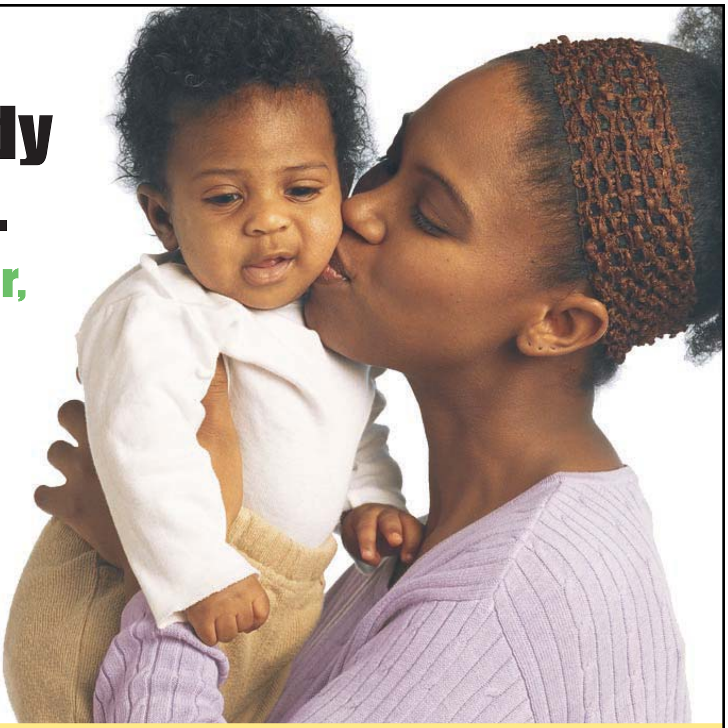

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ARTICLES

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> *"The uninsured delay needed healthcare services, and as a result, are more likely to be diagnosed with severe health problems. Those with chronic diseases are less likely to receive the care they need to control their conditions."*

Tarheel Footprints in Healthcare

Recognizing unusual and often unsung contributions of individual citizens who have made healthcare for North Carolinians more accessible and of higher quality

Recognizing Shirley Lucey and Virginia Scanlan and the Alice Aycock Poe Center for Health Education

Without the volunteer efforts of many of our state's citizens, North Carolina would not be the envy of so many others. Dozens of the wonderful programs and organizations for which this state is known sprang from the ideas, commitment, and determination of a few individuals who saw a need, convinced others of the feasibility of addressing it, and then led the effort to mobilize the resources to make a valuable initiative possible.

Such is the case with what is now known as the Alice Aycock Poe Center for Health Education in Raleigh, a statewide non-profit organization whose mission is to provide comprehensive programs and resources in healthy lifestyle education for all youth in North Carolina. This wonderful facility offers on-site instruction to more than 5,500 school-age participants each year, coming from many school districts throughout North Carolina. The Poe Center's theatre-style instructional programs are delivered by master teachers to classes of students from across the state who come to the Center for periods of a few hours or a whole instructional day. Classes are conducted in model classrooms, which are exceptionally well-equipped as teaching theaters dealing with: general health, nutrition, physical activity, dental health, drug education, and family life and reproductive health.

The Poe Center was first imagined as filling a need in the Wake County Schools, initially as an exhibit at the old North Carolina Museum of Natural History funded by the Wake County Medical Society Auxiliary. When the new museum was built, space for a health-focused exhibit was limited so members of the Auxiliary started exploring other educational program possibilities. Leaders of the organization decided to visit eight-to-ten free-standing health education centers around the nation to see how these facilities and programs operated and whether this idea might be feasible in central North Carolina. The result was a decision to start raising funds to construct a multi-classroom teaching facility, which could become a resource for all schools and school systems in North Carolina, thus extending the impact of regular classroom instruction on matters related to health and enlivening the content and presentation style associated with this information.

The two individuals who took primary responsibility for conceptualizing the Poe Center's program and for raising the funds to support its implementation, including its physical construction, were **Shirley Lucey** and **Virginia Scanlan**, who served as President of the Board of Directors of the Poe Center in 1987-1988 and 1988-1989, respectively. Ms. Lucey and Ms. Scanlan organized teams of their Wake County Medical Auxiliary colleagues in 1990 to approach dozens of corporate and individual donors, and they worked with area school systems to develop contracts with the Poe Center for the instructional programming that would be offered. Their efforts raised the $3.5 million necessary to build this fabulous teaching/learning facility and are a tribute to their dedication and determination. "Once the first $100,000 was raised, there was no turning back," Virginia Scalan recently recalled. Most of the counties in central North Carolina and beyond have benefited from their efforts as the Poe Center has taken shape. Today, the Poe Center offers programs of instruction for students from some 25 school systems throughout North Carolina, as well as special programs of teacher training, educational programs focused on specific disease and public health issues (e.g., breast cancer, family life, adolescent health, substance abuse, dental health), and active summer programs for children from preschool to age ten. Shirley Lucey recently gave credit to the physician members of the Wake County Medical Society, who collectively donated $1 million of the total cost of building this facility. The footprints of these leading Tarheel volunteers have made a deep impression on the lives and health of North Carolina's children.

Shirley Lucey (left) and Virginia Scanlan (right) inside the Alice Aycock Poe Center for Health Education

ARTICLE

Support for Tobacco Control Policies among Youth in North Carolina

Elizabeth Conlisk, PhD, Scott K. Proescholdbell, MPH, and William K.Y. Pan, DrPH

Abstract

Background: *The objective of this research was to examine attitudes toward tobacco control policies among middle and high school students in North Carolina. Specifically, we report data on knowledge of the harmfulness of secondhand smoke and support for restaurant and school-based smoking restrictions.*

Methods: *The statewide North Carolina Youth Tobacco Survey was administered to a representative sample of 3,073 middle school and 3,261 high school students in the fall of 2003. The overall response rate for the middle and high school samples was 77.0% and 77.4%, respectively. Support for tobacco policies was analyzed by smoking status and by knowledge of the harmfulness of secondhand smoke*

Results: *The vast majority of respondents in the middle school (87.6%) and high school (91.6%) reported that secondhand smoke was "definitely" or "probably" harmful. However, less than half of middle school (48.6%) and high school (40.2%) students responded that smoking should be banned in restaurants. Even among the select group of students who had never smoked and who believed secondhand smoke was harmful, support for such a ban was less than 60% at both school levels.*

Conclusions: *Youth in North Carolina are aware of the health risks of secondhand smoke, but are not convinced of the need to restrict smoking in restaurants. These results point to the need for more youth-focused advocacy and education around smoking restrictions, both to reduce youth exposure to secondhand smoke and to solidify voter support for such protections once they reach adulthood.*

Key words: *youth, tobacco control, smoking restrictions.*

Introduction

Over the past 20 years, exposure to secondhand smoke (SHS) has been associated with an increased risk of lung cancer, heart disease, and respiratory ailments in non-smokers and has been estimated to cause approximately 3,000 lung cancer deaths and 35,000 heart disease deaths in adult non-smokers in the United States each year.[1,2] In addition, SHS has been associated with adverse infant outcomes, such as low birth weight and Sudden Infant Death Syndrome, as well as childhood asthma and middle ear infections.[3] As awareness of the health risks of SHS has increased, so has support for policies that restrict smoking in public places such as restaurants, where SHS levels have been found to be two-to-five times higher than levels in the homes of smokers.[4] From 1992 to 1999, support for smoking bans in restaurants increased from 37.5% to 59.8% among adults in Massachusetts.[5] Unfortunately, not all states show majority support for such bans. A recent report compared the results of 20 statewide surveys on attitudes toward tobacco control policies in 2000.[6] In four of those states, less than half of the respondents favored policies to ban smoking in restaurants; support was lowest in North Carolina (44%), the largest tobacco producing state in the country.

As opposed to most adults, today's adolescents are growing up in an era when the risks of SHS are well established and smoking restrictions are not uncommon. Even in North Carolina, local smoking regulations were hotly debated and adopted in more than 100 municipalities/counties before a statewide preemption bill went into effect in 1993.[7] In addition, North Carolina has an active tobacco education and prevention

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program in the schools, and more than 80% of middle and high school students responded that SHS was harmful to non-smokers in a 1999 survey.[8] However, it is unclear whether that knowledge translates into stronger support for smoking restrictions among adolescents and whether they might be expected to solidify public support as they come into adulthood.

To our knowledge, few studies have examined attitudes toward tobacco control policies among youth,[9-12] and only two have examined support for smoking bans in restaurants. Albers et al.[11] reported that support for restaurant bans among Massachusetts youth in 2001-2002 ranged between 53% and 61%, depending on the strength of local restrictions on smoking in restaurants. Support was similar among adolescents in metropolitan Ohio, with 56% agreeing that smoking should not be allowed in restaurants without bars.[12] Our report adds to these findings by examining knowledge of SHS risk and support for restaurant bans among middle and high school students in North Carolina where there is relatively low adult support. As support for restaurant bans has been shown to vary by smoking status in adults[8] and youth,[11] data will be reported separately for current smokers and those who have never smoked. Support will also be analyzed by knowledge of the harmfulness of SHS, an analysis not previously reported.

Methods

Data were collected through the school-based North Carolina Youth Tobacco Survey (YTS) in the fall of 2003. Details of the YTS methodology used nationally have been described elsewhere.[13] In brief, the North Carolina Youth Tobacco Survey used a two-stage cluster sample design to produce a representative sample of public middle school (grades 6-to-8) and high school (grades 9-to-12) students. Sampling was stratified by region to assure a balanced representation of schools from the coastal, piedmont, and mountain areas.

The first-stage sampling frame consisted of all public schools (including charter schools) that included at least one grade between 6 and 12. Schools were selected with a probability proportional to school enrollment size. The second sampling stage consisted of systematic equal probability sampling of second-period classes in each school sampled. An average of three second-period classes was sampled per school. All students in the sampled classes were eligible to participate in the survey except those who are routinely exempt from written tests because of language or learning barriers. Participation was voluntary and anonymous, and school procedures for parental permission were followed. The overall response rate for the middle and high school samples was 77.0% and 77.4%, respectively. Non-participation was primarily due to absenteeism. The final sample included 3,073 students from 104 middle schools and 3,261 students from 96 high schools.

The self-administered, 78-item questionnaire included questions on tobacco use, SHS, and attitudes toward tobacco policies. The specific questions asked about SHS are given at the bottom of Table 1. Responses are reported for the total sample and for two subgroups defined by smoking status: current smokers and never smokers. Respondents who reported smoking within the past 30 days were classified as current smokers. Respondents who reported having never smoked a cigarette were classified as never smokers. The comparison of current versus never smokers intentionally omits former smokers to heighten the contrast based on smoking status; hence the number of current smokers and never smokers will be less than the totals reported in the table. All percentages reported are weighted to reflect the likelihood of sampling each student and to compensate for differing patterns of non-response. SUDAAN was used to compute variance estimates and 95% confidence intervals.[14]

Results

Among middle school students, 9.3% (95% CI 7.7 to 10.9) were classified as current smokers and 70.5% (95% CI 66.5 to 74.5) as never smokers. Among high school students, 27.3% (95% CI 24.0 to 30.6) were classified as current smokers and 40.4% (95% CI 36.3 to 44.5) as never smokers.

Middle school students were slightly less likely than high school students to believe that SHS was harmful, although the percentage for both groups was quite high, 87.6% (95% CI 85.3 to 89.9), and 91.6% (95% CI 90.0 to 93.2), respectively) (see Table 1). Current smokers were less likely than never smokers to respond that SHS was harmful, but the percentage that did was still high for both middle school (83.1%, 95% CI 77.3%, 88.9) and high school (85.1%, 95% CI 81.4 to 88.8) students. Less than half of middle school (48.6%, 95% CI 45.8 to 51.4) and high school (40.2%, 95% CI 37.0 to 43.4) students responded that smoking should be banned in restaurants. Support for smoke-free restaurants was much higher among those who had never smoked compared to current smokers: 55.4% (95% CI 51.4 to 58.4) vs. 22.6% (95% CI 15.0 to 30.2) at the middle school level and 58.8% (95% CI 55.0 to 62.6) versus 16.1% (95% CI 11.6 to 20.6) at the high school level. Similar data and trends were observed for the question on personal preference for smoke-free space. Support was much higher for the adoption of tobacco-free policy at schools—91.8% (95% CI 90.4 to 93.2) of middle school students and 75.5% (95% CI 72.5 to 78.5) of high school students favored such policies. Even among current smokers, there was majority support for tobacco-free school policies in both the middle schools (68.8%, 95% CI 60.6 to 77.0) and high schools (51.1%, 95% CI 55.6 to 56.6).

Support for tobacco control policies among never smokers tended to be higher among students who believed SHS was harmful (see Table 2). Still, support for smoking bans in restaurants at the middle or high school level never reached 60%, even among the select group of students who had never smoked and who believed SHS was harmful. Similarly, only 61.4% (95% CI 57.9 to 64.9) (middle school) and 54.2% (95% CI 50.1 to 58.3) (high school) of this select group stated that they preferred to eat in smoke-free restaurants. In contrast, support for tobacco-free schools was considerably higher in this group—96.6% (95% CI 95.6 to 97.6) and 89.7 (95% CI 86.3 to 93.1) for the middle and high school, respectively. Among current smokers,

Table 1.
Knowledge of the Harmfulness of Secondhand Smoke (SHS) and Support for Tobacco Control Policies among Middle and High School Students, North Carolina, 2003

		Middle School		High School	
		n	% (95% CI)	n	% (95% CI)
Believe SHS is harmful[1]	All*	2,934	87.6 (±2.3)	3,211	91.6 (±1.6)
	Current smokers	268	83.1 (±5.8)	861	85.1 (±3.7)
	Never smokers	1,927	88.6 (±2.6)	1,226	95.5 (±1.8)
Think smoking should be banned in restaurants[2]	All	2,901	48.6 (±2.8)	3,191	40.2 (±3.2)
	Current smokers	269	22.6 (±7.3)	854	16.1 (±4.5)
	Never smokers	1,896	55.4 (±3.0)	1224	58.8 (±3.8)
Prefer smoke-free restaurants[3]	All	2,882	53.0 (±3.1)	3,169	39.5 (±2.3)
	Current smokers	271	23.6 (±7.8)	851	18.9 (±4.2)
	Never smokers	1,874	60.0 (±3.6)	1,212	53.3 (±3.8)
Think it is important for school to be 100% tobacco-free[4,5]	All	2,547	91.8 (±1.4)	2,735	75.5 (±3.0)
	Current smokers	226	68.8 (±8.2)	726	51.1 (±5.5)
	Never smokers	1,679	95.9 (±1.0)	1,040	89.3 (±3.3)

1 Responded "Definitely yes" or "Probably yes" to the question "Do you believe the smoke from other people's cigarettes is harmful to you?"

2 Responded "Not allowed at all" to the question "In restaurants, to what extent do you think that smoking should be allowed?"

3 Responded "I prefer places where no smoking is allowed" to the question "When you go out to a place with your friends and family, what smoking policy do you prefer?"

4 Responded "Very important" or "Somewhat important" to the question "In your opinion, how important is it that your school district adopt a "100% tobacco-free school policy?"

5 Students who responded that their district was already 100% tobacco-free were omitted from the analysis.

The data collection protocol was approved by the Centers for Disease Control and Prevention and the research protocol was approved by the institutional review board at Hampshire College.

* All includes current, former, and never smokers. Details are only given for current and never smokers.

support for tobacco control policies was associated with SHS knowledge at the middle school level, but the confidence intervals were quite wide. Among current smokers at the high school level, knowledge appeared to have little impact on support for tobacco control policies.

Discussion

This paper is the first to examine support for restaurant- and school-based tobacco control policies among youth in a major tobacco-growing state. The results are mixed. Knowledge is high, with approximately nine of ten middle and high school students reporting that SHS is harmful to non-smokers. These results are comparable to those reported in the 2000 National Youth Tobacco Survey,[12] suggesting that North Carolina youth are as informed about the risks of SHS as youth nationally. Also, approximately nine of ten middle school students and three of four high school students supported the adoption of a 100% tobacco-free policy in their school districts. This latter analysis excluded the 11% (middle school) and 14% (high school) of students who responded that their district had already adopted such a policy, districts that presumably are more supportive of tobacco control measures in schools. Hence, the overall support for such a policy is probably even greater.

Support for bans on smoking in restaurants, however, was much less common. Less than half of students supported such bans, and support was no greater than that reported by North Carolina adults surveyed in 2000 (44%).[6] It is unclear why support among youth is not greater, given the high awareness

Table 2.
Support for Tobacco Control Policies among Middle and High School Students, by Knowledge of the Harmfulness of Secondhand Smoke, North Carolina, 2003

		Middle School				High School			
		Believes SHS is harmful[1]		Does not believe SHS is harmful		Believes SHS is harmful[1]		Does not believe SHS is harmful	
		n	% (95% CI)	n	% (95% CI)	n	% (95% CI)	n	% (95% CI)
Think smoking should be banned in restaurants[2]	All*	2,541	50.7 (±3.1)	342	34.1 (5.7)	2,905	41.8 (3.0)	263	23.9 (9.6)
	Current smokers	207	25.0 (±8.3)	56	12.5 (±9.9)	714	16.7 (±5.1)	126	13.1 (±8.2)
	Never smokers	1,703	57.2 (±3.7)	191	40.7 (±8.6)	1,165	59.8 (±4.2)	55	40.7 (±21.2)
Prefer smoke-free restaurants[3]	All	2,521	54.4 (±3.2)	344	43.8 (±7.3)	2,889	40.7 (±2.6)	261	27.0 (±7.2)
	Current smokers	208	24.1 (±9.8)	57	24.4 (±18.0)	712	19.6 (±4.8)	127	15.4 (±8.7)
	Never smokers	1,682	61.4 (±3.5)	190	48.8 (±8.7)	1,155	54.2 (±4.1)	54	34.1 (±23.2)
Think it is important for school to be 100% tobacco-free[4,5]	All	2,239	93.6 (±1.4)	289	80.3 (±5.2)	2,487	77.0 (±3.0)	229	60.0 (±7.2)
	Current smokers	170	72.7 (±8.5)	50	52.0 (±19.6)	603	51.8 (±6.0)	112	48.6 (±10.6)
	Never smokers	1,513	96.6 (±1.0)	163	89.7 (±5.5)	993	89.7 (±3.4)	44	78.5 (±15.3)

1 Responded "Definitely yes" or "Probably yes" to the question "Do you believe the smoke from other people's cigarettes is harmful to you?"

2 Responded "Not allowed at all" to the question "In restaurants, to what extent do you think that smoking should be allowed?"

3 Responded "I prefer places where no smoking is allowed" to the question "When you go out to a place with your friends and family, what smoking policy do you prefer?"

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of the risks of SHS and strong support for tobacco-free policies in schools (policies which are actually more restrictive as they apply to all tobacco use, and not just cigarettes). This apparent inconsistency could be due to a number of factors. Perhaps youth are aware of the risks of SHS, but do not perceive these risks as serious. Similarly, youth might view restaurants, unlike schools, as voluntary, short-term exposures and not as daily worksites for restaurant staff. Thus, they might not see the need for government regulation of what appears to be a voluntary risk.

It is also possible that these attitudes reflect the hard work of the school-based tobacco control programs, which have focused their advocacy work on the adoption of tobacco-free policies in school districts. These efforts appear to have been successful, both in the overwhelming support among youth for such policies and the tripling of tobacco-free school districts in the past two years—from 15 at the start of 2003 to 45 by the end of 2004. In contrast, less emphasis has been placed thus far on tobacco use in public places, such as restaurants. The results here point to the need for school-based advocacy around this issue as well, both in reducing youth exposure to SHS and helping to solidify voter support for such protections once they reach adulthood.

The percentage of students who prefer to patronize smoke-free restaurants is not much higher than those who support bans. Even among never smokers who are aware of SHS risks, only a modest majority prefers smoke-free space. As with tobacco use itself, knowledge is not sufficient for avoiding risk. This finding supports the innovative work of Albers et al., who examined the acceptability of smoking in restaurants to youth in Massachusetts relative to social norms, as measured by community-level smoking restrictions.[11] While the relationship between acceptability and community-level restrictions was not statistically significant, it was in the hypothesized inverse direction (acceptability declined as restrictions increased), which underscores the importance of social norms in both research and advocacy education at the school level. In this research, we attempted to examine support for tobacco control policies by tobacco-free school status; however, too few districts had implemented such policies at the time of this survey for a meaningful analysis. As we continue tracking support for tobacco control policies in the biannual YTS in North Carolina, we will broaden our analysis to include information about community-level norms as reflected by school-based policies. In tobacco-producing states such as North Carolina, analysis and policy may further benefit from the use of geographic mapping software to target interventions where tobacco use is high. We also encourage the Youth Tobacco Survey coordinators in other states to add questions on tobacco control policies so that such policies can be tracked and responded to nationally. **NCMedJ**

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North Carolina MEDICAL JOURNAL

POLICY FORUM
Covering the Uninsured

COMMENTARIES

> *"Most of the increase in the uninsured is due to the drop in employer-sponsored insurance. North Carolina experienced a greater loss in employer-sponsored insurance than other states."*

INTRODUCTION

Policy Forum:
Covering the Uninsured

More than 1.3 million North Carolinians have no health insurance, and these numbers are growing more rapidly in our state than in other states. As a result, the overall health of North Carolina suffers—the uninsured experience poorer health and miss more days of work and school; our healthcare institutions face financial strain; and those with insurance pay higher health insurance premiums as costs are shifted. Who are these people—the uninsured? Some may be surprised to learn that 78% of them work full-time jobs or live in a family where at least one person has a full-time job. Not surprising is that many people without insurance have incomes below 200% of the federal poverty guidelines.

To address this problem, the North Carolina Institute of Medicine, in collaboration with the North Carolina Department of Health and Human Services (NC DHHS), the North Carolina Department of Insurance, and the Cecil G. Sheps Center for Health Services Research at the University of North Carolina at Chapel Hill, convened a Task Force to study options that would expand health insurance coverage to more North Carolinians. They released their report and recommendations in April 2006. In this issue of the Journal, we highlight some of Task Force's work and provide further discussion through commentaries written by some of the Task Force members and other stakeholders.

The commentaries examine issues faced by: small employers providing health insurance coverage; physicians, dentists, and hospitals providing care to the uninsured, and state government officials who regulate the insurance industry and provide public health insurance via Medicaid. We also include discussions on why healthcare costs are increasing, strategies for controlling these costs, strategies for promoting legislative change, policy options for small employers and high-risk pools, and how the problem of lack of insurance manifests itself among our state's growing Latino population.

The Task Force was chaired by Carmen Hooker Odom, Secretary of the NC DHHS, and Thomas Lambeth, former Executive Director of the Z. Smith Reynolds Foundation. Under their leadership, the Task Force realized it could not develop a plan that would provide coverage for all who needed it, but believed a multi-pronged approach could be developed to help large numbers of the uninsured. They were further guided by the belief that everyone in North Carolina will benefit if more people have health insurance coverage. As more people gain health insurance coverage, they also gain needed access to healthcare and better health. Having healthier citizens in our state will lead to lower healthcare costs and insurance premiums, higher worker productivity, better school attendance, financially more secure healthcare institutions, and, ultimately, a stronger economic future. Ideally, all North Carolinians should have health insurance that meets their basic healthcare needs, but until this is possible, the recommendations found in the Task Force report would help expand coverage to thousands.

We hope this issue of the Journal helps bring greater understanding to a complex and painful problem for our state. North Carolina is fortunate to have a group of stakeholders willing to work together toward a solution. The collaborative efforts of this Task Force increase the likelihood for change and provide hope for new policy and a healthier North Carolina.

Gordon H. DeFriese, PhD
Editor-in-Chief

Kristie W. Thompson, MA
Managing Editor

ISSUE BRIEF

North Carolina's Uninsured

Pam Silberman, JD, DrPH, Carmen Hooker Odom, MRP, Thomas Lambeth, G. Mark Holmes, PhD, and Kristen L. Dubay, MPP

Most people in the United States have health insurance coverage through their employers. More than 61% of the non-elderly in this state have employer-sponsored insurance (ESI). The connection between health insurance coverage and employment dates back to World War II, when Congress passed the Labor Stabilization Act (1942), which restricted employers from offering wage increases to attract workers. The Act restricted wage increases, but did not limit the use of non-wage benefits. As a result, many employers began offering health insurance as a means of competing for scarce workers. The connection between employment and health insurance coverage was solidified in 1954, when the Internal Revenue Service ruled that employer contributions to health benefits plans were non-taxable benefits to employees. Health insurance purchased outside an employer-based system has never been afforded the same tax advantage.

> *"Workers who are in poor health are less productive, children who are sick miss more days of school, and the growing numbers of uninsured are creating an economic strain on the healthcare institutions that care for everyone."*

While most people obtain health insurance coverage through their employers, this connection has grown more tenuous in recent years. The percentage of non-elderly people with employer-sponsored insurance declined by nine percentage points in North Carolina, from 67.6% (in 1999-2000) to 61.5% (2003-2004). Nationally, there was only a six percentage point decline in employer-sponsored insurance in the same period, from 67.6% to 63.3%.[1] At the same time, there has been a 15% increase in the percentage of people with public coverage in North Carolina (from 17.3% in 1999-2000 to 20% in 2003-04), but this increase has not been sufficient to offset the loss of employer-sponsored insurance. The percentage of people with private, non-group coverage has remained relatively constant over the years.

The decline in employment-based coverage has led to a sharp growth in the numbers and percentage of uninsured. Since 1999-2000, the percentage of North Carolinians without health insurance coverage increased 15%, compared to a 10%

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increase nationally. This growth in both the number and percentage of uninsured is not part of the normal ebb and flow of insurance coverage. In 2003, North Carolina experienced the largest increase in both the numbers and percentage of people without coverage in any five-year period in the state's history since 1992. The year 2004 saw a slight rebound in the percent who were uninsured, but in general, there is still an upward trend in the percentage of people without coverage. In 2003-2004, approximately one out of every six people under the age of 65, or 1.3 million people, lacked health insurance coverage in North Carolina. While this problem is not unique to North Carolina, our state appears to have been disproportionately affected by the loss of coverage. The percentage of the state's population without health insurance has grown more rapidly in North Carolina than in most of the other states in the country.

There have been many reasons posited to explain this large increase in the numbers of North Carolina's uninsured. Studies show that the primary reason for the increase in the numbers of uninsured is rising health insurance premiums.[2] The downturn in the economy during the early part of this decade also contributed to the increase in the numbers of uninsured.[3] Extensive job losses in manufacturing and the simultaneous growth in the service sector have contributed to this problem. Regardless of the reason, North Carolina is now faced with more than a million people who lack insurance coverage.

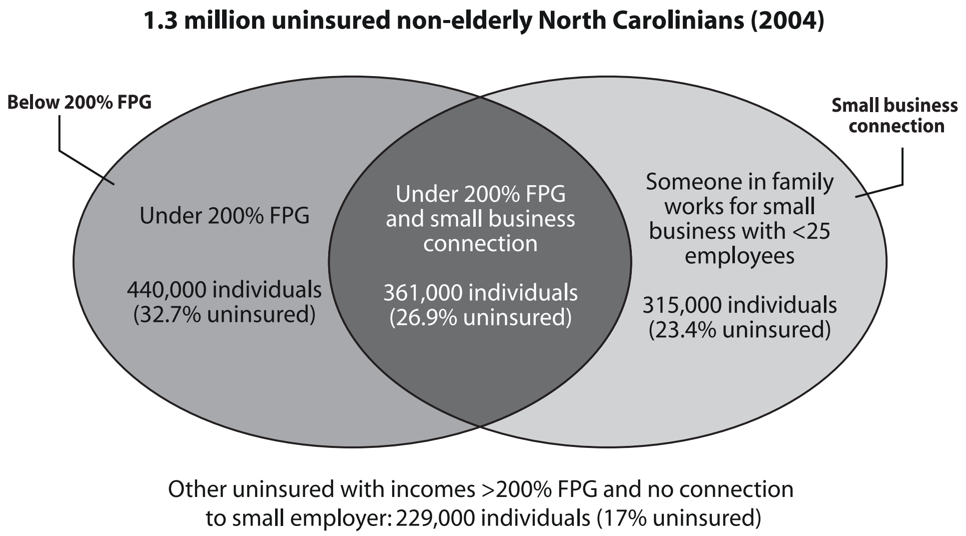
People who lack insurance coverage have a harder time obtaining needed healthcare, and as a consequence, their health suffers. But the rising numbers of uninsured have broader societal implications. Workers who are in poor health are less productive, children who are sick miss more days of school, and the growing numbers of uninsured are creating an economic strain on the healthcare institutions that care for everyone.

In 2004, the North Carolina Department of Health and Human Services (NC DHHS) obtained a State Planning Grant from the United States Department of Health and Human Services, Health Resources and Services Administration to analyze the numbers of uninsured and develop policy options to address this problem. In this effort, the NC DHHS partnered with the North Carolina Department of Insurance (NC DOI), the Cecil G. Sheps Center for Health Services Research at the University of North Carolina at Chapel Hill, and the North Carolina Institute of Medicine (NC IOM). As part of the State Planning Grant project, the NC IOM convened a task force to examine options to expand health insurance coverage to the uninsured. This issue brief describes the findings as well as some of the policy options considered by the Task Force. First, the issue brief describes the uninsured and the health consequences from lacking health insurance coverage. The issue brief also presents some of the reasons for rising healthcare costs and concludes with several options to expand coverage and healthcare services to the uninsured.

The Demographics of the Uninsured

In many ways, the uninsured are a microcosm of the state's population. They include workers and the unemployed; wealthy and low-income individuals; and men, women, and children of all races, ethnicities, and ages. Yet, while the uninsured are a broad cross-section of the state's population, there are certain groups that are more likely than others to be uninsured. More than four fifths (83%) of the uninsured fall into one or both of two groups: (1) those having someone in the family working for a small employer (an employer with 25 or fewer workers) or (2) those having a family income less than 200% of the federal poverty guidelines (FPG).[1]

Figure 1.
Uninsured in North Carolina: Primarily Those with Low Income or Employees of Small Firms



A common misperception about why people lack insurance coverage is because they do not work or have no connection to the workforce. In fact, more than three fourths (78%) of the uninsured are in families where someone is working full time, and one third (33%) are in families where two people are working full time. The size of a person's employer workforce is a major determinant of whether or not a person has health insurance coverage. Small firms, particularly those with fewer than ten employees, are far less likely to offer insurance than larger employers (see Table 1). Approximately half (55.3%) of the uninsured, or 776,000 North Carolinians, are employed by or in a family with someone who works for a small firm (with fewer than 25 employees). Connie Majure-Rhett and Kristen Dubay provide further insight into the

Table 1.
Percent of Firms that Offer Health Insurance, by Size of Firm (2002-2003)

Size of Employer	NC	US
Total	53.6%	56.7%
<10 employees	29.4%	36.2%
10-24 employees	67.5%	67.0%
25-99 employees	79.3%	81.7%
100-999 employees	99.3%	94.5%
1000+ employees	98.9%	98.7%

Source: Agency for Healthcare Research and Quality. Center for Financing, Access and Cost Trends. 2003 and 2002 Medical Expenditure Panel Survey – Insurance Component. Table II.A.3.

problems that small employers have in paying for health insurance in their commentary in this issue of the Journal.[4] The type of industry also impacts on insurance coverage as certain industries—particularly construction and agriculture—are less likely than other industries to offer health insurance.

Almost 60% of the uninsured, or 801,000 North Carolinians, have family incomes below 200% FPG, or $38,700 for a family of four in 2005.[5] While most of these individuals are workers, they are less likely than those with higher incomes to work full time, and they are more likely to work in industries that have lower rates of insurance coverage. Even if they are offered coverage, the employees' share of the cost may be too burdensome. The average total cost for employer-sponsored insurance in North Carolina was more than $3,200 per year for an individual employee and $8,200 for family coverage in 2002-2003.[a] The average employee-share of health insurance premiums in North Carolina was $558 for individual coverage and $2,200 for family coverage. Based on these figures, the average employee premium costs for a family living in poverty would be 12% of their gross income, or 6% for a family living at 200% FPG, not including other out-of-pocket expenses, such as deductibles, coinsurance, or copayments. Health insurance premiums are generally more expensive in the non-group market for similar coverage. Thus, individuals who do not have access to employer-sponsored insurance may have to spend more money if they try to purchase a comprehensive policy directly from an insurer. Adam Searing, Project Director of the North Carolina Healthcare Access Coalition, a consumer advocacy group, describes a research-based approach to effective policy advocacy on behalf on the uninsured population later in this issue of the Journal.[6]

In addition to those who have low incomes or work for a small employer, there are other groups that are more likely than the general public to lack insurance coverage. Racial and ethnic minorities have a much greater likelihood of being uninsured than do whites. Approximately 14% of white, non-Latinos are uninsured, compared to 18% of black, non-Latinos and 54% of Latinos. Many people believe that the growth in the Latino population has driven the rise in the uninsured in North Carolina. However, it is generally not the growth in the Latino population—or any racial or ethnic group per se—that drives our uninsurance rates; it is their relatively low income and access to employer-sponsored insurance or public coverage. This subject is more thoroughly discussed by Dr. Holmes in a commentary on page 202 of this issue of the Journal.[7]

Other groups that have a greater likelihood of being uninsured include young adults and those living in rural areas. Young adults ages 18-34 are more likely than those who are older or younger to lack coverage. Approximately 29% of young adults lack coverage, compared to 11% of children under age 18, 15% of those age 35-64, and less than 1% of those age 65 or older. Children are less likely to be uninsured than most adults because they have greater access to publicly subsidized insurance (either Medicaid or North Carolina Health Choice).

People living in rural areas are also disproportionately more likely to be uninsured than those living in urban areas (21% versus 17%, respectively). Given that the uninsured rate varies considerably by age, industry, firm size, and rurality, it is no surprise that the uninsured rate varies markedly across North Carolina. The Running the Numbers section of this issue includes county-level data on the uninsured. The county with the lowest uninsured rate in 2004 was Wake (13.9%), and the county with the highest (Tyrrell) had over double this rate at 28.3%. The demographic and socioeconomic characteristics of the county's population have considerable influence on the likelihood of residents to lack health insurance (see page 235).[8]

Health Effects of Being Uninsured

The uninsured are more likely to report being in fair or poor health, but are less likely to receive needed healthcare services. A rich body of research literature documents the adverse health impact from lacking insurance coverage. The Institute of Medicine of the National Academies did a meta analysis of research studies analyzing the impact of being uninsured (2002),[9] as did Jack Hadley for the Kaiser Commission on Medicaid and the Uninsured.[10] In addition, we have North Carolina-specific data that document the impact of being uninsured on access to health services and avoidable hospitalizations.

Uninsured North Carolinians are much more likely than people with insurance coverage to report healthcare access barriers. The State Center for Health Statistics, within the NC DHHS,

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[a] The full cost of employer-sponsored insurance—absent any employer contribution—would constitute 36% of the gross income of an individual living in poverty for individual coverage and 18% for a person living at 200% FPG. For a family of four living in poverty, the total cost of employer-sponsored insurance for a family would constitute 45% of their gross income, 22.5% for a family of four living at 200% FPG.

[b] The BRFSS is national health risk survey developed by the Centers for Disease Control and Prevention (CDC) and amended by individual states. It is administered and supported by the Division of Adult and Community Health, National Center for Chronic Disease Prevention and Health Promotion, CDC, and is an ongoing data collection program. All states, the District of Columbia, and three territories participate in the BRFSS.

is a participant in the Behavioral Risk Factor Surveillance Survey (BRFSS)[b] annually, a telephone survey of 15,000 adults across the state. Uninsured North Carolinians in 2004 were more likely to report they had no personal physician or healthcare provider (52%) compared to people who had insurance (13%).[11] They are four times more likely than people with insurance to report that there were times in the last 12 months when they needed to see a doctor, but could not due to the costs (44% versus 11%, respectively). Uninsured people with diabetes were more likely to report that there were times in the last 12 months when they could not afford their testing strips for diabetes due to the costs (49% versus 16%, respectively). Similarly, people without coverage are less likely to obtain preventive screenings, such as mammograms, prostate specific antigen (PSA) screenings, or colorectal screenings, than those with insurance coverage. North Carolina hospital discharge data show that the uninsured are more likely to be hospitalized for preventable conditions than those with private insurance coverage.[12] For example, the uninsured are 50% more likely to be hospitalized for asthma than those with insurance.

The national data also show access barriers similar to what we found in North Carolina. However, national studies have also been able to examine the effect that lack of coverage has on health outcomes. National data show that the uninsured are more likely to delay care and, as a result, be diagnosed with more advanced health problems, such as late-stage cancer. Those with chronic diseases are less likely to obtain the treatment or medications they need to manage their chronic illnesses. And, similar to North Carolina data, national data confirm that the uninsured are more likely to end up in the hospital for preventable conditions. Because of these access barriers, the national Institute of Medicine estimated that being uninsured increases the risk of dying prematurely by 25% over rates for those with insurance coverage.

Lack of insurance coverage affects more than the specific person's health status. The growing numbers of uninsured affect everyone. Children who are sick miss more school days and may have a harder time keeping up with school work. Workers in poor health are less likely to work or may work fewer hours. Research shows that workers with insurance coverage take fewer sick days and have shorter episodes of illness than workers who are uninsured.[13] The uninsured in North Carolina are more likely to report difficulties paying their medical bills, being contacted by a credit agency, and having to cut back on other living expenses—such as utilities, food, clothing, housing, or transportation—to pay for their medical bills.[12] Outstanding medical bills, in turn, are a leading cause of bankruptcy.[14] Further, the costs of providing health services to the uninsured are "shifted" to those with private insurance coverage, leading to higher premium costs. One study suggested that the costs of caring for the uninsured in North Carolina have led to a $438/year increase in employer-sponsored insurance premiums for individuals and a $1,130 increase for families.[15] In addition, the growing costs of caring for the uninsured are creating a financial strain on the healthcare institutions that serve everyone regardless of insurance status. William Pully, President of the North Carolina Hospital Association, describes the financial impact of the rising numbers of uninsured on hospitals across the state in his commentary in this issue of the Journal.[16]

Rising Healthcare Costs Are Leading to the Increased Numbers of Uninsured

Between 2000 and 2004, health insurance premiums have increased 65% nationally, far faster than wages (12.2%) or general inflation (9.7%).[17] These rising premiums are a major contributor to the increasing numbers of uninsured. More than half (55%) of the uninsured surveyed in North Carolina reported that they didn't have health insurance because it costs too much, and another 23% reported that they were out of work or between jobs, which could also make health insurance coverage unaffordable.[11] Similarly, 86% of employers who did not offer health insurance reported in a national survey that high premium costs were an important reason for not offering coverage.[18] Every 10% increase in premiums leads to a 2.5% decline in employers offering coverage, with smaller firms being more responsive to premiums than larger firms.[19]

In order to stem the increasing numbers of uninsured, it is also important to address rising healthcare costs. While there are many factors that lead to increased premiums, the primary driver is the increase in underlying healthcare costs.[c,20,21] We, as a society, are using more healthcare services, while at the same time, the underlying costs of many of these services have increased. The advent of new technology and treatment protocols, changes in overall disease prevalence or changing demographics, the costs of defensive medicine, and underlying labor costs all contribute to rising healthcare costs. One study showed that almost one third of the change in healthcare spending between 1987 and 2000 was attributable to the treatment of five major health problems: heart disease, mental disorders, pulmonary disorders, cancer, and trauma. Half of the increase was attributable to 15 conditions.[22] Many of these health conditions are exacerbated by our lifestyles or lifestyle-related diseases, including obesity, smoking, and problem drinking.[23] Sandra Greene, a Senior Research Fellow at the Cecil G. Sheps Center for Health Services Research, University of North Carolina at Chapel Hill, provides more information about the reasons for the increased healthcare expenditures in her commentary on page 192 in this issue of the Journal.[24]

Employers have responded to these rising premium costs by

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[c] One way of determining the extent to which underlying healthcare costs are driving premium increases versus underwriting profits of insurance companies is to compare the premium increases of fully-insured plans versus self-funded plans, as the premium costs in self-funded plans almost exclusively relate to underlying costs of medical claims. Studies that have compared the premium increases to determine the effect of insurance underwriting profits on premiums found almost no effect of underwriting profits between the springs of 2004 and 2005. Underwriting profits did play more of a role on the premium increases in the prior year, when premiums for fully insured plans increased 11.2%, but medical claims expenses only rose 7.4%.[19,20]

shifting more of the costs to their employees, either through higher premiums, deductibles, or other out-of-pocket spending. Between 2000-2005, the employee's share of health insurance premiums increased by 82%, with a 67% increase in family coverage.[25] One fifth of all employers are offering high-deductible plans, which have at least a $1,000 deductible for individuals and a $2,000 deductible for family coverage. Employers have also tied the increased cost-sharing to the services that are contributing significantly to rising healthcare costs, such as inpatient hospitalizations and prescription drug use.

In addition, more employees are now covered by plans that offer case management or disease management for high-cost and chronic health conditions. A small percentage of the population accounts for the majority of spending on healthcare. In 1996, for example, approximately 5% of the population accounted for 55% of all spending on healthcare, and 30% of the people accounted for 90% of healthcare spending.[26] Thus, 81% of employees with employer-sponsored insurance are in plans that use case managers to manage high-cost claims; and 56% of workers are in plans that offer at least one disease management program.[25]

Incremental Reform Efforts

Ultimately, the only way to fully address the problems of the uninsured is to ensure that every person has health insurance coverage. Offering health insurance on a voluntary basis creates incentives for adverse selection. In other words, people who are less healthy and likely to incur healthcare costs are more likely to enroll and pay for health insurance than those who are healthier. Thus, lower participation rates and a population of higher-risk individuals will increase the average cost per eligible.

Nonetheless, it is difficult to achieve universal coverage on a state-level basis; to date, no state has been able to fully insure its population. Further, the Task Force realized early in its deliberations that no single approach to providing universal coverage would gain the support of the different healthcare constituencies. Thus, the Task Force recommended a multi-pronged approach that included market-based reform efforts, private-public partnerships, and public initiatives to expand coverage to more of the uninsured.

The Task Force's priority recommendations focused on five areas:

- Expand the healthcare safety net to provide healthcare services to more uninsured.
- Promote personal responsibility for health to help improve population health.
- Create a lower-cost health insurance product for small employers who have not offered health insurance in the past.
- Develop a limited-benefit Medicaid expansion plan for low-income parents.
- Create a high-risk pool for individuals with pre-existing health problems.

Expand the Healthcare Safety Net

Many people are under the mistaken belief that people can get the healthcare they need, even if they do not have insurance. Under the federal Emergency Medical Treatment and Active Labor Act (EMTALA), hospitals are required to screen and stabilize anyone who seeks care in their emergency department.[d] However, this is not the most appropriate, nor is it the least costly, way for people to receive care. The North Carolina Institute of Medicine Safety Net Task Force examined the availability of safety net organizations that provide primary care services to the uninsured on a sliding-fee scale basis, such as community and migrant health centers, free clinics, public health departments, state-funded rural health clinics, or other non-profits with a mission to serve the uninsured.[27] Private physicians also provide care to the uninsured, often on a reduced cost basis. The Task Force found that these organizations are not available in every county. Statewide, only about 25% of the uninsured received care through a healthcare safety net organization. Further, national studies show that less than half of the uninsured are aware of safety net resources in their communities.[28] Safety net providers are also limited in the care they can provide, as many are unable to provide needed behavioral health or dental health services, specialty care, or access to necessary medications. In this issue of the Journal, Annette DuBard, a primary care physician working at a community health center in Alamance county, describes some of the frustrations and heartbreak she faces as a physician trying to address the healthcare needs of her uninsured patients.[29]

The North Carolina Institute of Medicine Task Force on Covering the Uninsured recognized that its recommendations would not lead to universal coverage for all of the uninsured. Thus, safety net services are needed to ensure that those who continue to lack coverage will have some access to services. **The NC IOM Task Force on Covering the Uninsured recommended that the North Carolina General Assembly increase funding to support and expand the healthcare safety net in order to provide services to more of the uninsured.**

Promoting Personal Health Responsibility to Improve Population Health

Lifestyle choices and lifestyle-related diseases contribute to the rising costs of healthcare. Smoking, heavy drinking, and obesity can lead to chronic health problems and, as a result, increased healthcare costs. For example, obese people have a higher risk of developing diabetes, hypertension, and heart disease. Smokers have a greater likelihood of developing lung cancer or heart disease. Problem drinkers have a higher risk of trauma through falls and motor vehicle accidents, and are at increased risk for pancreatitis and certain types of congestive heart failure. According to 2001 figures, 24% of the United States population is obese, an increase of ten percentage points since 1987.[30] The increased prevalence of obesity alone

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[d] EMTALA requires hospitals that participate in Medicare to screen anyone who requests treatment at the emergency department, regardless of ability to pay. 42 USC §1395dd.

accounted for 12% of the real per capita healthcare spending growth between 1987 and 2001.

One of the best strategies to reduce the rapid escalation in healthcare spending is to encourage people to live healthier lifestyles. On page 225 in this issue of the Journal, Robert Greczyn, President and CEO of Blue Cross and Blue Shield of North Carolina, presents ideas on how we can control healthcare costs in North Carolina.[31] The incidence of chronic diseases and, over the longer-term, the rate of growth in healthcare spending, could be decreased if people would eat healthier foods, exercise regularly, maintain a healthy weight, and reduce other risky behaviors. Thus, one of the Task Force's recommendations was to focus on improving population health. People have a responsibility to be better stewards of their own health, but society at large can help in that effort. **Specifically, the Task Force recommended that individuals be given the education, support, and resources needed to make informed healthy lifestyle choices; that individuals with chronic diseases be provided the information and access to health services needed to manage their conditions; and that individuals who engage in unhealthy behaviors be expected to pay differential premiums to cover some of the increased healthcare costs of their lifestyle choices. Further, the Task Force recommended that providers, employers, insurers, schools, and government all assist in promoting healthy lifestyle choices and encourage people to participate in evidence-based wellness initiatives.**

Low-cost Health Insurance Product for Small Employers

The Task Force focused on ways to reduce premium costs for small employers, as half of the uninsured have a family connection to a small employer. North Carolina's small-firm employees are less likely to be offered health insurance by their employer than nationally, but those who are offered insurance are more likely to enroll.[32] Focus groups with North Carolina employers, conducted by FGI Research as part of the State Planning Grant, confirmed that employers want to provide health insurance coverage to their employees. "We like to keep our employees healthy so they'll show up for work," noted one focus group participant. However, high premium costs were cited as the major barrier to offering coverage.

The Task Force focused on different ways to reduce premium costs for small employers. One of the primary ways to reduce costs is to reduce the benefits covered or greatly increase cost-sharing. However, there is a tension between offering pared-down benefit plans or plans with such high cost-sharing that the uninsured would find it unattractive, versus expensive plans that offered comprehensive benefits.

The Task Force's priority recommendation was to offer a publicly-subsidized health insurance product that would be targeted to small employers with 25 or fewer employees, sole proprietors, or employees who are not offered health insurance through their jobs. The state would be urged to provide reinsurance[e] to help reduce the premium costs by 30% over what is available in the private market. To further reduce the potential costs to the state, the proposal would be limited to employers who have not offered health insurance in the last 12 months and who also have a low-wage workforce (i.e., at least 30% of the employees earn $12/hour or less). Eligibility for sole proprietors and working individuals would be limited to those who had not had coverage in the last 12 months and who had family incomes less than 250% FPG. This model is based on the Healthy New York model, which has been in operation since January 2001 and now covers more than 100,000 previously uninsured individuals.[33]

The Task Force also recommended that commercial insurers develop tiered benefit plans, which offer very basic healthcare coverage (i.e., generally limited to a specified number of doctor's visits or have caps on hospitalization costs) at the lowest premium, with more comprehensive benefits and reduced cost-sharing available for a higher premium. While these products are unlikely to appeal to a significant portion of the uninsured, they may be attractive to those who are young and healthy and do not foresee the need for comprehensive coverage. Another recommendation from the Task Force was to review the state's small group reform laws enacted in the 1990s, which helped establish a small group rating methodology to stabilize the small group market. The North Carolina Department of Insurance established a work group to examine these laws to determine if there are potential modifications that could increase coverage among small employer groups. Barbara Morales Burke discusses the work of this committee in her commentary in this issue of the Journal.[34]

Limited-Benefit Health Insurance Product for Low-Income Parents

Three fifths of the uninsured have incomes less than 200% FPG. People with low-incomes have difficulty affording coverage, whether through an employer or in the non-group market. Many low-income people are covered through Medicaid or North Carolina Health Choice (the State Children's Health Insurance Program). For example, in March 2006, there were almost 1.2 million people covered by Medicaid and approximately 105,000 children under the age of 19 covered through North Carolina Health Choice.[35] However, because of categorical, income, and resource restrictions, these programs do not cover all low-income uninsured individuals. The United States Bureau of the Census Current Population Survey estimates that Medicaid and North Carolina Health Choice only cover approximately 35% of people living below 100% FPG, and

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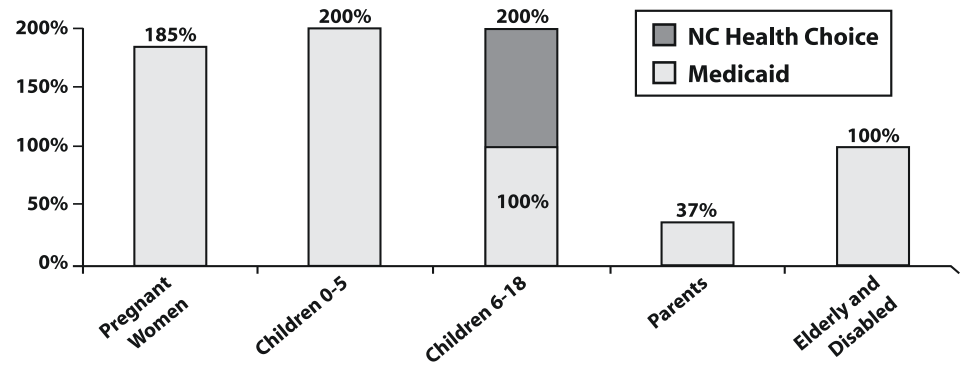
[e] Reinsurance is essentially insurance coverage for insurance carriers. If the annual claims for an individual in the plan reach some predetermined amount, then the reinsurer covers at least some part of the claims above that level. Under the Healthy New York program, the state reimburses private health plans for 90% of the claims costs between $5,000 and $75,000 per individual (called the "reinsurance corridor.") The NC IOM Covering the Uninsured Task Force did not recommend a specific reinsurance corridor, rather it recommended that the reinsurance corridor be set at a level that would result in 30% lower premiums than are available in the private market.

only 20% of those living between 200-200% FPG.[3] In order to qualify for Medicaid, a person must fall into a specified eligibility "category," including pregnant women, children under age 21, parents with dependent children, people with disabilities, or seniors age 65 or older. In addition, individuals must have incomes below a certain income limit; and, depending on the eligibility category, the person may have to meet certain resource restrictions (e.g., amount of money in the bank). Childless adults who are younger than 65 and not disabled will not qualify for Medicaid, regardless of how poor they are.

The Task Force explored different options to expand Medicaid to cover more low-income people. This is a lower-cost option to the state than developing a 100% state-funded program, as the federal government pays approximately 63% of program costs. North Carolina's income eligibility rules are comparable to or higher than many other states for pregnant women, children, older adults, and people with disabilities. However, North Carolina's income eligibility thresholds for parents, which limit their countable income to 37% FPG, are among the lowest in the country (see Figure 2).[36]

The Task Force's top priority for Medicaid expansion was to cover parents and pregnant women with incomes up to 200% FPG. In order to limit the cost to the state, the Task Force suggested that the state seek a waiver of the traditional Medicaid laws to design a more limited benefit package. The limited benefit package would focus on ambulatory care, with incentives for people to participate in disease and case management to help them manage their chronic health problems. Inpatient hospitalization would be limited to $10,000 total/year, and covered individuals would be expected to pay a sliding-scale premium and cost-sharing for the services they receive. Unlike traditional Medicaid, this expansion would not be an entitlement, so the state would have limited financial liability for the coverage. The Task Force decided to focus on Medicaid expansion for parents, rather than children, since the income limits for the working adults are so much lower than for children.

Figure 2.
Medicaid Income Eligibility as Percent of Federal Poverty Guidelines (FPG)



Analysis of the United States Bureau of the Census Current Population Survey (CPS) data suggests that there are tens of thousands of uninsured North Carolinians who currently qualify for Medicaid or North Carolina Health Choice, but are not enrolled.[37] National studies show that many people who are eligible for public programs do not enroll because they do not know about the program or eligibility criteria, or because the complicated eligibility process or stigma attached to the programs deter them from applying.[38,39] The NC DHHS has already done a lot to simplify and streamline the application processes. Yet, the Task Force recommended that more be done to increase outreach and simplify the application process to encourage uninsured individuals who are currently eligible to apply for these programs.

Another way to expand care for the uninsured is through the Medicaid Community Care of North Carolina (CCNC) networks. CCNC is comprised of community-based networks designed to improve the care provided to Medicaid recipients. The 14 regional networks cover 92 of the 100 counties and approximately 670,000 Medicaid recipients. Each network includes primary care providers, hospitals, departments of social services, health departments, and other healthcare providers and provide case management and disease management services to help patients manage chronic or high-cost conditions. L. Allen Dobson, Assistant Secretary for Health Policy and Medical Assistance for NC DHHS, discusses the importance of implementing CCNC cost-saving strategies (i.e., quality improvement, disease management, targeted utilization initiatives) along with providing continued support for the safety net in his commentary in this issue of the Journal.[40]

High-Risk Pool for People with Pre-Existing Health Problems

Ostensibly, people with pre-existing health problems are among those individuals most in need of health insurance coverage, but they often have the hardest time finding affordable coverage. People with pre-existing health problems cannot be excluded from coverage or charged higher premiums if they obtain their coverage through an employer. However, with limited exceptions, individuals who seek coverage in the non-group market can be denied coverage or charged unaffordable premiums. Later in this issue of the Journal, David Moore, past President of the North Carolina Healthcare Underwriters Association, discusses the merits of creating a high-risk pool in North Carolina.[41]

Blue Cross and Blue Shield of North Carolina is the only insurer in the state to offer health insurance coverage to anyone in the non-group market, regardless of their health status. However, premiums vary, based on the age, geographic location, sex, and health status of the individual. The premiums are established to cover the anticipated costs of the group of enrollees—thus, those with pre-existing problems are charged higher premiums than those who are healthy and presumed to use fewer health services. For example, non-group health insurance coverage for a man with significant health problems could cost more than $800/month (for a $1,000 deductible, 30% coinsurance plan), or more than $1,800/month for a 55-year-old man. Premiums for women are generally more expensive, especially if the woman chooses maternity coverage.

Thirty-three states have established high-risk pools to help subsidize the costs of health insurance coverage for people with pre-existing problems. Research suggests that approximately 1% of the non-elderly population has difficulty obtaining insurance due to their health status ("medically uninsurable").[42] The experience from other states suggests that between 10-30% of these individuals may enroll in a high-risk pool, depending on the premium price and whether the state offers additional subsidies for low-income people.[43] Most states cap the premiums charged to individuals enrolled in the high-risk pool to 150% of the standard price charged to healthier individuals. **The Task Force recommended that North Carolina establish a high-risk pool and that the losses from the pool be spread broadly among all insurers, including commercial carriers, third-party administrators, and reinsurance carriers.** Congress appropriated $75 million in grant funds in 2005 to help states offset some of the losses from a high-risk pool.[44] In addition, Congress appropriated another $15 million to provide start-up funds to states, like North Carolina, that have not yet established a high-risk pool.

Conclusion

The problems of the uninsured affect everyone in our state. Individuals stand to benefit by having affordable coverage that enables them to get necessary healthcare services. Providers will gain if there is a source of coverage for those individuals for whom they are already providing some services, but with minimal payments. Businesses benefit by having a healthier, more productive workforce and fewer bankruptcies. The state stands to gain by having a healthier, more competitive workforce and healthier children who are more likely to succeed in school. As more people gain insurance coverage, there will be less uncompensated care. This, in turn, will reduce the need to shift uncompensated costs of serving the uninsured onto people with insurance, which will help moderate rising healthcare costs for those with insurance.

Just as each group stands to gain by expanding insurance coverage to the uninsured, there is a shared responsibility to assist in the solution. Individuals should purchase health insurance when affordable coverage is offered. Employers can assist by offering insurance and helping contribute toward the cost of employee and dependent coverage. Insurers can help by subsidizing the costs of the high-risk pool. Providers can assist by accepting lower reimbursement rates for low-income individuals and small employers who were previously uninsured. And government can assist by helping to subsidize the costs of insurance for those who could not afford coverage in the private market.

The problems of the uninsured beg for a national solution; as it is difficult for any state to tackle this problem in a vacuum. However, states should not wait until the federal government acts. Many states are devising creative solutions to expand coverage to the uninsured. Some states are further along in their process than North Carolina and already have low-cost products for small employers and Medicaid programs that cover more of the uninsured. North Carolina can learn from these states and then develop programs that are tailored to the unique needs and strengths of this state. The Task Force's recommendations are a starting point toward this goal, but additional work will be needed in the future if the state is ever to realize the goal of universal health insurance coverage for all. **NCMedJ**

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COMMENTARY

Healthcare Costs:

The Engine Driving the Decline in Insurance

Sandra B. Greene, DrPH

The increase in the percent of the population that is uninsured in both North Carolina[1] and across the nation[2] is driven by the increasing costs of health insurance premiums. Nationally, health insurance premiums increased 65% between 2000 and 2004. This rise was more than six times greater than general inflation (9.7%), and more than five times the wage growth (12.2%).[3] The increase in premiums makes it harder for employers to offer insurance to employees and for individuals to purchase healthcare coverage. Research indicates that for every 10% increase in health insurance premiums, the number of firms that offer health insurance to their employees falls by roughly 2.5%.[4]

Most of the increase in health insurance premiums is due to the increase in the underlying costs of healthcare.[5,6,7,8] Healthcare costs increase for a variety of reasons, some due to the increased cost of individual services, some due to greater utilization of services, and some due to changes in overall disease prevalence. This commentary examines trends in personal healthcare spending in North Carolina between 1990 and 2000, changes in unit costs and utilization of different services, and the effects of changes in disease prevalence and demographic changes on healthcare spending. The commentary concludes with how these changes impact health insurance premiums and how employers and individuals respond to rising premium costs.

Total Personal Healthcare Spending in North Carolina (1990-2000)

Data from the Office of the Actuary of the federal Centers for Medicare and Medicaid Services show that North Carolinians spent $31.3 billion dollars on personal healthcare expenses in 2000.[9] Table 1 shows how the dollars were spent and the increases in expenditures by service type between 1990 and 2000 (the most recent data available).

In 2000, more than one third of personal health spending in

Table 1.
Per Capita Personal Healthcare Expenditures, North Carolina, 1990, 2000

Healthcare Services or Products	1990	1990 % of total	2000	2000 % of total	% Increase 1990-2000
Hospital Care	$5,905	42.8%	$12,060	38.6%	104.2%
Physician and Other Professional Services	$3,748	27.2%	$8,025	25.7%	114.1%
Dental Services	$662	4.8%	$1,508	4.8%	127.8%
Home Healthcare	$288	2.1%	$1,150	3.7%	299.3%
Prescription Drugs	$1,110	8.0%	$3,882	12.4%	249.7%
Other Non-Durable Medical Products (e.g., diabetes test strips)	$546	4.0%	$679	2.2%	24.4%
Durable Medical Products (e.g., wheelchairs or walkers)	$215	1.6%	$477	1.5%	121.9%
Nursing Home Care	$1,115	8.1%	$2,524	8.1%	126.4%
Other Personal Healthcare	$208	1.5%	$979	3.1%	370.7%
Total	*$13,797*	*100.0%*	*$31,284*	*100.0%*	*126.7%*

Figures are in millions

Source: Centers for Medicare & Medicaid Services, Office of the Actuary, National Health Statistics Group. North Carolina Personal Health Care Expenditures (PHCE), All Payers 1980-2000.

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North Carolina was spent on hospital care (39%), and approximately one quarter (26%) on physicians and other professional services.[9] These expenditure rates are similar to those at the national level (36% and 29%, respectively) and accounted for more than half of the increase in total expenditures from 1990-2000. Hospital care accounted for 35% of the increase in spending, while physician and other professional services accounted for 25%. However, in recent years, prescription drugs have been one of the fastest growing components of healthcare spending. Prescription drugs accounted for 16% of the increase in overall healthcare spending between 1990 and 2000. As a result, prescription drugs constituted 12% of North Carolina's personal healthcare expenditures in 2000, compared to 8% in 1990.[a,9] Long-term care (home health and nursing care) also constituted 12% of North Carolina's personal healthcare expenditures in 2000, with spending on home healthcare increasing more than 300% since 1990.[b]

Changes in Unit Cost and Utilization of Different Services

Expenditures for healthcare services are a function of two components: price per unit of service and the number of units (amount of services received). Understanding whether the price or use of a service is increasing, or both, can help policymakers determine how to respond to healthcare cost increases. As described in more detail below, an increase in unit costs explains the rising costs of hospital inpatient care, while increased utilization explains the rising costs of hospital outpatient services and technology (particularly imaging). For prescription drugs, there has been both an increase in utilization and unit costs.[10]

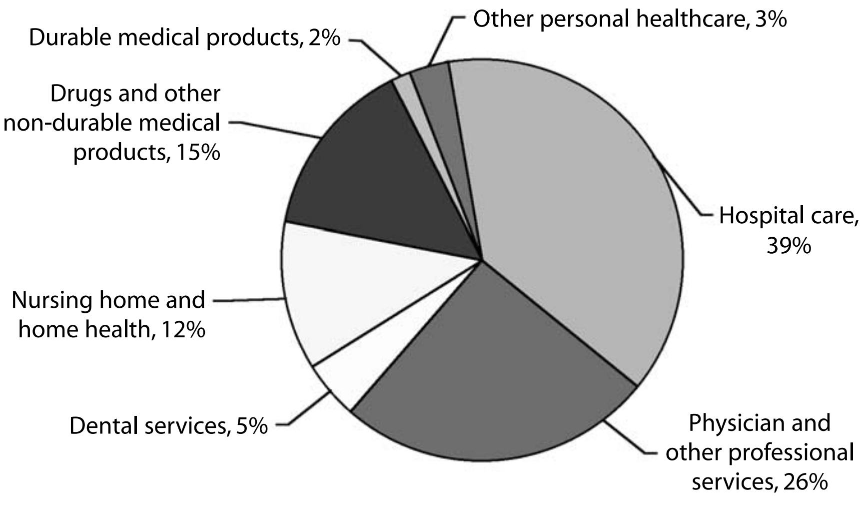
Previous efforts to curb rising costs of care have focused primarily on price because it is easier to address what something costs than to manage its utilization. Providers contribute to increased utilization, as changes in technology or treatment protocols lead to increased use of certain services or procedures. Defensive medicine—or ordering unnecessary tests or procedures to prevent a potential malpractice claim—also increases utilization. Consumers' demand for services and medications also contributes to rising healthcare utilization. Controlling utilization is generally more difficult than trying to control costs because the public often views the former as restrictions on accessing needed healthcare.[11] However, recent strategies have designed consumer cost-sharing to influence patient utilization rates. By placing more financial responsibility on consumers, patients may reduce their use of marginally useful or unnecessary healthcare services.[c,12]

Hospital Care

Between 1990 and 2000, hospital spending increased 104% in North Carolina (see Table 1) and accounted for 35% of total growth in personal healthcare expenditures. Hospital spending includes that spent on both inpatient and outpatient services. More recent national data showed that hospital inpatient spending increased 6.2%, while hospital outpatient spending increased 11.3% between 2003 and 2004.[13]

The increase in hospital services expenditures is due primarily to an increase in unit price, rather than an increase in utilization. Nationally, hospital utilization increased only 2.9% in 2004, but hospital unit costs for inpatient and outpatient services combined increased 7%.[13] On a population basis, North Carolinians are spending less time as inpatients than a decade ago. In 1989, North Carolina residents' utilization of inpatient hospital services was 752 days per 1,000 persons, compared to

Figure 1.
North Carolina Personal Health Expenditures, 2000



Source: Centers for Medicare & Medicaid Services, Office of the Actuary, National Health Statistics Group. North Carolina Personal Health Care Expenditures (PHCE), All Payers 1980-2000.

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a Prescription drugs, by themselves, constituted 12.4% of personal healthcare expenditures in North Carolina in 2000; non-durable medical products amounted to another 2.2% of the state's personal healthcare expenditures.[9]

b Long-term care expenditures, unlike most other healthcare expenses, are highly dependent on the payer. Public insurance programs, such as Medicare and Medicaid, account for a substantial portion of total spending on long-term care.

c The most notable work in this area stems from the RAND Health Insurance Experiment conducted in the late 1970s. Utilization was lower in plans that had greater cost sharing, but there was mixed evidence on whether the healthcare services were necessary. Health status for most people was unaffected by their reduced services, but for the sick and poor, health was adversely affected.

only 542 days per 1,000 in 2003.[14] The most dramatic decline in utilization occurred among the elderly population.

By contrast, the cost per day spent in the hospital or per admission is escalating because there are more services, treatments, and procedures provided to patients once they enter the hospital. In addition, as more non-emergent healthcare needs can be treated on an outpatient basis, inpatient utilization for those services decreases, and the more intensive, higher-cost services account for a greater proportion of inpatient services, which raises costs. Further, hospital labor costs for nursing and other healthcare professionals have increased.[15,16]

Costs for hospital outpatient care are also increasing as the result of both higher utilization and greater unit price.[13] This increase is a reflection of more services and procedures, such as biopsies, surgeries, and chemotherapy, which are now safe and acceptable when performed on an outpatient basis. In the past, some of these services would have been performed solely on an inpatient basis. Thus, while outpatient costs have been increasing, some of this increase in utilization helped offset the use of more expensive inpatient services. However, there is not a direct one-for-one correlation between increased use of outpatient services and a decrease in inpatient utilization. Further, unit costs for outpatient care are not as well controlled as costs for inpatient care, where the use of diagnosis related groups (DRGs) or similar prospective payment methods limit charges per admission.[d]

> *"Previous efforts to curb rising costs of care have focused primarily on price because it is easier to address what something costs than to manage its utilization."*

Technology

Greater availability and use of technology are also significant healthcare cost drivers.[17] Radiographic imaging has been one of the most significant technological advances in medical care. X-rays, introduced in 1895, were the first form of imaging. Newer forms of imaging emerging in the late 20th century included computed tomography (CT), magnetic resonance imaging (MRI), and positron emission tomography (PET). The current (2004) cost of a CT scan is more than $1,200, an MRI is generally just under $2,000, and a PET scan costs approximately $2,300.[9]

The availability of freestanding MRI and CT technology is associated with higher utilization and spending on these services.[17] However, the use of these imaging technologies for diagnosis has generally proven to be additive, rather than substitutive. A clinician may first order an x-ray or CT scan and then order another imaging technology, such as an MRI, to confirm or further investigate a suspected malady.[17] Therefore, while a diagnosis may be more accurate, the costs associated with determining that diagnosis are increasing.[18] The latest imaging technology, PET, uses radioactive substances to examine body functions, and it is increasingly used in screening for cancer and heart disease despite professional disagreement over some specific uses of this scanning technique. Between 1970 and 1985, North Carolina had only three PET scanners in the state, located at the largest hospitals. However, since 1985, 19 more PET scanners have been approved, and now all teaching hospitals have at least one PET scanner, and moderate size hospitals are applying for their use. This pattern of diffusion is typical for a new technology and will result in rising costs because of the wider availability of the scanners.

Prescription Drugs

The rising cost of prescription drugs is also a major contributor to increasing healthcare costs. In North Carolina, expenditures for prescription drugs increased 250% between 1990 and 2000 (see Table 1). More recent national data show that prescription drug expenditures increased 47% between 2000 and 2003.[19] Both public and private insurance programs have experienced double digit annual increases in prescription expenses.[20] This increase is due both to rising cost per prescription and an increased number of prescriptions filled.[13]

The rising costs of medications may be explained, at least in part, by the introduction of new medications into the market. The National Institute for Health Care Management (NIHCM) conducted a study of 1,035 new drug applications to the Food and Drug Administration between 1989 and 2000 and found that only 35% contained new active ingredients, while the remainder contained currently available active ingredients.[21] Furthermore, only 24% of the drugs offered clinical improvement. Of all the new drug applications, only 15% were both highly innovative and offered significant clinical improvement. In addition, of the $67.4 billion increase in spending on prescription drugs between 1995 and 2000, only 33% of the expenditures were spent on the pharmaceuticals that offered clinical improvements. This raises questions about the cost effectiveness of the increased spending on pharmaceuticals.

A significant factor in the high utilization of new prescription drugs is direct-to-consumer (DTC) advertising.[22] DTC advertising is a successful marketing tool. Drugs that are heavily advertised experience a significant increase in their use.[23] Yet, there are a

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[d] Diagnosis related groups (DRGs) is a hospital payment system used by Medicare and many third-party insurers. It prospectively sets the hospital payment based on the patient's primary and secondary diagnosis, surgical procedures, age, sex, and the presence of complications.

number of concerns about such advertising techniques. Advertisements generally contain limited information about side effects and promote expensive brand name drugs over generics. Patients who see these ads may exert pressure on their physicians to prescribe drugs they have seen advertised, and this may lead to use of higher-cost drugs, rather than generic versions. In some cases, this could lead to inappropriate clinical use.

Malpractice

Rising malpractice premiums have been noted as a problem for some physicians in particular specialties and geographic areas. It may also negatively affect patients living in areas where physicians are no longer practicing presumably as a result of high premiums. Malpractice also contributes to rising healthcare costs because it leads to defensive medicine. Physicians may order unnecessary tests or procedures or avoid some high-risk patients, out of fear of potential malpractice liability.[24] While it is difficult to fully quantify the costs of defensive medicine, several recent studies suggest that malpractice costs and malpractice insurance premiums are not primary contributors to the rising costs of healthcare. One study reported that only 7% of the annual increase in healthcare costs can be attributed to litigation and risk management,[25] while another showed that malpractice costs account for a very small proportion of healthcare premium costs.[26]

Changes in Disease Prevalence and North Carolina Demographics

Changes in the prevalence of certain health problems underlie some of the increased use of health services and, consequently, relate to a portion of the increase in national healthcare spending. Healthcare spending is concentrated in a relatively small number of health problems. For example, almost one third of the change in healthcare spending between 1987 and 2000 was attributable to the treatment of five major health problems: heart disease, mental disorders, pulmonary disorders, cancer, and trauma.[29] Approximately half of the increase in health spending was attributable to 15 conditions.

For four conditions, cerebrovascular disease, mental disorders, pulmonary conditions, and diabetes, increased spending was due primarily to an increase in treated prevalence or number of cases.[e] In contrast, the increased cost per treated case was the primary factor underlying greater spending on trauma, pneumonia, infectious diseases, and heart disease. Overall population growth generally accounted for only 20-30% of the changes in healthcare spending for any specific condition.

Certain lifestyles choices and lifestyle-related illnesses contribute to many healthcare problems. Smoking, heavy drinking, and obesity[f] can lead to chronic health problems and, as a result, increased healthcare costs.[27] The growing epidemic of obesity is a major contributor to rising healthcare costs. Obese people have a higher risk of developing certain health problems, such as diabetes, hypertension, and heart disease. According to 2001 figures, 24% of the United States population is obese, an increase of ten percentage points since 1987.[28] The increased prevalence in obesity alone accounted for 12% of the real per capita spending growth between 1987 and 2001. Sturm analyzed self-reported health risk data from a national household survey and compared this to reported inpatient, outpatient, and prescription drug utilization. He found that obesity increased healthcare and medication costs by 36% and 77%, respectively, compared to someone with a normal weight.

Obesity has a much greater effect on the prevalence of chronic conditions than current or past smoking and problem drinking. However, current or past smoking also increased healthcare service costs 21% and medication costs 28-30%, depending on whether the individual was a current or past smoker. Compared to obesity, which increased absolute inpatient and ambulatory care costs by $395 per year, current or ever smoking was associated with a $230 increase, and problem drinking was associated with a $150 increase.[29]

North Carolinians, like Americans in general, are much more likely to be obese than they were even 15 years ago. In 1990, 12.9% of adult North Carolinians were clinically obese; in 2002, nearly one quarter (23.5%) were obese (see Figure 2). This trend in population health, although not a major contributor to the increase in healthcare costs, is generally appreciated by society. Although conventional wisdom holds that the increase in the proportion of the population that is overweight and obese is a major driver of cost trends, other factors outlined above, such as increasing use of technology, are more important.

A recent study found that many obese individuals do not realize they are obese.[29] Over 70% of normal weight individuals accurately identified themselves as such, but roughly 15% of obese people knew they were obese. All groups reported their height and weight equally well. This finding suggests that there is a need to increase awareness in the population of what a normal weight is.

It is a common misconception that our aging population is a major factor in explaining increases in healthcare costs. Adults over the age of 65 years do spend more per capita on healthcare than younger individuals. Therefore, as the overall population ages, healthcare spending also increases. However, the aging of the overall population is modest from one year to the next, so while it may have a long-term impact on costs, it does not significantly contribute to spending increases from year to year.

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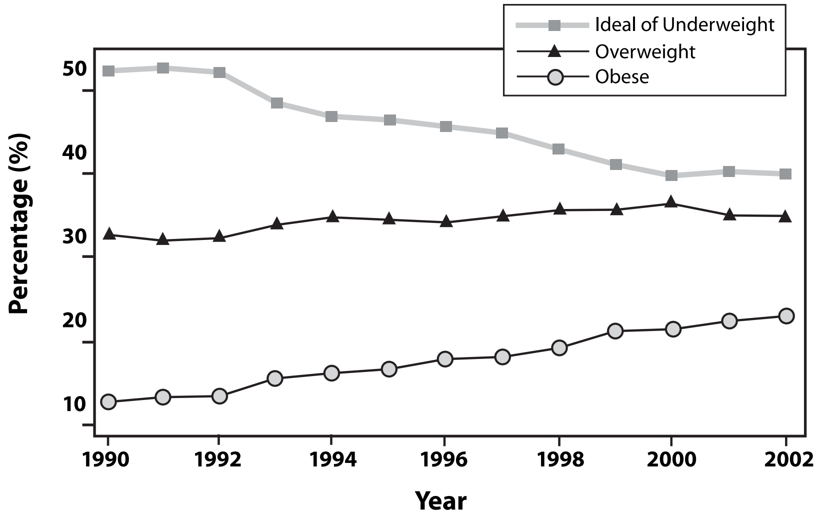
[e] Depending on the condition, the increase in treated prevalence can be due to an increase in epidemiological prevalence of the condition (e.g., diabetes) or to the rate of treatment for a particular condition (e.g., mental health).

[f] In July of 2004, the United States Department of Health and Human Services announced its Medicare coverage policy would treat obesity as an illness. Obesity is defined as having a body mass index (BMI, calculated as weight in kilograms divided by height in meters squared) that is 30 or more.

Figure 2.
Weight Status of North Carolina Adults, 1990-2002



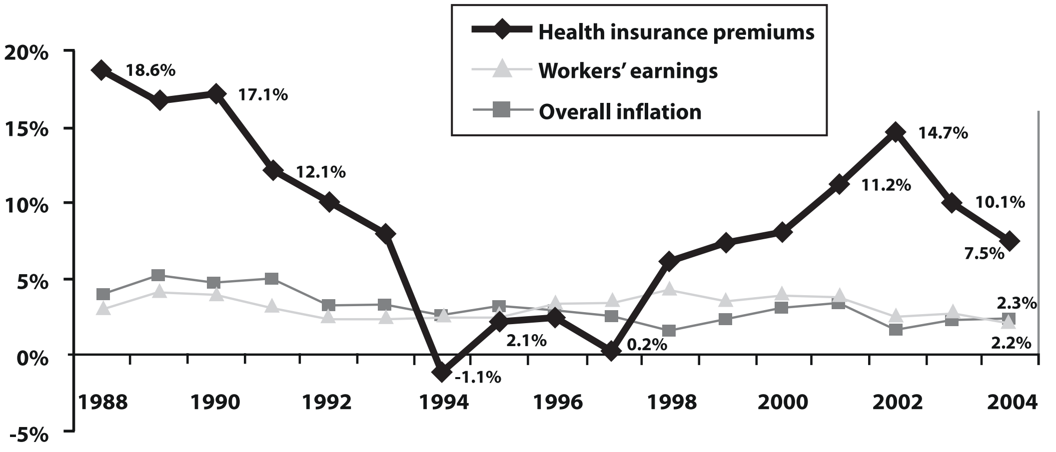
Source: Behavioral Risk Factor Surveillance System, Centers for Disease Control

Rising Health Insurance Premiums and Employer Response

One of the most closely watched measures of changing healthcare costs is the national Mercer/Foster Higgins survey of health benefit costs among public and private employers. This survey represents 600,000 employers with at least ten employees and more than 90 million full- and part-time employees.[g] Figure 3 illustrates changes in the total cost of healthcare benefits from 1988 to 2004. With the exception of a few years of modest increases during the mid-1990s, the cost of health insurance premiums has substantially increased each year since the late 1980s. Healthcare inflation increased at a greater pace than the general rate of inflation. Recently, those increases have moderated, and in 2004, benefit cost increases were 7.5%, down from increases of 10.1% and 14.7% in 2003 and 2002, respectively. While still significantly above inflation, it is the lowest annual increase in five years. However, there is a concern that this recent moderation in benefit cost increases underestimates the true cost escalation in the healthcare system. Rather than increasing premiums, many employers have shifted some of the healthcare costs to employees through increased out-of-pocket expenses, such as deductibles and copays. Figure 3 does not reflect the total increase in healthcare costs because it does not include out-of-pocket expenses.

A 2005 survey of employers by the Kaiser Family Foundation and Health Research and Education Trust indicates that many believe shifting costs to the employee is an effective way to control rising health insurance premiums (see Figure 4). This may be because employers feel they have run out of other viable options. But there could be unfortunate implications for their employees. Past studies suggest that higher out-of-pocket costs do deter utilization, and that individuals are equally likely to forgo necessary care as well as unnecessary care.[30] This is a

Figure 3.
Changes in Health Insurance Premiums, Inflation, and Workers Earnings, 1988-2004



Source: Mercer/Foster Higgins National Survey. (1988-2004). Wage data from: United States Department of Labor. Bureau of Labor Statistics. Average Hourly Earning s of Production Workers, Seasonally Adjusted. April data 2000-2004. General inflation data from: United States Department of Labor. Bureau of Labor Statistics. Consumer Price Index. All Urban Consumers. Not Seasonally Adjusted. April data 2000-2004.

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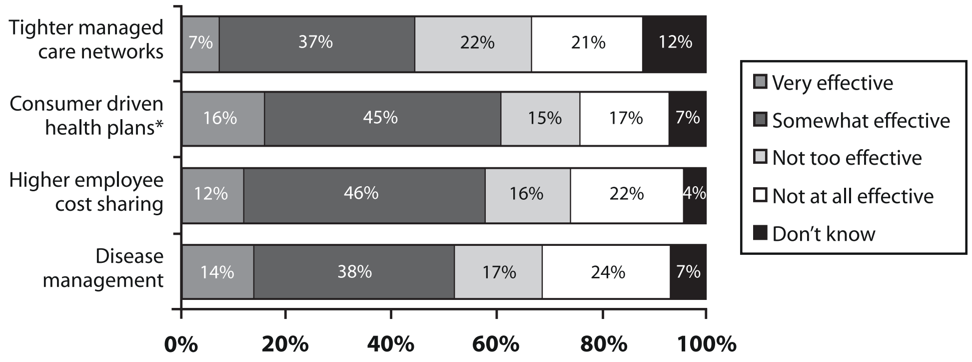
[g] Another national survey conducted by the Kaiser Family Foundation (Kaiser) and Health Research and Education Trust (HRET) results in somewhat different estimates of premium increases. For example, in 2004, the Kaiser/HRET study showed an 11.2% increase from 2003. This study includes employers with three or more employees. The Mercer Foster Higgins study also includes public programs. These differences in study design help explain the different estimates of premium increases.

Figure 4.
Employers Opinions on the Effectiveness of Different Cost Containment Strategies



Source: Kaiser Family Foundation and Health Research and Education Trust. Employer Health Benefits 2005 Annual Survey. Exhibit 12.5.

*Consumer Driven Health Plans include high-deductible plans with a personal or health savings account.

particularly significant problem for low-income people, who are more likely to forgo necessary care and suffer adverse health outcomes as a result.

Employers are also trying to control rising healthcare costs by managing high-cost claims. A small percentage of the population accounts for the majority of spending on healthcare. In 1996, approximately 5% of the population accounted for 55% of total spending, and 30% of the population accounted for 90% of total healthcare spending. This trend has been consistent over time.

People with chronic conditions are included in the high-cost groups and many employers are trying to manage the high costs of chronic conditions through disease management (DM) programs. More than four fifths of covered workers (81%) are enrolled in plans that use case managers to coordinate the care of persons with high-cost conditions. More than half (56%) of all workers with employer-sponsored health insurance are in a plan with at least one disease management program. Of those covered by disease management programs, most workers are covered by programs that manage diabetes (99%), asthma (86%), hypertension (82%), and high cholesterol (66%).[31] Fifty-two percent of employers surveyed in 2005 indicated that disease management was a very or somewhat effective strategy to control rising healthcare costs,[32] although a review of studies examining the return on investment of disease management programs shows mixed results.[h,33] Given the frequent use of disease management programs in employer-sponsored insurance programs, there is a need for more evaluation of their effectiveness to understand where investments of this kind will pay off.

The Elusive Fix

It is not surprising that employers continue to struggle, with little success, in controlling the increases in their healthcare premiums. The healthcare system—the way it is structured, managed, and reimbursed—is complex. Solutions will be equally complex and can't be unilaterally imposed by any single segment of the healthcare system. Some critics say the problem is that patients and providers alike are too insulated from the costs of goods and services and suggest that plans that more closely align consumer/patient and insurer interests (such as Consumer Directed Health Plans[i]) would increase consumer awareness. Others call for more (or less) competition in the healthcare system to control costs. And others put the blame on lifestyles, and call on all of us to take better care of ourselves to reduce illness and healthcare use. While there may be some truth to all of these observations, our problems are more complex than these convey. It is true we have little competition in the provision of healthcare services, but competition rarely works in healthcare as it does in other sectors of the economy. Two high-cost open heart surgery programs in one community do not result in price competition. And arming patients with price information rarely is useful except for elective care, and then only when assuming there is a choice of providers. Patients usually go where their trusted physician directs them. Once a patient is sick and enters the healthcare system, tests and procedures are ordered *for* them, and there is little a patient can do to control the costs associated with their care. The American healthcare system tends to defer to the professional judgment of the physician as to what tests, procedures, and treatments are necessary to ensure the well-being of the patient. Healthier lifestyles are a laudable goal and should be a focus for employers and employees alike. Yet, the healthiest among us will most likely experience health problems at some point through no fault of their own. And once in the healthcare system, the costs are so great that most individuals need some form of assistance in the form of health insurance to afford their care.

Unfortunately, redesigning the American healthcare system

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[h] A recent Cornell-Medstat study concluded the jury is still out on whether disease management programs deliver a return on investment. A review of 44 studies analyzing the economic impact of DM programs found mixed results for those targeting depression, diabetes, and asthma, which are the most common diseases targeted. However, those programs targeting congestive heart failure and multiple chronic conditions were more likely to be successful.

[i] The premise of Consumer Directed Health Plans (CDHP) is that there is costly, unnecessary use of healthcare services, and by transferring more responsibility for accessing and paying for care to the individual, cost-effective decisions will be made. CDHPs take multiple forms, and may include high-deductible plans, healthcare spending accounts, and tiered benefit plans.

to resolve these problems is an unrealistic goal. In the early 1990s, the American public soundly rejected the Clinton Plan to overhaul the system. And as the HMO backlash of the late 1990s taught us, Americans have been loathe to accept aggressive utilization review that would eliminate marginally beneficial healthcare services, so addressing the "demand" side of the equation is not likely to be fruitful. An alternative method of limiting the use of expensive healthcare services is to limit the supply of expensive technology. In North Carolina we do this to some extent with the Certificate of Need (CON) program. This is not without controversy and often leads to adversarial relationships as healthcare institutions and physicians disagree on whether a service in a particular community is warranted. As a society, we tend to question the use of expensive technology in the abstract. But most of us would have little difficulty advocating for the service when a loved one has even a small probability of benefiting from an expensive procedure. This disconnect between what is in *society's* and the *individual's* best interest is at the heart of the dilemma. Consequently, our attempts to fix the healthcare system will be limited to modest tampering around the edges of this monstrous system, and from modest reforms, we can only expect minimal improvements. **NCMedJ**

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COMMENTARY

Hospitals and the Uninsured:

One Hemorrhage at a Time, Please

William A. Pully, JD

Hospitals' promise to the uninsured: our open-to-everyone doors will never close on you. The bleeding reality: the closing doors of other providers and the narrowing reimbursement streams threaten hospital services, not only for the uninsured, but also for the insured.

North Carolina's safety net hospitals are straining under the weight of the rapidly rising numbers of uninsured and climbing demands and shrinking Medicare and Medicaid reimbursements. In addition to facing higher treatment costs, hospitals today are further stretched when other providers either cannot or elect not to continue services to specific populations. Hospitals are *their* safety net also.

One Hospital's Story

Centered in the state's southeastern coastal plain, Duplin county is agrarian, home to more than 50,000 residents. Agricultural jobs here make up over 16% of the workforce, a rate 23 times higher than the state average. Unemployment has fallen in recent years, but residents vividly recall 2000 and 2001 when the county's 23.1% and 24.8% respective joblessness rate ranked worst and next-to-worst in the state. The county also has one of the state's fastest growing immigrant populations. Hispanics, the majority of whom are uninsured, comprised 15.1% of Duplin county residents in 2000 and 18.6% in 2004, numbers that—like farm jobs—are several multiples higher than the state's 4.7% average.

> *"The combination of these losses has devastated the hospital's financial picture, drowning the $1.5 million excess of revenues over expenses in 2000 under a four-year pool of red ink."*

Duplin General Hospital in Kenansville attempts to serve everyone. Eighty-nine of its 101 licensed beds are staffed and open. Twenty of those are for mental health patients, 20 are for those needing skilled nursing care, and nine are for intensive care patients. The hospital's emergency department welcomes 15,000 visitors annually. The surgery suites see 2,200 cases. The hospital discharges 4,200 patients annually and serves 48,000 outpatient visitors—almost one visit for every county resident each year. A more classic example of a "safety net hospital" does not exist.

Two categories of hospital services reveal distinctly different problems facing this hospital. Duplin General delivers between 600 and 700 babies each year. Obstetrics services seldom cover their costs. The percentage of births from the largely uninsured Hispanic population has mushroomed. In 2001, 33% of births at Duplin General were Hispanic. Births to the Hispanic population surpassed 40% in 2002. Over the past three years, more than half of the deliveries were by Latino mothers.

Meanwhile, Medicare and Medicaid patients are turning to the hospital's emergency department in greater numbers. Physician reimbursement rates that have either declined or failed to keep pace with rising costs are constricting access to primary care for these populations. These older, poorer, often sicker patients turn to hospital emergency departments when other healthcare options are closed. In the past year at Duplin General, Medicare patients accounted for 27% of emergency department visits; Medicaid patients 20%; and self-pay patients—the hospital field's euphemism for the uninsured—counted for 24%.

Similar percentages are setting off alarms all over the state. In the aggregate, North Carolina hospital emergency departments

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saw Medicare visits climb to 24%; Medicaid to 22%; and uninsured to 22%. All three groups' usage of emergency departments grew markedly—Medicare by 11%, Medicaid by 6%, and the uninsured by 10%. Combined, Medicare, Medicaid, and uninsured patients accounted for 2,169,006 of 3,432,486 emergency department visits in North Carolina hospitals last year.

For Duplin General, these numbers reflect not only growth among the county's uninsured population, but rising percentages of patients on Medicaid. The hospital's payer mix is over 40% Medicare, and Medicaid patients have reached or surpassed 20% each of the past five years. The hospital receives just over 85 cents on each dollar of its costs from these federal-state-local partnership payers. In one recent year, Medicaid reimbursement to the hospital was more than $750,000 below the incurred treatment cost for Medicaid patients. Statewide, hospital payments from Medicaid in 2005 fell almost $300 million below hospitals' costs. The estimated Medicare reimbursement shortfall ranges from slightly higher than the Medicaid shortfall to more than double that amount.

And, while government payments falter, Duplin General is seeing its totals for the conjoined twins of bad debt and charity care skyrocket. In 2000, their combination was more than $4 million. Bad debt and charity care totals surpassed $5 million the following year, eclipsed $6 million in 2003 and $7 million in 2004. This year the hospital expects bad debt and charity care to total $7.5 million. Statewide, hospitals provided more than $350 million in charity care in 2005 and estimated that bad debt costs were more than $530 million.

The combination of these losses has devastated the hospital's financial picture, drowning the $1.5 million excess of revenues over expenses in 2000 under a four-year pool of red ink. In 2003 and 2004, the hospital lost $2.2 million and $2.4 million, respectively. The depth of red ink decreased in 2005 before plunging to a loss of more than $600,000 through the first half of this fiscal year.

For Duplin General, the dollars are the easily countable portions of the effects of rising numbers of uninsured patients and inadequate government payments for Medicare and Medicaid patients. Harder to enumerate are the uninsured patients who do not have a family physician, although most will come to the hospital's emergency department for primary care. This inappropriate use overcrowds the facility and frustrates emergent patients, increasing dissatisfaction and fueling more liability cases. The low physician reimbursement rates, combined with climbing liability insurance coverage costs, push physicians away from private practice. The hospital finds itself forced to employ physicians, lose money, cut margins, and eliminate services. Some of the costs get shifted to other payers, making premiums spike and prompting employers to drop coverage for their workers. More people without insurance are the result. Not fixing one problem makes another accelerate exponentially.

The cascading financial woes that attend high Medicare, Medicaid, and uninsured populations push hospital trustees into difficult decisions regarding which services to continue and which to eliminate. Duplin General Chief Executive Officer Doug Yarbrough revealed his hospital has already dropped its physician clinic and its diabetes program. They are now squinting suspiciously at any other non-emergent service that does not cover expenses.

Widespread Misery

Duplin General is neither alone nor the worst case. Consider two measures of utilization for uninsured patients—the percentage of hospital charges in the self-pay category and the percentage of patient days in self-pay. Tracking those measures through general acute care patients and for all patients reveals how remarkably representative of North Carolina hospitals Duplin General is. Responses to the North Carolina Hospital Association's Advocacy Needs Data Initiative Survey indicate that 24 of 103 other hospitals in the state had greater percentages of charges in the self-pay category for general acute care and 32 others of 106 had greater percentages of charges for self-pay across all care. Duplin General is even more mainstream when viewed through the percentage of patient days prism. Forty-nine of 102 other hospitals had greater percentages of self-pay patient days for general acute care and 70 of 105 other hospitals had greater percentages of self-pay patient days for all categories of care.

The impact on a hospital's operating margin from high Medicare, Medicaid, and uninsured percentages is not subtle. In 2003, North Carolina hospitals with these high percentages averaged -0.6% from operations. The year 2004 was drastically worse, with a -3.3% average operating margin. Thanks to voluntary reporting of quality indicators opening access to a full market basket update on Medicare payments, 2005 average operating margins for hospitals with these high percentages were -0.5%. Hospitals with moderate percentages of Medicare, Medicaid, and uninsured patients averaged positive but narrow margins, while hospitals with the lowest percentages of these patients averaged operating margins of almost 5% or greater.

Such widespread misery—brought on by government underpayment for Medicare and Medicaid and government indifference toward the uninsured and those who serve them—jeopardizes care for all North Carolinians. **NCMedJ**

Latinos, Immigrants, and the Uninsured

Mark Holmes, PhD

I have presented data on the North Carolina uninsured a number of times over the past couple years to a variety of audiences. Typically each audience finds a particular point of interest—one audience may ask questions about the low-income uninsured, while another may be interested in the working uninsured—but in almost every situation, one of the first few questions is how either Latinos or immigrants (or both) affect the uninsured rate in our state. This question is not altogether unanticipated. The issue of immigration, legal and illegal, is particularly topical given the tremendous population growth over the past decade and the current political focus. An often cited statistic is that, on a percentage basis, North Carolina's Hispanic population was the fastest growing in the country from 1990 to 2000. Congress's consideration of immigration reform, and the subsequent public demonstrations, has focused national interest on the issue. Based on this widespread attention to immigrants in general, and how they contribute to the uninsured rate in particular, there is a cry for objective evidence. How much of the uninsurance problem *can* be attributed to Latinos and immigrants?

> *"...two thirds of the difference in the uninsured rate among Latinos and non-Latinos can be explained by factors other than being Latino..."*

The simple answer, of course, is that there is no simple answer. Like most topics worth considering, there is no definitive answer and data can be used to support conflicting conclusions on the issue. However, when one examines the constellation of statistics on this issue, there is only one defendable conclusion: although Latinos and non-citizens in general are more than three times as likely to be uninsured than non-Latinos and citizens, other factors are more important causes of the problem.

Popular media coverage often blurs the definition between *Latinos, immigrants, non-citizens*, and *illegal* (or *unauthorized*) *immigrants*. Often, it appears, many people consider these groups identical. In North Carolina, however, 32% of non-citizens are not Latino, and 35% of Latinos were born in the United States.[1] Non-citizens include both those who are in this country legally (i.e., with work, student, or other visas), as well as those in the country without documentation. Although much of the consternation on this issue relates directly to undocumented (illegal) immigrants, most of the data sources on the uninsured contain no information on an immigrant's legal status.[a,2] Thus, this commentary focuses on ethnicity (Latino or non-Latino) and citizenship (citizen or non-citizen). In addition, I limit my focus specifically to insurance coverage. A broader assessment of the costs and benefits of North Carolina's immigrant population is well beyond the scope of this analysis.

Simple Comparisons of Uninsured Rates

It is useful to start with simple comparisons. As often mentioned elsewhere in this issue of the Journal,[3] most analyses of the uninsured consider only the non-elderly, since due to Medicare, less than 1% of the elderly are uninsured. Table 1 presents the uninsured rate by citizenship and Latino ethnicity. Slightly less than 18% of non-elderly North Carolinians were uninsured in 2004, although there are marked differences by

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[a] One study estimates that 55.5% of North Carolina's Latino population is "authorized."[2]

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Table 1.
Uninsured Rate by Ethnicity and Citizenship, North Carolina 2003-2004

	Not Latino	Latino	Total
Non-citizen	21.9%	73.0%	57.7%
Citizen	15.1%	25.2%	15.4%
Total	15.2%	53.6%	18.0%

Source: Current Population Survey Annual Social and Economic Supplement, US Census Bureau and Bureau of Labor Statistics

both citizenship and ethnicity. While 15% of North Carolina citizens are uninsured, more than half of non-citizens are uninsured. Likewise, 15% of non-Latinos are uninsured compared with 54% of Latinos.

The data can also be considered from another perspective. Latinos represent approximately 7% of the North Carolina population, while non-citizens represent 6%. Of the 1.3 million uninsured, however, Latinos and non-citizens are overrepresented: 22% of the uninsured are Latino, and 20% of the uninsured are non-citizens. Of North Carolina's 1.3 million uninsured, approximately 170,000—just over one in eight—were born in Mexico.

Trends

Another way to consider the role of Latinos and non-citizens would be to look at changes over time.[b] In 2000, roughly 13.4% of non-Latinos were uninsured; that grew to 15.0% in 2004, an increase of 1.6 percentage points. That is, examining only non-Latinos, the uninsured rate grew from 2000 to 2004. The uninsured rate for Latinos, however, grew substantially, from 37.8% to 51.8%, an increase of 14 percentage points. Likewise, the number of uninsured increased by more than 200,000 for non-Latinos and roughly 125,000 for Latinos. Given the total increase of 334,290 in the uninsured, the growth in the number of non-Latino uninsured represented 63% of the total increase in the North Carolina uninsured from 2000 to 2004.

Another way to analyze the changes is to try to discern whether the increase in the number and percent of uninsured Latinos is due to changes in the state's demographics (the percent of population that is Latino), or changes in the within-demographic uninsured rate (the percent of citizen Latinos who lack health insurance). Performing this analysis shows that one quarter to one third of the change in the percentage of North Carolinians who are uninsured between 2000-2004 were driven by changes in the population. The remaining two thirds to three quarters are due to uninsured increases within each group. Note that the percent of citizen non-Latinos—93% of the North Carolina population in 2000—who were uninsured increased 1.4 percentage points from 2000 to 2004. Thus, the increase in the uninsured rate in citizen non-Latinos alone was responsible for roughly 1.3 percentage points statewide—almost half the increase in the uninsured rate from 2000 to 2004.

Nationally, states with proportionately more Latino and/or non-citizens have higher uninsured rates. The question, of course, is whether this relationship is a direct result of high Latino/non-citizen populations, or whether Latino/non-citizen individuals have other risk factors making them likely to be uninsured.

Behind the Curtain—Latinos and Immigrants Have Increased Risk Factors for Being Uninsured

Of course, Latinos and non-citizens have other factors beyond their ethnicity/citizenship status that make them likely to be uninsured. For example, both Latinos and non-citizens are more than twice as likely to have incomes below poverty guidelines, and full-time workers are nearly twice as likely to

Table 2.
Single Year Estimates of the Uninsured Population of North Carolina, 2000-2004

	Percent Uninsured			Number of Uninsured		
Year	Non-Latino	Latino	Total	Non-Latino	Latino	Total
2000	13.4%	37.8%	14.8%	839,752	139,940	979,692
2001	14.4%	43.5%	16.3%	960,877	202,401	1,163,278
2002	16.8%	52.2%	19.0%	1,128,732	233,312	1,362,044
2003	15.8%	58.2%	19.4%	1,051,870	361,796	1,413,665
2004	15.0%	51.8%	17.5%	1,049,697	264,285	1,313,982
Change 2000-2004	1.6%	14.0%	2.7%	209,945	124,345	334,290
Percent of non-elderly North Carolina uninsured population				63%	37%	100%

Source: Current Population Survey Annual Social and Economic Supplement, US Census Bureau and Bureau of Labor Statistics

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[b] The data in Table 2 do not use the two-year averaging used elsewhere in the commentary, so the numbers are slightly different.

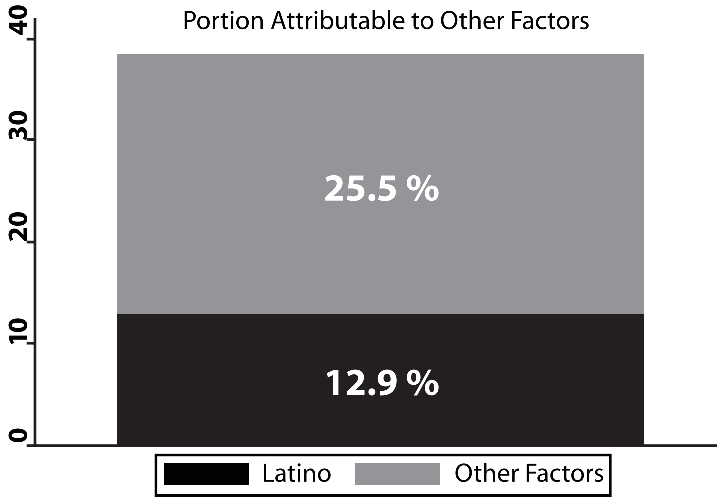
work for a small employer (less than 25 employees). Both low-income and small-employer workers are more likely to be uninsured. Other risk factors for being uninsured are higher among Latino and non-citizen populations. Both groups are much more likely to be male, young adults (25-34), and work in low-coverage industries, such as agriculture, construction, and hospitality.[c,4] In addition, low-income Latinos, especially recent immigrants or people without documentation, are also less likely to qualify for publicly-subsidized insurance, such as Medicaid or North Carolina Health Choice.[d]

After adjusting for the differences in these underlying characteristics, the difference in the uninsured rate attributable to being Latino decreases by 67%, from 38 percentage points to 12 percentage points. In other words, two thirds of the difference in the uninsured rate among Latinos and non-Latinos can be explained by factors other than being Latino *per se*. Similar results hold for citizenship. Note that differences in the rate of being uninsured remain even after adjusting for demographic and socioeconomic differences between the Latino and non-Latino populations.

The Final Answer: A Considerable Contributing Factor, but Not the Largest Driver of the Increase

The evidence, taken in totality, presents a mixed picture. Some statistics in this commentary may seem to prove that Latinos and/or non-citizens are the primary driver of the uninsured rate in North Carolina. Viewed in totality, though, the evidence suggests that other factors, such as socioeconomic status, place of employment, and inability to access publicly-subsidized insurance, may be the factors driving the lack of coverage. The evidence here is consistent with other research, taken from a national perspective, which found that the primary driver of the increase in the uninsured is the increase in health insurance premiums and not changes in demographic or socioeconomic characteristics of the population. One analysis of changes in the uninsured rates of metropolitan areas found that the primary determinant was the increase in the cost of health insurance.[5] Changes in the percent of the metropolitan area residents that were foreign born were generally unrelated to changes in coverage. Another study found that changes in the socioeconomics and demographics of working adults from 1987 to 2002 predict a half a percentage point decrease in the nationwide proportion uninsured. The authors found that the increase in the percent of population that is Latino explained half a percentage point increase in the uninsured rate.[6] A study of immigrants in Los Angeles county found that socioeconomics explained most of the difference in coverage rates between non-native born and native born, but undocumented immigrants remained 16 percentage points more likely to be uninsured after accounting for the differences in employment and other characteristics.[7] The authors claim that extrapolation of their data to national trends suggests that undocumented workers are responsible for about one third of the increase in the number of uninsured adults nationally from 1980-2000. Another study found that nationally white non-Hispanics experienced the greatest increase in the percent of people who were uninsured (1.9 percentage points).[8] The percentage of Hispanics that were uninsured declined 0.3 percentage points from 2000 to 2004. Note the difference in finding from the Gilmer and Kronick article, which underscores the sensitivity of the relationship between the growth in the Latino population and the increase in the rate of uninsurance.[9] Of course, these are national data, which may or may not translate to the specific experience of North Carolina.

Figure 2.
Proportion of Difference in Uninsured Rate between Latinos and Non-Latinos Attributable to Other Factors



Other factors include income, gender, age, working status, industry and employer size. Unadjusted difference is 38.4 percentage points.

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[c] Other differences exist, including some that cannot be evaluated specific to North Carolina. One study, for example, found that non-citizens were more likely to work at firms that did not offer health insurance.[4]

[d] Federal Medicaid and State Child Health Insurance Laws limit coverage to individuals who meet certain eligibility requirements. To qualify, a person must be either a citizen or an immigrant with certain immigration status who has been in the country for at least five years. Additionally, individuals must meet other categorical and eligibility requirements, such as income or resources. Thus, many low-income Latinos are ineligible to receive regular Medicaid or North Carolina Health Choice benefits, even though they might otherwise meet the eligibility requirements.

The Latino and non-citizen populations of North Carolina continue to increase and are likely to continue growing as they have over the past decade. As we monitor more closely the increasing ranks of the uninsured, the Latino and non-citizen populations will bear closer inspection. Potential policy solutions should be constructed that are cognizant of the large numbers of uninsured who are ineligible for public programs due to their citizenship status. However, the majority of the North Carolina uninsured are non-Latino *and* citizens, so equating "the uninsured problem" with "the immigrant problem" is inaccurate. Addressing the increasing numbers of uninsured is within the realm of our state-level policy capability, and it does not depend on marginalizing our newest North Carolina residents. **NCMedJ**

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Health Insurance Coverage:

A Luxury for Most North Carolina Latinos

Javier, his wife and three children moved to North Carolina in June 2000, after Javier lost his job in San Luis Potosí in central Mexico. When first moving to Siler City, Javier worked as a day laborer, doing odd jobs for anyone willing to hire him for a few hours a day. As a day laborer, Javier met the owner of a small landscaping company, and eventually, started working for him full-time. The landscaping business was small, with only four employees, and did not offer health insurance coverage to its workers. Urgent care clinics expected to be paid in cash the day of the visit, and the family doctor in the area charged more per visit than Javier made per day. Javier and his family had no choice but to rely on the emergency room for care.

After six months of working in the landscaping world, Javier found a job at a local poultry plant working third shift. He looked forward to working at a job indoors, where the weather would not impact his ability to earn a living. At this new job, Javier was offered health insurance for his family: $110 a week, $440 a month. However, Javier and his family rely on every penny of his paycheck to buy food and clothing; therefore, not making the purchase of health insurance coverage an option.

Javier's ten year–old son, Gabriel, has asthma, which gets worse in the winter months. In the past few years, the family has learned to manage his asthma. However, a couple of times a year, Gabriel's mother wakes up in the middle of the night to hear Gabriel struggling for air. She offers him chamomile tea and gives him a bath, hoping that the steam will help him breath better. Her remedies help—most of the time. But some times, he continues coughing and struggling for air, even after she has exhausted all of her home remedies. Not knowing what else to do, she takes him to the emergency room, where he receives the care he needs; and she is lectured about the importance of Gabriel using his inhaler on a daily basis. She is too embarrassed to explain to the nurse that without health insurance coverage, unless her husband is given the chance at the poultry plant to work overtime hours every week, his family cannot afford the cost of Gabriel's asthma medication, which is more than $100 a month.

Currently, Javier owes the emergency room over $6,000 in medical bills. For Javier and his family, depending on the emergency room is their only option for medical care. They have learned that even if emergency room visits are expensive, they can make small monthly payments and do not need to have cash on hand. Not being a United States Citizen or a Legal Permanent Resident, Javier's family does not qualify for Medicaid or North Carolina Health Choice, the publicly funded safety net insurance programs for most low-income North Carolina residents. Their family has no safety net; their only hope is that Gabriel will outgrow his asthma. For Javier and his family, like for most low-income families in our state, purchasing private health insurance is not an option, but a luxury they cannot afford. This case, unfortunately, is not an exception, but one that reflects the reality of many Latinos living throughout our state.

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COMMENTARY

Caring for the Uninsured:

A Physician's View from the Safety Net

C. Annette DuBard, MD, MPH

Making do without health insurance is an experience familiar to an increasing number of Americans. By now, 13% of non-elderly adults have had at least one gap in coverage during any two-year period. Included among them are a disproportionate number of racial and ethnic minorities and an alarming proportion of the poor. Lack of health insurance typically does not reflect a lack of need for healthcare. On the contrary, the uninsured consistently have worse clinical outcomes and suffer greater risk of premature death than the uninsured.[1] The uninsured share something else in common—a front-row view of the worst our healthcare system has to offer: maldistribution of primary and preventive care availability, fragmentation of services and lack of communication between providers, and the exorbitant price inflation that results from layers of overhead costs and complex payer arrangements.

Inside the Safety Net

I work in the so-called safety net, as a family physician in a federally-supported community health center, where virtually all patients live below 200% of the federal poverty level, and 40% are uninsured. Community health centers pride themselves on providing affordable, comprehensive, patient-centered primary care regardless of a patient's ability to pay. By multiple measures, such clinics provide a quality of care that equals or exceeds that of other healthcare providers, alleviates the health disparities that are plaguing our nation, and reduces overall healthcare costs by decreasing preventable hospitalizations and emergency department use.[2-8] We are only one small piece of the safety net puzzle, which includes health departments and free clinics, hospitals and outpatient teaching clinics, and the countless private practice physicians who absorb much of the cost of caring for the uninsured.

It is a joy to provide a true medical home for patients who are so accustomed to being shuffled around and receiving band-aid solutions for immediate, acute healthcare needs, with no plan for follow-up care beyond "anywhere but here." Uninsured patients who find their way into a stable source of ongoing, affordable, comprehensive primary care must learn a whole new way of interacting with the healthcare system. It becomes possible for them to think beyond immediate concerns, toward long-term approaches to maintaining good health and responsibly managing chronic disease. My vantage point debunks the negative mythology that surrounds the uninsured. I don't feel like anyone is looking for an opportunity to sue me, or wanting "something for nothing." I don't feel a lack of "gratitude." Typically, the more I understand of my patients' lives, the more I respect what they're up against. Nationally, more than 8 in 10 uninsured come from working families. My billing office, which discounts charges based on the patient's income, reports that 90% of our patients pay 100% of what is asked of them.

> *"More than 40% of the uninsured have no regular source of care, and 20% consider the emergency room to be their regular source of care. Almost half have had to postpone seeking care because of cost within the past year."*

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The Skill Set of Safety Net Providers

The core competencies of my job—what I know of the social, behavioral, and environmental determinants of health, the workings of social services, and the politics of healthcare—I've learned on the job, patient by patient. Taking care of the indigent uninsured requires a skill set that is not measured by any degree, board certification, or compensation system. It requires communication in a language that the patient can understand—for almost half of my patients, that means Spanish. For so many others, it's English at a fifth grade level. It requires a willingness to accommodate to the demands of my patients' lives—their complicated work schedules, frequent changes of address and intermittent phone service, the unpredictable availability of transportation or childcare from a friend or family member—which means working in one more patient at the end of today who didn't show up yesterday and taking on far more than just the "chief complaint" at any visit. It requires agility in pharmaco-economics at the micro level: emptying the grocery sack full of assorted pill bottles and samples or scrutinizing the stack of unfilled prescriptions from the last hospital discharge and starting over based on the amount of cash in the patient's pocket. Which can be substituted with a cheaper alternative? Could we get this one from a patient assistance program? What must be filled today; what can wait until the next paycheck; and what can we do without?

We learn, in the primary care safety net, an alternative way of doing medicine: what you can with what you've got. Expertise in our field requires knowledge of at least two approaches to any diagnostic or therapeutic problem. If you come to me with worsening asthma, or severe headaches, or abnormal liver tests, or infertility, I will flip straight to the section of your chart that tells me whether you have insurance. I will provide you the best care I can, but it will be tailored to your situation—which medications you can afford to try, which tests you can afford to undergo, how likely a specialist is to see you in consultation. I shoulder the knowledge that if my patient has a need that I can't take care of, that need will likely go unmet. So I've learned how to apply dental varnish for children who can't see a dentist. I do office procedures for which insured patients would be referred elsewhere. I work into my rushed visits tidbits of dietary guidance for diabetics who have no access to a dietician and brief counseling for patients suffering mental illness who have no access to a mental health professional. It is not enough.

When the Safety Net Falls Short

When patients' needs extend beyond primary care, my role is to help them navigate the healthcare system outside my doors, which is a challenge for anyone, but a particularly daunting task for those with no buying power (even if, like my patients, they live within 45 minutes of four hospitals, in a region of the state with one of the highest concentrations of specialist physicians). The tertiary medical center will say, "that sounds like something that can be handled at the local hospital," and the local hospital will say, "that sounds more appropriate for the tertiary medical center." For less urgent requests for consultation, any number of barriers may fly up. Patients may be asked to pay in full up front, to arrange an appointment with a financial counselor before a medical appointment can be made, to bring their own interpreter if Spanish-speaking, to send in written information or prior medical records for review and await a phone call if the referral is deemed appropriate. Important and substantial exceptions to this can be identified in every community, but institutional barriers to getting patients to the care they need grow in direct correlation with growth in the number of uninsured and under-insured. Too often, that means patients leave my office with the disgraceful advice: "you'll just have to go to the emergency room the next time it happens (the chest pain, the gallbladder attack, the seizure, the severe headache)."

It's Time for Real Solutions

All this is to say that strengthening the primary care safety net is a good and critical thing, but it will never be a substitute for universal health coverage. Despite federal initiatives that have emphasized expansion of safety net capacity in recent years, healthcare providers serving the uninsured are feeling increasingly strained. The 1.3% increase in total federal spending for care for the uninsured from 2001-2004 pales in comparison to the 11.2% increase in the number of uninsured over this time period.[9] More than 40% of the uninsured have no regular source of care, and 20% consider the emergency room to be their regular source of care. Almost half have had to postpone seeking care because of cost within the past year.[10]

Is it not shameful that in this, the richest nation on earth, 45.5 million people cannot count on access to basic healthcare services? Are we to be proud of our achievements in building the "best medical care in the world" while rationing that care in the most vicious of ways: all for some and none for so many? When I go to work tomorrow, I can expect to see someone whose colon cancer wasn't diagnosed until too late because screening was not available to her. I will see someone who has been disabled by a stroke because he never received adequate care for his high blood pressure and diabetes. I will see someone who keeps missing work or school because of asthma attacks, but cannot afford the medicine that would prevent them. What my patients need is not a safety net, but a healthcare system that makes sense. **NCMedJ**

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COMMENTARY

A Perspective on the Dentally Uninsured

M. Alec Parker, DMD

For many fortunate North Carolinians, "access to care" is something that is taken for granted. Through employer-funded benefit plans, many people have dental insurance benefits that help defray some of the costs of dental care for themselves and their families. These dental plans have been especially popular within the benefit packages that are offered by larger companies and corporations as a way to recruit and retain employees. But this trend is changing. As employers seek ways to cut costs, some employees are experiencing cutbacks in their dental insurance coverage. Others are seeing those benefits disappear altogether. Although the loss of dental benefits is not nearly as devastating as the loss of medical coverage, it does create a financial hardship for those who do not have the discretionary income to spend on oral health needs.

Lack of Dental Insurance Affects Vulnerable Populations

In 2000, the United States Department of Health and Human Services published *Oral Health in America: A Report of the Surgeon General*,[1] which found that 108 million children and adults in the United States had no dental insurance—twice the number of Americans who had no medical insurance. And it seems that those who suffer the most as a result of the lack of insurance are the most vulnerable—the very young and the very old. Like any other problem, the first step toward finding a solution is awareness. Unfortunately, one of the most frustrating problems is that those individuals and groups who tend to be at the highest risk for dental diseases seem to be the most overlooked or most unaware. For example, some parents do not recognize the importance of caring for their children's primary teeth because most of those teeth will be gone by the time they are in middle school. They don't realize that they are important not only in the development of proper speech and a healthy self-image, but that they allow the permanent teeth to erupt into proper position. Others do not realize the negative impact that diets high in sugar can have on oral health. Of particular concern is the amount of soft drinks consumed by school-age children. It is alarming to note that 51 million school hours are lost each year due to dental-related health problems.

> *"...one of the most frustrating problems is that those individuals and groups who tend to be at the highest risk for dental diseases seem to be the most overlooked or most unaware."*

Elderly people face a different scenario. Many still harbor the belief that they should expect to lose their teeth as they get older. This belief tends to cause older adults to decrease the number of dental visits for routine preventive care at a time when their dentition is beginning to become more vulnerable. Tooth loss can lead to a multitude of dietary and lifestyle compensations. Many older adults find themselves in nursing homes or other assisted living facilities that can limit their access to dental care within their communities. Although some of these facilities have contracts with dentists to provide dental care to their residents, most utilize the offices of private practitioners to deliver care for those who are healthy enough to be transported. Without access to regular checkups and preventive visits, older adults face an increased likelihood of chronic oral pain resulting from periodontal diseases and tooth loss due to extraction for cases of untreated decay. If left untreated, these dental problems can limit normal daily activities, affect their nutritional intake, alter their level of independence, and complicate other existing overall health issues.

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Dental Insurance

In order to understand the impact of being dentally uninsured, it is important to understand that there are some basic differences between dental insurance and medical insurance. One of those differences is that dental insurance plans have traditionally offered financial incentives for patients to seek regular preventive dental care, such as cleanings, examinations, and radiographs. These incentives are built into the reimbursement rates whereby patients receive up to 100% coverage for these diagnostic and preventive services. This encourages patients to visit their dentist regularly so that potential problems can be diagnosed and treated before they become both more complex and more costly. This arrangement works well for both the patient and the insurance company since it saves both parties time and money.

There are three types of dental insurance plans available in the marketplace—traditional insurance, managed care plans, and direct reimbursement. It is important to look at the most common features of traditional dental insurance plans and then see how those features compare with the other types of insurance. First, the traditional plan allows patients freedom of choice when it comes to selecting their dentist. There is no financial incentive for them to choose one dentist over another. Second, most traditional dental insurance plans have an annual maximum benefit. This is usually $1,000 to $1,500 per year for each individual covered by the plan. To further help promote preventive care and to control costs, most plans pay up to 100% of the cost of diagnostic and preventive services. For more routine restorative procedures, such as fillings, most plans pay about 70 to 80%. Reimbursement levels usually drop to about 50% for more complex restorative needs, such as crowns and other prosthetic appliances.

Managed care plans work differently. Insurance companies market these plans in an effort to help control their administrative fees and serve as an alternative to employers who might be looking to lower their premium costs while continuing to provide dental benefits to their employees. The most popular managed care plans being marketed in North Carolina are called "Preferred Provider Plans." Insurance companies seek to assemble a network of providers ("Preferred Providers") who agree to serve the dental needs of those patients whose employers have chosen to purchase the plan for their employees or offer the plan as an individual group purchase option. Managed care plans offer similar incentives to patients by encouraging regular preventive care. They also have annual maximum benefit levels as well as a tiered payment system based on the agreed upon fee schedules accepted by the participating dentist. The cost savings are available to the insurance company by recruiting dentists who agree to accept a fee schedule that is usually discounted 10-to-30% below the prevailing fees within the geographic area. In return for agreeing to discount his/her fees to those within this plan, the insurance company places the dentist's name on a list of their "Preferred Providers." As an incentive for patients to seek care in the office of a "Preferred Provider," they are often offered an additional discount relative to their out-of-pocket co-payments or deductible amounts.

The third, lesser known, type of plan is Direct Reimbursement (DR). This option was developed by the American Dental Association as a self-funded, tax deductible strategy to help employers control escalating premium costs while providing their employees with excellent dental benefits. Unlike traditional plans, there are no monthly premiums for employers to pay since there are no administrative costs built into DR. Employers only pay when an employee utilizes the plan. (Administrative fees charged by insurance carriers can account for up to 25% of the total annual costs of the plan.) Organizations that choose DR have the opportunity to select a dollar amount plan designed specifically for their employees, while setting an annual maximum limit for the year. This allows them to know their total investment for the plan without the worry of increasing premium costs year after year. It is interesting to note that since 1985, DR has experienced only a 2% turnover rate compared to the 10% or higher termination rate within other types of plans. This retention rate can be attributed to the cost-effective, non-networked dental benefits that are appreciated by both employers and their employees. Direct Reimbursement in North Carolina currently has 200+ participating groups covering more than 80,000 people, and it continues to gain market share in this very competitive environment.

Dentists Helping Low-Income Patients without Dental Insurance

For those individuals who are not fortunate enough to have dental insurance benefits and cannot afford to pay the total costs of obtaining dental care in a traditional fee-for-service environment, there are several opportunities for them to obtain dental care. Medicaid benefits are available to many low-income residents of North Carolina. The major barrier with having these benefits is finding a dentist who can afford to provide care given the low Medicaid reimbursement rates. Many counties have dental clinics within their health departments that charge fees on a sliding scale based on household income in an effort to make care more affordable. There are numerous "free clinics" sponsored by local dental societies where practitioners volunteer their time in the evenings or on days off to provide care at no cost. Often dental supply companies donate supplies to help support these charitable efforts. Finally, there are many dentists who provide care at reduced fees for those individuals and families in their practices and in their communities who cannot afford to pay their usual fees.

In addition to these ongoing efforts, there are also other events sponsored by local dental societies and charitable organizations that offer free care by targeting specific populations at different geographic locations throughout the state. For example, the American Dental Association and the North Carolina Dental Society co-sponsor "Give Kids A Smile" on the first Friday in February each year. On that day, each of the 100 counties in North Carolina has an event that provides some type of free dental care to children. Since the program began in 2001, more than 34,000 North Carolina children have received in excess of $3 million in dental care from more than

4,500 dental volunteers. The Duke Endowment and the Kate B. Reynolds Charitable Trust provide financial support for Mission of Mercy Projects scheduled in different locations across our state throughout the year. These are usually two-day events where volunteer dentists set up portable dental equipment in large buildings to provide free care to local low-income residents. It is not unusual for these events to provide free care to several hundred people in a single weekend.

Like any other problem, the first step toward a solution is awareness. The challenge is to effectively educate all of our citizens about the benefits of good oral healthcare regardless of their age or income level. This is especially true for those individuals who are in positions to affect public opinion and public policy. These state and community leaders must be made aware of the overall health risks that are exacerbated by poor oral health habits. If policy makers were aware of the growing body of evidence that suggests a very strong link between oral and systemic health, most would take a more proactive position on assuring that there were mechanisms in place to improve the oral health of our citizens. Improvements in Medicaid reimbursement rates for both children and adults would go a long way in helping to address care to the dental uninsured.

Improving Oral Health Depends on Our Commitment to Dental Care

The real answer to the problem of the low-income dentally uninsured population lies with our society and its degree of commitment to dental care. It is interesting to note that our government provides food stamps to help low-income populations purchase food. Those who are eligible for food stamps can use them at any grocery store to purchase food at 100% of the face value indicated on the food stamp coupons. Also, Medicaid reimbursements for covered *medical* procedures are reimbursed to our medical colleagues at amounts that are equal to 90 to 100% of the Medicare allowable rates. And although progress is being made to increase dental Medicaid reimbursement rates, many procedures continue to be reimbursed at levels less than 50% of their usual costs. At those rates, dentists are losing money each and every time they perform dental procedures for Medicaid recipients. The harsh reality is that society has determined that providing food and medical care for low-income individuals is more important than providing them with dental care. And, until the citizens of North Carolina, and specifically those who serve in our legislature, begin to think differently, we will continue to struggle to find innovative ways to address the dental, emotional, and other health-related problems that low-income individuals experience as a result of those current priorities. **NCMedJ**

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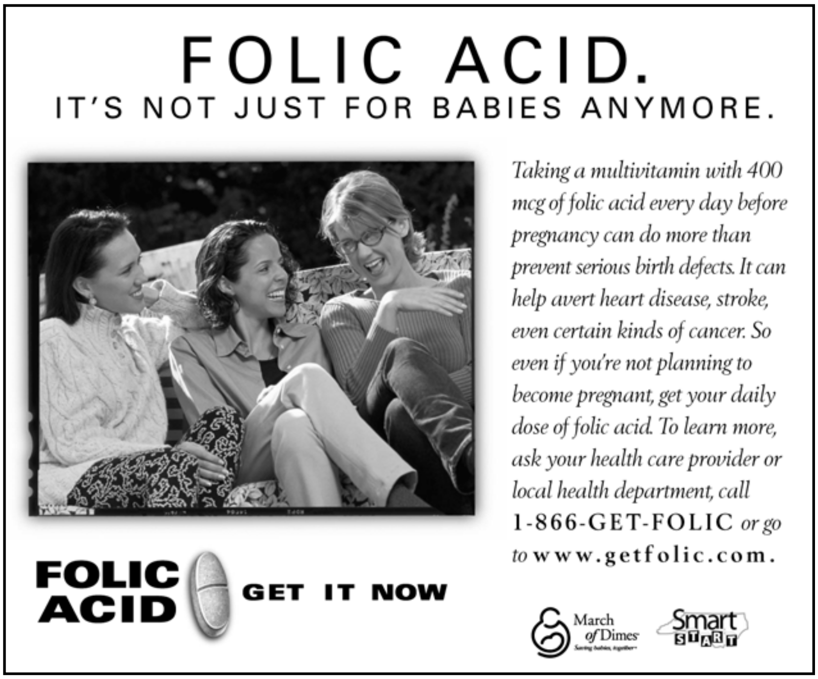

Small Employers and the Provision of Small Group Health Insurance Coverage

Connie Majure-Rhett, CCE, and Kristen L. Dubay, MPP

Overview

Employers are the main source of health insurance for North Carolinians. In 2004, more than 60% of non-elderly North Carolinians accessed health insurance coverage through an employer-sponsored health insurance program.[1] However, small businesses are much less likely to offer health insurance coverage than larger business. In 2002 and 2003, only 29% of North Carolina firms with fewer than ten employees offered health insurance coverage, compared to 68% of firms with 10-24 employees, 79% of firms with 25-99 employees, and 90% of firms with 100 or more employees.[2]

One reason that fewer small firms offer health insurance coverage may be due to higher health insurance premiums, on average, for smaller firms. In North Carolina, 2002-2003 the average annual health insurance premium for workers in small firms with fewer than 50 employees was $3,597, compared to $3,206 for firms with more than 50 employees.[3] Small employers, those with 50 or fewer employees, are subject to health insurance rates set by state "small group" rating laws. These laws were modified in the 1990s to reduce the variation in premiums charged to small employers with similar employment characteristics. Small group rating laws are used to spread the health risks of small employer groups across a larger pool of workers. However, despite these laws, small-firm premiums continue to vary widely, and health insurance premiums are still higher on average for small firms than for larger firms.

Reasons for (Not) Offering Health Insurance

Nonetheless, some small employers still feel that it is important to offer health insurance to their employees. Some employers choose to offer health insurance in order to attract the most qualified workers. This may gain importance as our population ages—a serious concern for small employers. Beginning in 2006, for every two "baby boomers" who retire, only one new worker will join the workforce.[4] The decreasing size of the workforce is making the hiring process more competitive for small employers. As a result, the ability to offer a comprehensive benefit package, particularly one with healthcare coverage, is integral to attracting the most talented and qualified employees.

> *"Many workers remain in jobs that might not be their preferred position because of good health insurance."*

Offering health insurance is also connected to worker retention. Many workers remain in jobs that might not be their preferred position because of good health insurance. For example, married men who receive health insurance from their employer are approximately one-third less likely to leave their jobs than married men not receiving health insurance from their employers.[5,6]

A few small employers choose to offer health insurance coverage to employees because the employer would be unable to access affordable insurance for themselves or their own family members in the non-group market due to pre-existing health conditions. Other employers offer health insurance coverage in lieu of providing higher wages. Research indicates that some employees would support that decision. A survey conducted

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for *The Wall Street Journal Online's* Health Industry Edition found that more than 60% of adults with employer-sponsored health insurance would prefer no pay increase while maintaining or increasing health insurance coverage rather than receiving a pay increase and a decrease in health insurance coverage.[7]

Nonetheless, employers' desires to provide health insurance coverage often contrast with their financial abilities to afford coverage. There are many reasons that employers choose not to offer health insurance coverage, but the main reason is cost.[8] In addition to the higher average health insurance premium costs for small businesses compared to large ones, small business owners also are often unable to hire a benefits manager and must spend considerable time completing the administrative tasks associated with offering health insurance.[9] Facing annual premium increases, many small businesses shop around for lower prices, compounding the administrative burden imposed on the owners or managers. Finally, in a small business group, a serious health event experienced by a covered worker can also significantly increase the premiums for the group as a whole in the following year, thus making it difficult to continue to offer insurance and maintain participation rates.

Another barrier that small businesses face is minimum participation requirements. Many health insurers require businesses to insure at least 50-75% of eligible employees in order to offer the coverage. Presumably, insurers have this requirement in order to prevent adverse selection into the plan. However, this requirement can be very challenging for small businesses, particularly for those with a high proportion of lower-income workers who cannot afford their share of the insurance premium. There are many small employers around the state who would like to offer coverage, but who cannot because they cannot meet the minimum plan participation requirements.

The Role of Small Businesses in the North Carolina Economy

Small businesses play an integral role in the state's economy. Therefore, everyone stands to benefit from ameliorating the challenges facing small businesses and their employees in their quest to obtain affordable health insurance coverage. In 2003, approximately 74% of private-sector establishments in North Carolina were small businesses with less than 50 employees, and 55% were very small businesses with less than ten employees.[10] Of all employees working in private-sector establishments in North Carolina in 2004, more than 26% of workers were employed by an employer with less than 50 employees, and 11% worked for an employer with fewer than ten employees.[11] Additionally, annual payrolls for North Carolina small firms with less than ten employees accounted for more than $9.5 billion in 2003, and small firms with less than 20 employees accounted for more than $15.8 billion in annual payroll.[12]

Therefore, when small businesses are unable to offer health insurance coverage to their employees, the economic impact is felt across the state. People without health insurance coverage use fewer healthcare services and often end up with health conditions that could have been prevented. As a result, the lack of insurance impacts worker productivity. Workers without insurance have 10% more sick days than those with healthcare coverage.[13] Additionally, some estimates indicate that providing health insurance coverage to those without it increases annual productivity and earnings by 10-30% annually.[14] Nationally, the Institute of Medicine of the National Academies estimated that between $65 billion and $130 billion is lost annually due to the poorer health and premature deaths of the uninsured.[15]

Policy Options for Small Business Health Insurance Coverage

Expanding health insurance coverage across North Carolina for all population groups would be beneficial, but the need for some immediate solutions is particularly acute for small businesses. There are a number of potential policy options at both the state and national levels for expanding health insurance coverage to small businesses. Some of them were highlighted in the North Carolina Institute of Medicine's *Covering the Uninsured Task Force report,*[16] and others have been introduced into the North Carolina General Assembly or in the United States Congress.

The North Carolina Institute of Medicine (NC IOM) Task Force recommendations that would particularly benefit small businesses include: development of a Healthy North Carolina program, implementation of a high-risk pool, expansion of the Medicaid program for low-income parents, and reviewing the impact of the state's small group reform laws. The Healthy North Carolina program would be targeted specifically for small businesses and sole proprietors. It would use government reinsurance to reduce the costs of a new private market health insurance plan for small employers, low-income individual workers, and self-employed individuals previously without health insurance coverage. It is expected that Healthy North Carolina would provide a 30% premium cost reduction over similar plans in the healthcare market, leading to health insurance coverage for approximately 33,500 currently uninsured North Carolinians.

The Task Force also recommended implementing a high-risk pool in North Carolina. There are many individuals with pre-existing conditions who work in or own a small business who would benefit from participation in a high-risk pool. A high-risk pool would control the premium costs of health insurance for individuals with greater health risk factors and take some of them out of the small group market. This could potentially have the effect of lowering the overall market risk and, thus, reducing costs for health insurance coverage in the small group market.

Another Task Force recommendation could benefit workers in small businesses through premium assistance for employer-sponsored insurance. The Task Force recommendation suggests expanding Medicaid to cover parents with incomes less than 200% of the federal poverty guidelines. Through this expansion and an associated waiver from the federal government, Medicaid-eligible parents could use state Medicaid funds to buy into their employers' health plans. As a result, this would help small businesses with low-income workers meet the plan participation requirements of insurance carriers.

Tiered benefit plans were also recommended by the Task Force; however, there is some concern among small businesses regarding the potential this could have for reducing healthcare coverage to "bare bones" plans offering only minimal coverage. Catastrophic coverage is very important to a small business because if a small business owner experiences a serious health event without catastrophic coverage, it could result in the bankruptcy of the entire business. Therefore, unless tiered benefit plans were linked with catastrophic coverage, these plans would not be optimal for small businesses. However, even limited insurance coverage is preferred to none.

North Carolina must also steer clear of supporting association health plans. Association health plans are a way for small businesses to pool their employees to spread health risks across a larger group in order to access lower premiums for health insurance coverage. In North Carolina, association health plans are required to meet the state consumer protection laws outlined by the Department of Insurance, which includes specific mandated services. However, there is a new bill in Congress, S1955 Health Insurance Marketplace and Modernization and Affordability Act of 2006, introduced by Senators Michael Enzi and Ben Nelson, that would enact national standards for regulating and administering health insurance. This bill would favor small group rating laws that lead to larger premium variations charged to small employers.[17] As a result, insurers could avoid offering state-mandated benefits if they offered a benefit plan that includes the mandates covered by the state employee health plans of the five most populous states. As such, insurers offering non-state mandated plans could attract the healthier consumers, thereby increasing the average health risks for the population remaining in health plans with mandated benefits. This could lead to higher premium costs and continued loss of insurance coverage for the smallest businesses and businesses with the highest-risk workers.

At the state and national levels, there are a number of other policy options that could be beneficial to small employers, particularly in the form of tax incentives for businesses that offer and/or contribute to health insurance for their employees. House Bill 20 was introduced into the North Carolina General Assembly in 2005 by Representatives Holliman, Bordsen, Goforth, and Ross. The bill recommends providing a tax credit for small businesses that pay for at least 50% of health insurance premiums for all eligible employees.[18] At the national level, United States Senator Olympia Snowe recently introduced the "Small Business Health Insurance Relief Act of 2006" (S2457), which would provide tax incentives to small businesses offering health insurance coverage to their employees. In particular, the law would offer greater tax credits to the smallest businesses, which have fewer than ten employees, and enable small businesses to offer "cafeteria plans" with non-taxable benefits.[19]

In addition, both the House and Senate of the North Carolina General Assembly have discussed the idea of a Healthy North Carolina model, similar to the one recommended by the North Carolina Institute of Medicine Task Force. In the 2005-2006 Session, the Senate discussed a proposed committee substitute, which focused on a version of the Healthy North Carolina model. The House of Representatives Select Committee on Health also chose a Healthy North Carolina model as one of their recommendations from the full committee, making it eligible for consideration in the 2006 short session.

Every year, small business surveys indicate that health insurance coverage is one of the top issues of concern to North Carolina small business owners. Small businesses need to remain steadfast in their work to find effective and realistic ways to access more affordable health insurance coverage for their workers. Supporting the introduction of the Healthy North Carolina program and a high-risk pool are two of the most important efforts small businesses could make to affect change in the near-term. At the federal level, support for tax incentives could also offer some relief. Small business owners and employees make up more than a quarter of the state's workforce and face much greater challenges accessing health insurance than workers in larger firms. To continue to keep North Carolina's economy strong and supported by this workforce, greater access to healthcare should be made available to small businesses. **NCMedJ**

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COMMENTARY

North Carolina High-Risk Insurance Pools

David R. Moore, CLU

Imagine this: You are a 58-year-old man. You have worked all your life, paid taxes, and helped support your family. Two years ago you had a mild heart attack. Your wife has diabetes and high blood pressure. Luckily, you had health insurance through your job that helped you pay for the hospitalization, doctor's visits, and necessary medications for you and your wife. With a new diet, exercise, and the medications, you both are doing well managing your health problems. A little over a year ago, you lost your insurance when your company downsized. You found another job, but your current employer doesn't offer insurance. Your wife also works, but she works for a small employer that does not offer coverage. So, you pay approximately $600/month for continuation coverage (COBRA) for your wife and yourself through your former employer. Last month, you found out your COBRA coverage is about to end. You want to continue to buy insurance coverage, but you were told that purchasing a comprehensive policy with a $1,000 deductible (70% coinsurance) that covers your needed medications would cost more than $4,000/month for your wife and yourself.

All of us know people with health problems; these are the people who most need health insurance. But, have you ever stopped to think about how difficult or expensive it is to buy health insurance if you have pre-existing conditions? As a health and life insurance underwriter (independent insurance agent), I frequently work with families who want to buy health insurance, but have problems because of their past health history or ongoing health problems.

State and federal laws provide some protections for people who have health problems if they work for an employer who offers coverage. Under these laws, people with employer-based coverage cannot be charged higher premiums or excluded from coverage because of their pre-existing health problems. However, these same protections don't generally apply to individuals who want to purchase health insurance in the non-group market. There is currently only one insurer in North Carolina—Blue Cross and Blue Shield of North Carolina (BCBSNC)—that will cover anyone, regardless of their health status. However, the premiums charged are high, because people with pre-existing health problems typically incur greater than average healthcare costs. The premiums charged to people with the most serious health problems may be seven times higher than the premiums charged to a healthy individual. This premium is unaffordable to most families.

Thirty-three other states have established high-risk pools to offer comprehensive health insurance coverage to people with pre-existing health problems. These high-risk pools are similar to high-risk auto insurance. In North Carolina, individuals with poor driving records can purchase automobile insurance—at a higher rate—through the state's high-risk automobile pool. The pool is financed through premiums and an assessment on all of the automobile insurers in the state.

The states that offer high-risk health insurance typically cap the premium charged to families to make the coverage more affordable. Generally, the premium can be no more than 1.5 times (or 150%) of the standard rate charged to comparable healthy individuals.[a] However, because these premiums do not cover the full costs of the healthcare services that the insured high-risk individuals use, states pay for the deficits through assessments on insurance companies, state appropriations, or other means.[b,1] For the last five years, the North Carolina Health Underwriters Association has advocated that North

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[a] Most states cap the premium at 150% of the standard rate; however, a few states allow premiums to be up to 200% of the standard rate. Health plans typically vary insurance premiums based on the person's age, gender, and geographic location. In a high-risk pool, the 150% cap would be based on a healthy person with a similar age and gender and living in the same geographic area of the state.

[b] Twenty-seven states finance the losses in their high-risk pool through an assessment on insurers. Of these, 11 states provide full or partial tax credits to offset the assessment, effectively shifting the costs back to the state. Seven states have a broad assessment on insurers, including commercial insurance carriers, stop-loss or reinsurance carriers, third-party administrators on a per-person/per-month basis. Two states pay for the losses through a surcharge on hospital bills, and five states use general revenues to fund their losses.[1]

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Carolina join the majority of other states and create a high-risk pool to provide affordable coverage to the people with pre-existing health problems.

Two bills have been introduced in the North Carolina General Assembly that would create a high-risk pool: HB 1895 (introduced by Representatives Insko, England, Nye, and Wright, with 28 other co-sponsors) and SB 1681 (introduced by Senator Purcell). The House Select Committee on Health and the North Carolina Institute of Medicine's Task Force on Covering the Uninsured supports similar legislation. While these bills may change as the legislation is debated in the General Assembly, the proposed legislation accomplishes the goal of providing more affordable health insurance to people with pre-existing health problems.

Under the introduced legislation, people with pre-existing health problems would be eligible for the pool if they had been turned down by two insurers due to pre-existing health problems, charged premiums by two insurers with higher rates than offered through the high-risk pool, or offered a health plan by two insurers with conditional riders that exclude coverage for the pre-existing health conditions. Individuals could also qualify if they have specific health problems that were identified by the plan administrators as eligible for coverage, such as HIV/AIDS. Certain other people who do not have pre-existing health problems can also purchase health insurance through the pool if they are unable to find better health insurance coverage in the private market. These include individuals who are guaranteed coverage in the non-group market under the federal Health Insurance Portability and Accountability Act (HIPAA) laws (described previously), or people who lost their insurance when their employer downsized or closed due to the Trade Adjustment Act.

> *"Many of these individuals want to buy health insurance, but can't afford the policies that currently exist."*

Like most other states, the current legislation caps the premium at 150% of the standard rate charged by other insurers offering health insurance to individuals. Rates can be adjusted by age, sex, and geographic variation in claims cost in accordance with established actuary and underwriting practices. In addition, the bills that were introduced would also provide an additional premium subsidy for lower- or moderate-income families to help them afford their health insurance premiums.

The pool would offer several different plans, including Preferred Provider Organization (PPO) plans with different deductibles and cost-sharing levels and at least one high-deductible Health Savings Account plan (HSA).[c] The plans must include at least a $1 million lifetime limit and sliding-fee scale annual limit on out-of-pocket expenses of $2,000-$5,000 based on family income.

This is not the first time that high-risk pool legislation has been introduced in the North Carolina General Assembly. Similar legislation to either establish or study the need for a high-risk pool has been introduced at various times dating back to the 1980s. Historically, the major stumbling block has been the mechanism to finance the uncovered claims costs (e.g., the healthcare costs that are in excess of the premiums collected). Insurance companies have opposed past attempts to finance the uncovered costs through assessments on covered lives. They were concerned that an assessment focused solely on commercial insurance companies, like Blue Cross and Blue Sheild of North Carolina, United Healthcare, Cigna, Wellpath, Fortis, and all other providers of health insurance products in North Carolina, would raise the costs of their premiums, leading more employer groups to self-insure in order to avoid paying the assessment. Provider groups similarly opposed any attempts to cover losses through a provider assessment, arguing that the assessment was nothing more than a "sick-tax" (e.g., tax on sick people). The General Assembly has never been willing to appropriate state funds to finance a high-risk pool.

This year, the legislation is structured differently. Instead of singling out any one group to bear the burden of financing the losses, the legislation spreads the burden across multiple groups. The bill limits provider reimbursement to the Medicare rates, which is lower than what is typically paid through commercial insurance plans. By accepting this lower reimbursement, providers help by lowering overall healthcare costs and therefore, the amount of financial loss to the plan. The proposed legislation also assesses insurers to help pay for the losses. However, unlike past attempts that focused the assessment on commercially insured plans, this legislation calls for a broader-based assessment on commercially insured plans, multiple employer welfare arrangements (MEWAs), third-party administrators (TPAs), administrative service organizations (ASOs), and reinsurers. This helps spread the costs to employer groups that purchase health insurance through commercial insurers, and indirectly, to those who self-insure (by assessing third-party administrators or reinsurers). The legislation also calls for a general appropriation to help subsidize the costs of insurance coverage for lower-income or moderate-income individuals. Congress also appropriated $75 million annually through 2010 to help states offset some of the losses incurred in high-risk pools, and another $15 million to provide

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[c] A Health Savings Account is a high-deductible health plan combined with a pretax savings account. Both employers and employees can contribute to the savings account with pretax dollars. Individuals can withdraw funds from the savings account to pay for healthcare expenses up to the deductible amount.

grants of up to $1 million to help states, like North Carolina, establish a high-risk pool.[2]

> *"The premiums charged to people with the most serious health problems may be seven times higher than the premiums charged to a healthy individual."*

Making health insurance coverage affordable to people with pre-existing health problems is not only the "right thing to do," it is also a smart investment. People who have chronic illnesses or other serious health problems (such as cancer) are more likely than healthier people to need healthcare services. Many of these individuals want to buy health insurance, but can't afford the policies that currently exist. So instead of creating a health insurance product that captures the premium dollars these people are able to afford, we force many people to go without insurance coverage. Without insurance, they are more likely to forgo the care they need to manage their health problems, and their health suffers as a result. Many end up in the hospital with problems that could have been prevented, with no way to pay for the outstanding hospital bills. Large outstanding healthcare bills (often caused by lack of insurance coverage) is one of the primary reasons that people go into bankruptcy.[3] This affects not only the individual family and specific healthcare providers, but other creditors as well. Further, all of us who have health insurance pay higher premiums to help cover the costs of services provided to the uninsured. Thus, by creating an affordable insurance product for those with prior health problems, we both make it easier for these individuals to obtain needed health services in a timely way in an appropriate—and hopefully less costly—setting, but also help capture the funds these individuals can afford to pay for needed healthcare services. **NCMedJ**

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Advocating for Healthcare

In 1983, I began a journey that taught me the inadequacies of the health insurance industry. My daughter was born with a birth defect known as microtia. Within 18 months of her birth, my husband became unemployed, and as a result, we lost our health insurance coverage. My husband found employment in North Carolina, and we moved in 1985. During this time, I spent countless hours researching microtia and seeking medical care for my daughter.

In 1989, I finally found doctors who could care for my daughter, and I thought our troubles were over. However, we were quickly denied coverage because she wasn't born on the health insurance plan that we were now under. The reality was that the insurance plan included a clause that exempted all claims for a child with a birth defect unless the child was born under the plan. This was not a pre-existing clause that would give coverage after a period of time, but a clause that prohibited payment at any time for that defect. We chose to fight the claim denial since we had not been able to secure a proper diagnosis for our daughter previously, and the surgery that she needed was not usually done prior to the age of seven years. With the help of our daughter's doctors, we advocated for her care and won our case. Once again, we believed our troubles were over since our daughter was going to receive her much needed medical care. We hoped that this chapter of our life was closing, and life would move on.

As life would have it, in the next few years my husband was laid off from his job again. In a funny coincidence the company he was working for (a small business with less than ten employees) was denied health insurance coverage. One week after his lay-off, the company secured health insurance coverage. Tired of living through unemployment at life's twists and turns, we decided to open our own business. We thought that we had taken control of our own fate, but now we became our own small group seeking health insurance coverage. This presented a challenge all it's own without having the additional difficulty of a child with a congenital defect.

During the ten years we owned our business, we were never able to obtain health insurance for two main reasons:

- The cost was prohibitive—in the mid-1990s, I received quotes for health insurance for our family that were between $800-$1,000 per month.
- We were asked to sign a waiver that stated we would not seek coverage for anything related to our daughter's birth defect.

After our previous experience with insurance claims, we were not comfortable signing an agreement that gave up our daughter's right to coverage for her medical condition, and as a result, we weren't insurable. In the end, we resolved the situation by closing our business. Our overwhelming concerns for our family's health lead us to seek employment with large employers where our daughter's condition would not be a factor in health insurance coverage. We knew we had an overwhelming obligation to our entire family and how devastating a medical emergency could be financially. We went through a difficult transition as we adjusted to less monthly income, but we felt more secure knowing that our children were now protected by a health insurance plan.

Today, we are glad that our situation has been resolved. However, I continue to be greatly concerned about healthcare in the United States and the countless others who are not able to find alternate employment to reconcile issues such as these. Everyday, I hear the concerns of others who are struggling with insurance issues and finding it increasingly difficult to maintain their families' financial and physical health.

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COMMENTARY

Insuring North Carolina's Working Poor:
Building the Foundation

L. Allen Dobson, MD

The work of the Covering the Uninsured Task Force of the North Carolina Institute of Medicine and the subject of this Journal forum is extremely timely and focuses on maybe the most important healthcare issue facing our state in decades. Basic affordable healthcare is essential to the health of our state, our citizens, and our economic future. There are no simple solutions, but we must start now building the foundation programs that will allow us to assure all our citizens have access to needed basic healthcare and affordable health insurance in the future.

North Carolina has made great strides over the past decade in providing health insurance for our states poorest children through expansion of our Medicaid and Health Choice programs. Medicaid, while covering over 800,000 North Carolina children and mothers, also serves a vital role in providing care for our 400,000 poor elderly and disabled citizens. Despite recent difficult economic times and severe state budget shortfalls, North Carolina has avoided many of the draconian cuts and eligibility reductions experienced in other states. While North Carolina has not been forced to exercise major cuts to its Medicaid program, controlling Medicaid spending remains a top priority. Through expanding our successful Community Care of North Carolina program statewide and inclusion of the aged, blind, and disabled Medicaid recipients in our clinical management strategies, we can reduce the rate of expenditure growth in the Medicaid program without sacrificing quality or access to needed services. Community Care networks are now well organized regional networks of physicians, hospitals, health departments, and social service agencies charged with developing improved local systems of care for Medicaid recipients focusing on quality, disease management, and targeted utilization initiatives. This public-private partnership between the Department of Health and Human Services and community providers has produced needed savings, slowed the Medicaid growth rate, and improved the quality of care provided to our Medicaid recipients.

> *"As we focus on exploring low-cost options for providing health insurance to more of our citizens, it is important to support and expand the fragile safety net of providers available to our poorest citizens without insurance until coverage is available to all."*

As we focus on exploring low-cost options for providing health insurance to more of our citizens, it is important to support and expand the fragile safety net of providers available to our poorest citizens without insurance until coverage is available to all. Increased funding to these traditional providers, such as community health centers, public health departments, rural health clinics, and free clinics, is needed to help meet the needs of poor citizens. The care of the poor and uninsured, however, can not be left solely to these providers. A coordinated, community system of free care is needed until we are able to provide more of our citizens with affordable health insurance. The success of Project Access in Asheville and the many similar projects across the state, initially funded by federal Healthy Community

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Access Program (HCAP) grants, illustrates the importance and often unstated role of private physicians in the community safety net. The success of these community efforts to include private primary care access as well as traditional safety net providers in an organized system has successfully expanded the capacity of the system to care for the poor without significant increases in funding. Providing basic primary care through these community-organized systems prevents delay in needed care and often more serious, costly, and unnecessary complications.

This Journal expertly outlines the many options available for expanding affordable health insurance to many more North Carolinians. While the task of covering everyone seems daunting, the recent announcement of the Massachusetts federal waiver approval that creates state-subsidized insurance for low-income working adults and also mandates health insurance for all citizens should illustrate that universal coverage is possible to achieve. Each option presented by the North Carolina Institute of Medicine Task Force on Covering the Uninsured report, *Expanding Health Insurance Coverage to More North Carolinians*[1] is important in providing insurance to different populations of citizens who have no insurance. While Medicaid and North Carolina Health Choice provide health insurance for many of our poorest children, their parents are often uninsured. Childless adults, no matter how poor, have no options for coverage. Many working citizens simply cannot afford the cost of health insurance. It is clear that no one strategy alone will provide for everyone. We must start small, recognizing that there are not sufficient funds available to accomplish the task of full coverage immediately. Long-term success will come from developing programs that also include quality improvement, disease management, and utilization management as important components to assure that the cost of new programs do not grow at a rate that would jeopardize their future. Community Care of North Carolina has shown that such strategies, when implemented locally, can save money while improving quality.

As additional savings are realized in our Medicaid program, it will be important to reinvest some of those savings in building the foundation programs to expand health insurance to all North Carolinians. Building the foundation for providing affordable health insurance for all of our citizens will require a continuing dialog and a strong commitment not only from government, but also businesses, healthcare providers, and citizens. We must start now. It is time for North Carolina step forward to assure healthcare for all of our citizens. **NCMedJ**

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Public Policy Options for Small Employer Health Insurance

Barbara Morales Burke, MHA

Despite the fact that fewer people are covered under an employer health plan than have been in the past, employer-based insurance is and likely will remain the cornerstone of our health insurance system for the foreseeable future. Employees of small firms are less likely than employees of large firms to be offered insurance through their job and, as a result, more likely to be uninsured. For example, data from the 2002-2003 Medical Expenditure Panel Survey showed that only 57.2% of employees working in firms with fewer than 50 employees were offered health insurance. Small firms employ a significant portion of North Carolina's workforce, so the lack of insurance among these firms is a serious public policy concern. Policy options aimed at improving our rate of insured among employees of small firms can and should be considered.

> *"Small group regulation cannot be adjusted to produce dramatic change because [it] is based on cost shifting..."*

Before considering these options, it is useful to understand certain aspects of North Carolina's regulation of small group health insurance premiums. Premiums for small employer groups (those ranging in size from self-employed individuals up to firms with as many as 50 employees) are set using a methodology known as "adjusted community rating with rate bands." The "community rate" is the statewide expected per-person annual claims cost for an insurer's entire book of small group business. The "adjusted community rate" is the differentiation in premium costs from the community rate for a particular small group, based on the small group's "case characteristics," which are defined as age, sex, family composition, and geographic location.

Using the community rate creates a substantial subsidy effect on the premiums charged to groups whose members have higher than average medical risk, because the premium rate for all small group insureds, regardless of risk status, is generated from the same starting point. In other words, higher-risk groups benefit from subsidies because the costs are spread across the groups that are less costly to insure. Working from the community rate, each small employer's premium is adjusted to reflect their differences in expected medical costs due to case characteristics and the specific benefit plan chosen. In addition, premiums are permitted to differ—up to 20%—based on the estimated medical risk of the specific group. Thus, North Carolina laws governing small group health insurance premiums reflect a balance of three rating philosophies: a substantial subsidy effect for groups with higher medical risks, full differentiation based on demographics, and limited differentiation based on medical risk.

Potential Changes to Current Small Group Regulation

Small group regulation cannot be adjusted to produce dramatic changes because this regulation is based on cost shifting rather than the underlying healthcare costs that influence insurance premiums. However, some pricing improvements can be achieved through modest adjustments to current law.

Some employers and interest groups advocate for increasing the subsidy effect for the higher-risk employees, while others advocate for reducing the subsidy effect so coverage wouldn't be too expensive for lower-risk employees. A change to our current system will create undesirable tradeoffs at either extreme since it is based on a cost-shifting approach. Because increasing the subsidy effect produced by the rating process shifts more expense to employers and employees who have fewer health risks, fewer employers will be able to afford the higher-cost insurance, and the youngest and healthiest employees offered coverage on the job may decide it is not a good value and opt out. As those with fewer health risks (i.e., the number of those who cost the least insure) leave the market, the community rate

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rises. Therefore, in reality, increasing the subsidy effect too much would actually produce the opposite of the effect intended—it would inadvertently lead to a lower subsidy effect because there are fewer healthy people in the group to diffuse the costs incurred by those with higher health risks. On the other hand, a rating system that extracts a smaller subsidy from the low-risk groups would increase the likelihood that coverage would become prohibitively expensive for the high-risk groups. Therefore, too great a decrease to the subsidy effect would benefit only the healthiest people and would cause higher numbers of uninsured among less healthy employees. A balance between [these opposing forces] providing a sufficient subsidy effect to help those who cost the most to cover, but not so much subsidy that it drives the low-risk employees out of the market—produces the most beneficial overall results from a public policy standpoint.

The North Carolina Department of Insurance (NCDOI) recently recommended to the North Carolina General Assembly House's Select Committee on Health Care adjustments to the state small group rating laws that would reduce premiums for groups with lower medical risks or certain demographic factors that make them less costly to cover. These changes would result in a modest decrease in the subsidy effect for groups with higher medical risks or certain demographic factors that make them more costly to cover. An additional effect of these changes would be *lowering* premiums or to reducing premium increases for all small groups. This would occur because more lower-risk employees would be able to buy and retain coverage, which would depress the average claims cost and boost the subsidy effect that the community rate has for higher-risk employees. This latter effect is the reason that NCDOI recommends these rating changes.

Some state and federal legislation—most notably bills proposing special treatment for association groups[a]—purport to reduce the high cost of health insurance for small groups. However, these approaches have been flawed due to the fact that they would reduce (or eliminate completely, by fragmenting the small group market) the subsidy effect for higher-cost small employers without providing any offsetting benefit to these groups. Some of these proposals go even further, suggesting the deregulation of association health plans, which would create an un-level playing field within the market and deprive some citizens of consumer protections under state law. As a result, lack of insurance would become an even greater problem for employers whose employees are higher-risk. Association health plans are not a part of the solution for small employers.

New Product Options

New health insurance products may keep coverage affordable for employers who currently offer health insurance coverage to their employees. These products may also appeal to some employers and individuals currently unable to afford to offer or buy coverage. Examples of these products include: high-deductible health plans offered alone or in conjunction with health savings accounts, "limited benefit plans" that cover a certain amount of costs up-front or after meeting a high deductible, and so-called "tiered benefit plans" where an employer contributes toward a base plan with the option for employees to "buy up" to a richer plan. In a few cases, a change to state law would be required to allow these products to be offered or to enable these products to function as intended; in other cases, insurers can and do offer them now.

Proliferation of plans that provide less coverage raises concerns over the financial barriers to obtaining necessary care and whether some employers now offering more comprehensive plans will "trade down." But the reality is, without alternatives, some employers who currently offer coverage may drop it in the future due to cost, and people who cannot afford coverage now will continue not to have any options. A more pressing concern is that these products actually offer value to someone who presently does not have insurance; without value, these products will not even provide incremental improvement in the numbers of uninsured among employees of small firms.

Realistically, alternative products are needed as a part of any multi-pronged approach to sustaining and expanding the small group market. Although tempting from a public policy standpoint, placing limitations on the sale of certain products in an attempt to prevent them from being substituted for more generous coverage is not practical, since there is no way to identify employers or employees who would have to drop coverage due to cost in a future period, but for having the ability to switch to an alternative product. However, requirements can and should be used to preclude the offering of alternative products in a way that subverts small group regulation.

Additional Ways to Subsidize the Cost of Coverage

Because health insurance premiums are simply unaffordable for some employers and employees, additional forms of subsidy may be required to enable some to buy or continue to buy insurance at its present true cost. Attention in our state has focused on tax credits for employers offering coverage and on a program (dubbed "Healthy North Carolina") offering coverage reinsured[b] by the state. Ideas for other, more simple subsidy mechanisms should also be considered.

Tax credits for employers' contributions toward health insurance may help some employers continue to afford offering coverage when they might not otherwise be able to do so. Critics of tax credits rightly point out that credits will reward employers who would offer coverage even without a credit, and therefore are not an efficient use of state funds. Targeted credits, such as credits for employers with lower-paid employees or those not currently offering coverage could be a more effective

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[a] Association Health Plans are groups of small employers pooling together to self-insure.

tool to contain or decrease the ranks of the uninsured.

The Healthy North Carolina proposal, modeled after an existing program in New York state, would rely upon state-provided reinsurance to reduce the level of premiums that insurers would charge eligible employers and workers for coverage. For this program to work in North Carolina, key differences between this state's and New York's insurance market must be addressed. Funding for the reinsurance needs to be both adequate and reliable in order to have the desired effect on premiums. Premiums and benefits need to appeal to the target population. Eligibility and other program rules need to be set in such a way as to avoid attracting only high-risk groups to the program and also avoid causing erosion of the existing small group insurance market. Even with all of these conditions satisfied, the opportunity to buy health insurance at subsidized rates does not guarantee increased uptake among small employers and employees. However, if there is the will to use state funds for a program such as this, the task of properly structuring it is doable, and the opportunity to thoroughly explore this option should not be passed up.

Addressing the Cost of Medical Care

Although the other policy options discussed here may present some opportunity to reduce the net (or effective) premium costs paid by small employers and their employees, they do not address the primary driver of the cost of health insurance—the cost of the medical care that the insureds receive. Containing the cost of care will entail employing a wide variety of tactics to exploit numerous opportunities for improvement. Chief among these are reducing the amount and level of care needed through promotion of healthy lifestyles, better disease management, and improved treatment protocols. The full impact of initiatives to address these and the other factors fueling the growth of healthcare costs will not be realized all at once or in the short-term. However, tackling medical costs is the only way to achieve meaningful, sustained improvements to the insurance market as a whole.

Conclusion

The small group health insurance market in North Carolina can be improved through a number of policy approaches that can work individually or in combination.

- First and foremost, maintain the basic framework of our current small group regulation. Do not allow or support changes to small group regulation that would fragment the market and benefit only the healthiest workers. This is necessary regardless of any other policies adopted.
- Make adjustments to the details of small group rating law as recommended by the Department of Insurance, in order to realize modest beneficial effects on premiums.
- Allow insurers to offer alternative benefit plans that can help employers continue to afford offering insurance and appeal to some of those employers and employees in the small group market who do not currently offer or buy coverage. Do not allow or encourage products that would undermine the small group market by circumventing small group regulation.
- Use state fiscal policy to subsidize the cost of coverage in order to help employers who currently offer coverage to continue offering it, and enable or encourage employers who are not offering coverage to do so. Target these funds to help those most at risk of having to drop coverage due to cost and those who are the least able to afford insurance today. Make sure that no mechanism used to provide subsidies has a harmful effect on the small group market.
- Implement policy and support specific initiatives to reduce the total cost of medical care provided over the long term.
- Take actions aimed at reducing the numbers of uninsured outside of the small group market that also have a positive impact on small groups. Examples include approving a limited expansion of Medicaid for low-wage workers so that the burden of uncompensated care on all (including the small group market) will be reduced, and establishing a high-risk pool for individual coverage so that removing self-employed individuals (the most risky of all small groups to cover) from the small group market can be considered as an option in the future, and the cost of subsidizing these costly groups can be spread beyond the small group market. **NCMedJ**

> *"The small group health insurance market in North Carolina can be improved through a number of policy approaches that can work individually or in combination."*

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b Reinsurance is essentially insurance coverage for insurance carriers. If the annual claims for an individual in the plan reach some predetermined amount, then the reinsurer covers at least some part of the claims above that level.

COMMENTARY

Controlling Healthcare Costs:
The Key to Making Coverage Affordable

Robert J. Greczyn, Jr.

Never before in our history have Americans enjoyed such a wealth of healthcare options. The diagnosis, treatment, and cure of illness and disease have rapidly improved in recent history, thanks to groundbreaking research, blockbuster drugs, and technological innovations.

But the seemingly unlimited care and treatment options we have grown to rely on come at a price—to us individually and as a society. For those with health insurance, it takes an increasingly large chunk of each paycheck to cover insurance premiums and medical care. For those without insurance, the cost of their care is left to taxpayers and paying customers, and that burden is growing larger every year.

We're at a point in time in which we can no longer continue business as usual in our healthcare system. As health costs continue their upward march, attention is squarely—and rightly—focused on what can be done to expand access to medical care. The health insurance industry is actively engaged in developing solutions to the growing problem of the uninsured, both in North Carolina and across the nation.

> *"Never before in our history have Americans enjoyed such a wealth of healthcare options."*

The Root Cause

The collective cost of medical procedures, drugs, and devices has risen to the point that the United States now spends 16% of gross domestic product (GDP) on healthcare,[1] which is more than ever before. One reason is demographic: our population is older, with a vast cohort of baby boomers reaching 60 this year. Perhaps more important from a public health standpoint, our society continues to engage in unhealthy living. Poor diet, lack of physical activity, and tobacco use are driving up healthcare costs.

The price we pay for this lifestyle is increased rates of costly chronic illnesses, such as heart disease, cancer, and diabetes. Obesity rates have skyrocketed in adults and in children, with frightening consequences. Once a rarity among children, Type II diabetes (in a simpler era called "adult onset diabetes") is occurring more frequently and condemning children to a life of poor health and increased healthcare costs. We all share in the cost of treating an unhealthy society.

For Blue Cross and Blue Shield of North Carolina (BCBSNC), the unhealthy segment of our membership has a greater impact on our total costs. Our data show that 80% of our costs are driven by only 18% of our members.[2] This puts tremendous pressure on the insurance system, driving premiums up at a faster rate than earnings for employers or their workers. This cost crunch inevitably shrinks the percentage of businesses that offer insurance benefits to their employees. In the end, we cannot broaden access to health insurance without a solid plan for addressing underlying cost pressures in healthcare.

Some say that higher healthcare costs are a good trade-off for getting the best and most up-to-date medical care. We pay more because medical care is so much better, so what's the problem? One of the most frustrating aspects of the United States' cost spiral is that, although we spend more per person on healthcare than any other nation, we are far from the healthiest nation. By various measures, including data from the World Health Organization, the United States ranks about 30th in the world for the health of its people. We don't seem to be getting value from all the additional dollars pouring into healthcare.

Insurers' Response

To address the uninsured problem, the question we must ultimately ask is, "What can we do to stem the tide of rising healthcare costs to make coverage affordable for more people?"

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There is no simple answer, and progress clearly depends on individuals, families, insurers, employers, providers, government, public health—all healthcare stakeholders—working together. It will also require a sea change in how we value preventive medicine in relation to more reactive care.

Insurers grapple with how to be involved in this long-term process while still delivering cost-effective insurance products that meet customer needs today. We have to balance investment in new approaches with the likelihood that our customers will see a reasonable return on these investments. Some health promotion efforts accrue benefits to our members immediately. Others take time to realize. Efforts to educate patients with diabetes or asthma, for example, on how to take better care of themselves provide a quicker return by reducing the need for emergency room visits and hospital stays. The payback on heart disease, meanwhile, is more long-term.

One new trend among insurers is the movement to consumer-directed health plans. These plans offer coverage at lower premiums but with higher deductibles, giving consumers more choices in designing and paying for a health plan. One of the most promising aspects of consumer-directed healthcare is Health Savings Accounts (HSAs) that pair health coverage with tax-advantaged savings accounts to pay for medical care. HSAs can also be designed to cover limited preventive health services at no charge.

For the consumer-directed model to succeed, patients will need to not only engage in purchasing decisions—based on information from their physicians, insurers, and other sources—but they'll also need to change their behavior. In our current model, consumers tend to act on what their doctors recommend, with the understanding that their insurer will pick up the tab. The consumer-driven approach says that patients are more in charge of their own care since they have a greater financial stake through higher deductibles, health savings accounts, and other methods of paying for the services provided.

In another change, insurers have found success in helping consumers reduce their costs by promoting the use of generic prescription drugs. Generics are equal to brand-name drugs in active ingredients, yet cost 30% to 70% less.[3] Blue Cross and Blue Shield of North Carolina instituted programs waiving co-payments on generic prescriptions for our members in late 2004 and early 2006, encouraging them to make the switch from brand-name drugs to more cost-effective generic substitutes. Over a three-month period in 2004, BCBSNC members collectively saved approximately $17.6 million in out-of-pocket costs.[3] But there are also long-term benefits: about 22% of members stayed with generics,[3] leading to significant savings in coming years. Our challenge now is to show physicians the value of generics when appropriate for their patients so that the cost advantages can be spread to all patients, not just BCBSNC members.

Additional efforts in North Carolina show promise for a long-term payoff. As the largest health insurer in the state, BCBSNC in 2000 established a foundation to address health needs in North Carolina. Two years ago the Blue Cross and Blue Shield of North Carolina Foundation entered into a five-year, $10 million partnership with the North Carolina Association of Free Clinics to sustain and expand the free health clinic model throughout North Carolina. Funds from the Foundation already have allowed six new clinics to open. By the end of the five-year period, the capacity of free health clinics to serve the uninsured in North Carolina is expected to double.

In another partnership, the BCBSNC Foundation is contributing to the expansion of the Community Practitioner Program run by the North Carolina Medical Society Foundation. The goal of this $10 million grant by the BCBSNC Foundation—which triggered $5 million in matching funds from the Medical Society Foundation—is to help place primary care physicians and nurse practitioners in underserved areas of North Carolina, such as rural areas and inner cities with few medical providers, and keep them there.

Consumer Awareness

One of our challenges is to help make consumers more aware of the true costs of healthcare in today's world. For many, healthcare costs begin with the insurance premium and end with a small co-payment or deductible. This means there is little understanding of the actual costs of physician services, hospital care, or drug treatments.

This disconnect between costs and services undermines market forces that exist in other sectors of our economy. The result is that medical services may be overutilized, or at the very least, that care is not delivered in the most cost-effective way. For example, doctors and patients alike are focused on treating diseases and conditions after they emerge. But there's much less focus on preventive health, counseling, and lifestyle changes that could head off serious health problems before they ever develop.

Enabling consumers to connect costs to medical care could go a long way to helping individuals determine the wisest use of their money. Online services offered by many health insurers, including BCBSNC, let consumers see the costs of various medical services and treatments.

Another method is to measure and present data on the quality of healthcare, which serves dual goals of providing incentives for physicians and hospitals to deliver high-quality care and allowing consumers to see which providers do the best job. As employer-led quality initiatives such as Bridges to Excellence (for physicians) and Leapfrog (for hospitals) gain acceptance, the thinking is that quality incentives will help mitigate rising healthcare costs by shifting the focus to preventive care and reducing the likelihood of costly medical errors and complications.

Beyond educating consumers on the wise use of healthcare benefits, it also must be a primary goal to build awareness of how personal lifestyle choices drive costs in the system. While many Americans understand that an unhealthy lifestyle can lead to obesity, heart disease, and diabetes, few make the leap to connecting increased costs to those lifestyle choices.

North Carolina is facing a growing crisis when it comes to obesity. Obesity-related problems cost North Carolina employers an estimated $3,000 per employee in rising healthcare costs and absenteeism.[3] There is ample evidence in BCBSNC data that overweight individuals have significantly higher medical costs. Still, few individuals seem to make the connection that unhealthy lifestyles cause premiums—including the employee-contributed portion—to rise. While Americans expect the best available care, wide freedom of choice, and access to cutting-edge technology, we often do not take ownership of our own lifestyles.

When it comes to car insurance, the safest vehicle—as judged by accident data—is the least expensive to insure. With homeowners insurance, smoke detectors, burglar alarms, and other preventive devices can help lower your premium. Shouldn't we encourage individuals to show the same respect toward our bodies and our families as we do our possessions?

Collaboration Is Key

While it will be extremely difficult to reduce overall healthcare expenditures and thus increase access to healthcare, by working together we can help slow the rate at which healthcare costs are rising. Although no easy task, this is the key to keeping health coverage affordable.

Insurers can work with providers to develop incentives for preventive care, for example. Employers can work with public officials to design workplaces and communities that encourage physical activity. Health plans can respond to consumer needs by offering coverage designed to fit an individual's specific needs. The list of steps that can make a difference is a long one.

In the end, our challenge goes beyond financial. Reducing cost is a big part of the picture, but it's only a means to an end. The ultimate goal is a healthier North Carolina, one whose residents enjoy longer, happier and more productive lives. By reducing costs—especially for costly chronic diseases—we can also ensure the long-term availability of affordable coverage.

A healthy North Carolina is what it's all about. After all, it's our home. **NCMedJ**

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COMMENTARY

Insuring North Carolina's Children

E. Stephen Edwards, MD, FAAP

Quality health insurance for all North Carolina children has been a long-term goal of the North Carolina Pediatric Society (NCPS). Currently 265,000 children under the age of 18 remain uninsured. Two thirds of this number are eligible for either Medicaid or North Carolina Health Choice, the State Child Health Insurance Program. Thus, there are approximately 85,000 North Carolina children who are both uninsured and ineligible for current public insurance programs.

Leaders of the NCPS along with other child advocates and political leaders are exploring options to insure these children. Should there be a state subsidy for children in families with incomes above 200% of the federal poverty guidelines (FPG) or $40,000 for a family of four? If so, should there be a sliding-fee scale, and what should those rates be? At what level should that scale end (300% or 400% FPG)? How could we best assure that there would not be a "crowd out" effect where currently insured children would transfer from private plans to state-offered plans? While the assumption is that co-payments would be required for those above 200% FPG, how much should those co-payments be? Should immigrant children who are ineligible for federal subsidies be offered state subsidies?

One of the most difficult questions involves the benefit package. Currently the benefit package for Medicaid and North Carolina Health Choice is very comprehensive, including preventive healthcare; sick child care; therapy for hearing, speech, and visual problems; and dental and mental health problems. Can we afford that same package for the working poor?

Our state's Enhanced Case Management System has worked well in the Medicaid and North Carolina Health Choice populations to reduce expenditures. It has improved the health of children with chronic diseases, such as diabetes and asthma, while reducing costs by decreasing emergency room and hospital usage. Should that be extended to this new group of insured?

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Physician fees have to be considered. In North Carolina, Medicaid and North Carolina Health Choice payments for services to children are 95% of Medicare-allowable fees. By national standards this is generous, but with expanded numbers of children covered by the program, will those who care for children be able to stay afloat financially? This will be of special concern if the "crowd out" factor pushes more children from private insurance to the state program. (My impression is that our adult medical colleagues aren't very happy even with 100% of

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Medicare-allowable fees.) We certainly don't want to create programs that financially punish healthcare professionals who participate.

And, finally, how do we pay for the system? In Massachusetts, where an individual mandate law has just been signed by Governor Romney, some contend that there is already enough money in the system to finance healthcare for all. This remains to be demonstrated. In North Carolina, at least initially, additional funds would be required from state appropriations. Where would we get those dollars? Are there creative ways to bring more federal dollars to North Carolina by increasing the ceiling for Medicaid and North Carolina Health Choice above 200% FPG?

These are just some of the questions that are being explored by the NCPS and others interested in child health—and they are important questions. These questions could be resolved rapidly if there were indications that we are ready for change. As a society we have committed to nutrition and education for all children. How long can we continue to ignore child health? Data are available to show that uninsured children fail in multiple facets of life, such as missed school days and poor school performance.

We live in the richest society in the world. We tried the employer mandate route in 1990 with the Matsui Bill and in 1993 with the Clinton health plan. There was vigorous objection to both, especially from the business and insurance sectors. Massachusetts has now adopted an individual mandate where each citizen is required to purchase health insurance. We adopt a somewhat similar program for automobile liability insurance. Is the health of our children not more important than our automobiles?

There are obviously some difficult questions of equity and financing involved in health insurance for all children. But a nation that sent men to the moon with a single decade's effort is smart enough and rich enough to provide health insurance for our children. What we lack is not the money, nor the brain power, but the WILL.

If we choose to establish child health as priority, implementation could be accomplished quickly and relatively inexpensively. While the NCPS has focused primarily on child health, I believe that the organization would enthusiastically join any coalition to promote health insurance for all North Carolinians. **NCMedJ**

It's Not the Uninsured, Stupid:

Two Hurdles on the Track to Affordable Healthcare Coverage for All in North Carolina

Adam G. Searing, JD, MPH

Moving North Carolina policy toward affordable healthcare coverage for all requires dealing with two problems ignored by many people and organizations interested in this issue. First, the dominant way stories about lack of affordable healthcare coverage are portrayed in the media is helping to stifle efforts for reform. Contrary to conventional wisdom, so-called healthcare horror stories—far from being helpful in showing the need for reform—focus attention on individuals rather than systemic solutions while insulating political leaders from responsibility. Changing the conversation about healthcare reform isn't enough, however. The second problem lies in irresponsibility on the part of the federal government that has resulted in huge tax cuts aimed largely at the wealthiest Americans, an exploding federal budget deficit, and consequent current and future cutbacks in existing healthcare programs like Medicaid and Medicare. If we can't maintain our current healthcare coverage, the prospect of bringing more people into the current healthcare coverage system is remote indeed.

The Healthcare Horror Story Doesn't Work

A common media tactic used for years when health policy analysts, advocates, policy makers, and others attempt to "address the problem of the uninsured" is to rely on the story of the Medicaid recipient struggling to make ends meet while living with a serious disability, or the mechanic who makes a decent living, but not quite enough to afford health insurance for his family. Advocacy organizations[1] compile "story banks" of these sorts of healthcare failure stories for distribution to reporters. Health policy textbooks highlight the "horror story" illustrative tactic for students.[2] The media actively looks for these sorts of stories and frequently inquires if health clinics, hospitals, doctors, and others know someone without insurance who is willing to tell their story.

The prospect of such healthcare horror stories regularly sparks dread among targeted industries and politicians. For example, filmmaker, Michael Moore, is collecting healthcare horror stories for a new film on the uninsured and America's healthcare system. The pharmaceutical industry is especially worried: "For every horror story Michael Moore produces, we can produce 1,000 success stories, but he's not interested in them," said Ken Johnson, the senior vice-president of the trade group Pharmaceutical Research and Manufacturers of America."[3]

Despite fear from the targeted and enthusiasm from the mobilized, the idea underlying the healthcare horror story—that evoking sympathy with a story of hardship or poverty will translate into support for change in policy—has been shown to be dead wrong. Such stories even have the opposite effect by depressing support for changes in policy and diverting attention from the real problems. After seeing a healthcare horror story, people tend to think of the problem of the uninsured as that particular family's or individual's problem and not a problem that can be solved by government. The focus on the story shifts the focus away from the responsibility of politicians, as leaders of government, to act and address the problem for everyone.

> *"...refocusing media attention from the individual story of the poor uninsured person to the systemic problems that underlie the lack of affordable healthcare should be a top priority."*

The idea that "horror stories" might not be so effective was first raised in the 1980s when Shanto Iyengar and Donald

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Kinder published *News that Matters*,[4] a critical look at the rise of television news and its effect on policy agenda setting. Conducting multiple experiments they determined that:

> [C]ontrary to much conventional wisdom, news stories that direct viewers' attention to the flesh and blood victims of national problems prove no more persuasive than news stories that cover national problems impersonally—indeed, they tend to be less persuasive. This undermining of agenda-setting may be particularly powerful when viewers in effect blame the victims for the problems that have befallen them. Perhaps visual presentations are generally less persuasive in part because they are so successful as melodrama. Viewers may get so caught up in one family's troubles that they fail to make the connection back to the national condition. Overwhelmed by concrete details, they miss the general point.[5]

Iyengar expanded on this work with more research. In addition to confirming his earlier views, he found that such "episodic framing," or focusing on individual stories and not the bigger picture, also insulated politicians and other public officials from responsibility for fixing the problems. Iyengar writes, "By simplifying complex issues to the level of anecdotal evidence, television news leads viewers to issue-specific attributions of responsibility, and these attributions tend to shield society and government from responsibility."[6] It only makes sense. A story about a family in poverty focuses attention on how to help that particular family, not on the policy decisions that lead to that family being in poverty. Connecting the actions of a politician in Raleigh or Washington to the plight of a particular family is often just too much of a stretch for the average person.

Shifting the Focus: "Sympathy for the Poor" versus "Economic Planning"

More recent research has confirmed and expanded on Iyengar's work. The Ford Foundation has funded extensive research on this topic by the communications firm Douglas Gould & Company.[7] A 2004 survey of 3,205 registered voters compared different "frames" or ways of talking about issues impacting low-wage workers. The "sympathy for the poor" frame, which used the type of classical horror story described above, failed to generate much support for policy fixes. Instead, people felt that the responsibility for solving the problems was incumbent upon the people experiencing the problem.

Researchers then tried what they called the "economic planning" frame. Here they talked about the same problems they had with the "sympathy for the poor" frame, but now they focused on the economy, jobs, and future prosperity. Instead of the horror story, trends and broader influences were used to illustrate the problems. For example, the argument was presented that the nation should not focus on "short-term profits and short-term thinking," but think long-term and "build good-paying jobs with benefits."[8]

The Gould study concluded that moving away from the horror story toward talking about the economy, jobs, trends, and future prosperity significantly increased the public's acceptance of and desire for policy solutions. A recent example of this type of coverage is the wide notice given to retailer Costco for its generous employee benefits, larger contributions to employee health insurance, and low turnover.[9] The theme? Treating your employees well is good for the company, business, customers, and the community.

Other studies involving multiple focus groups, a national study of registered voters, and detailed analysis of news coverage all support the above conclusions.[10-12]

A New Way of Talking about Affordable Healthcare for Everyone

When the predominant way the story of the uninsured is covered in the media is ineffective in building support for policy change, supporters of healthcare for everyone must change their strategy. This means a huge shift in how supporters for change refer to those without health coverage, a change in the examples used to illustrate the need for health coverage, and a relentless focus on the collective responsibility of citizens and government to solve this problem.

First, refocusing media attention from the individual story of the poor uninsured person to the systemic problems that underlie the lack of affordable healthcare should be a top priority. Highlighting solutions is a key part of this effort. Successful collaborations, such as Project Access in Buncombe county,[13] where low-income residents can get comprehensive, affordable healthcare regardless of whether they can afford coverage from work need to be given prominence. Profiles of North Carolina employers who are offering comprehensive healthcare coverage along with decent wages should be used as models. The system is broken—but we have the will and ability to fix it—should be the key message.

Refusing to be drawn into the "find-a-person-without-insurance-to-be-profiled" media trap isn't enough, however. In every story about the lack of affordable health coverage, there should be mention of how this lack hurts the economy, means lack of decent jobs, and imperils future prosperity. To build a strong economy, we need a healthy workforce, and that means everyone needs to be able to see a doctor when they are sick.

We should create jobs in North Carolina, but we shouldn't think short-term. Long-term thinking means creating jobs with good benefits and decent salaries, so people can have a reasonable place to live, connect to their towns and cities, raise their families, and contribute to the future of the community. If families are being driven into bankruptcy by high medical bills that hurts not only them, but our future prosperity. Someone who is bankrupt because of hospital bills isn't going to buy a new car down at the local Ford dealership.

Finally, the way the lack of guaranteed affordable health insurance coverage affects everyone should be made clear. The message here is simple. Why should North Carolinians worry that a job loss or change, a desire to strike out on their own and start a new business, or a sudden disability might mean loss of health coverage for themselves and their families? What kind of economic engine would we unleash if anyone with a great idea could start a business knowing that affordable health coverage was easily available? How many modern-day Wright brothers are trapped between the need to maintain responsible health coverage from their current company and a dream to strike out and invest in their own innovative ideas?

Fixing Federal Budget Problems Is The Second Component Necessary to Advance North Carolina's Health Agenda

Unfortunately, shifting the message and focus to the economy, jobs, and future prosperity will not be enough to move North Carolina toward affordable health coverage for everyone. A huge roadblock remains in the form of the current devastating fiscal irresponsibility of the federal government. For wealthier states, few prospects of new federal funding for health coverage and increasing federal budget cuts limiting federal healthcare money are not as insurmountable. Massachusetts[14]—with a $52,000 annual median income and a low 11% uninsured rate compared to North Carolina's $39,000 median income and 17% uninsured rate—can credibly move toward universal affordable coverage.[15]

This is not so in North Carolina. Too often, supporters of affordable health coverage for everyone shy away from describing just how to pay for the solutions they proscribe. But building an economy where families don't have to worry about losing affordable health coverage is going to cost money. Sure, if we rebuilt the health system from the ground up, we could probably save enough in administrative, paper-pushing costs to bring everyone in. However, as imperfect and wasteful as our current system is, 85% of the population is more or less happily covered under our current system, and the other 15% isn't marching in the streets for radical change.[a,16]

Indeed, the benefits that more expensive medical care brings—stronger communities, healthier workers, and longer lives—are worth paying for. But, before we look to find more money for expanding care, there remains a huge problem. Current federal tax policies mean that we cannot afford the programs we have in place right now, much less to expand them in the future. A top priority of the President and current Congressional leadership is making tax cuts since 2001 permanent. These tax cuts are disproportionately aimed at top income-earners. People with incomes over $1 million will receive a tax reduction of nearly $112,000 this year, while someone in the middle of the income scale can expect only a $748 reduction.[17] Another priority with broad bipartisan support is to balance the federal budget. As the Center on Budget and Policy Priorities points out, those two goals are simply not compatible without cuts that would be unthinkable to many.

The sad truth is that expanding costs for healthcare combined with drastically reduced tax revenues and an exploding federal deficit mean a sharp fiscal squeeze. Add to this the now nearly $10 billion a month being spent on the war in Iraq and Afghanistan (a cost that has risen almost $2 billion a month in the last year),[18] and it's clear the country is heading for a crisis. In fact, realistic estimates of the budget deficit over the next ten years put the federal government in the red by $4.8 trillion.[19] This is simply unsustainable and puts current healthcare programs like Medicare and Medicaid in serious jeopardy.

What Would it Take to Balance the Budget While Preserving the Tax Cuts?

To balance the budget by 2016 while making the tax cuts permanent, policy makers would have to:

Cut Social Security benefits by 45%

Or cut defense spending by 66%

Or cut Medicare by..56%

Or cut every other program except Social Security, Medicare, defense, and homeland security by 32%

Source: Federal Budget Outlook. Budget presentation. Washington, DC: Center on Budget and Policy Priorities. Available at: http://www.cbpp.org/budget-slideshow.htm. Accessed May 24, 2006.

One effect of the federal funding crunch is less money to help states facing tough economic times. Over the last several years, multiple states have enacted large cuts in Medicaid eligibility and benefits in response to the economic downturn. Last year, the biggest health issue debated in North Carolina was the proposed denial of Medicaid eligibility to 65,000 elderly, blind, and disabled residents. Although the state's fiscal fortunes seem to be rising in 2006, the same is not true at the federal level.

This year Congress enacted $39 billion in budget reductions, which will mean more people without insurance and will shift billions in child care assistance and welfare reform costs to the states. For example, North Carolina currently is grappling with an unfunded federal mandate to require a birth certificate from the 1.2 million North Carolinians getting healthcare through Medicaid.[20] Finding birth certificates for over a million people on Medicaid who are overwhelmingly elderly, disabled, or under 18 years old is a Herculean task North Carolina's taxpayers will now be expected to finance. Many elderly African Americans, born in a south with segregated hospitals, will have even more difficulty—their "birth certificate" may only be a notation in the family Bible. Cost savings for the federal government translates into huge budget and human costs at the state level.

It's simple. Any honest talk about major expansions in health coverage for North Carolinians has to start with the federal government getting its own fiscal house in order. Otherwise the healthcare coverage debate in North Carolina for the foreseeable future will be about how to preserve current coverage in the face of gigantic federal cutbacks.

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[a] Political participation by low-income people (i.e., voting, protesting, contacting legislators, joining advocacy groups, giving campaign donations) is far lower than for people in the middle- and upper-income brackets. This hasn't changed much over the last century.[16]

This political medicine is tough, but necessary, if we want to build a North Carolina economy for the next century where everyone benefits. It will require a balanced, bipartisan approach with strict fiscal rules, reconsideration of ill-advised tax cuts, and an honest assessment of where substantial savings can be made in Medicare and Medicaid spending. This is a contentious process, but some ways to start would be:

- Reinstate "pay-as-you-go" rules that require Congress to pay for all tax cuts and increases in entitlement programs before such tax cuts or increases can be enacted.
- Don't make permanent any tax cuts that are not clearly paid for.
- Rethink tax cuts going to people with annual incomes over $400,000—the top 1% of the population—and devote resulting revenues to reducing the federal budget deficit and strengthening Medicare and Medicaid.
- Revise the Medicare Part D prescription drug legislation to allow the federal government to negotiate directly with drug companies and obtain the lowest possible prices for drugs.
- Invest in research that compares the effectiveness and value of prescription drugs, healthcare procedures, and other health initiatives.

A Positive Outlook for a Strong Future Economy

As our technology becomes more sophisticated, our population ages, and our state population grows, we face a critical choice. A strong future North Carolina economy means good jobs with quality benefits and access to the best and most innovative healthcare that the many medical resources in our state have to offer. A long and healthy life should be attainable for every North Carolinian whether they work in a tourism job on the coast or a research and development job in the Research Triangle Park. A big part of creating the economy and prosperity people want is ensuring affordable healthcare coverage for all. This is an attainable goal, but two necessary steps on the road to reform require rethinking the message around affordable healthcare coverage and demanding true fiscal accountability from the federal government. **NCMedJ**

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[1] North Carolina Institute of Medicine. Expanding Health Insurance Coverage to More North Carolinians. Durham, NC. April 2006. Available at: http://www.nciom.org/projects/uninsured/uninsuredreport.html. Accessed May 8, 2006.

The Task Force was a collaborative effort of the North Carolina Department of Health and Human Services, the North Carolina Department of Insurance, the Cecil G. Sheps Center for Health Services Research at the University of North Carolina at Chapel Hill, and the North Carolina Institute of Medicine. The Task Force was generously funded through a one-year State Planning Grant from the Health Resources and Services Administration of the United States Department of Health and Human Services. The primary staff direction of the overall State Planning Grant Task Force work was the responsibility of Dennis Williams, Associate Director, and Anne Braswell, Senior Analyst, of the Office of the Research, Demonstrations, and Rural Health Development, NC DHHS.

Running the Numbers

A Periodic Feature to Inform North Carolina Healthcare Professionals about Current Topics in Health Statistics

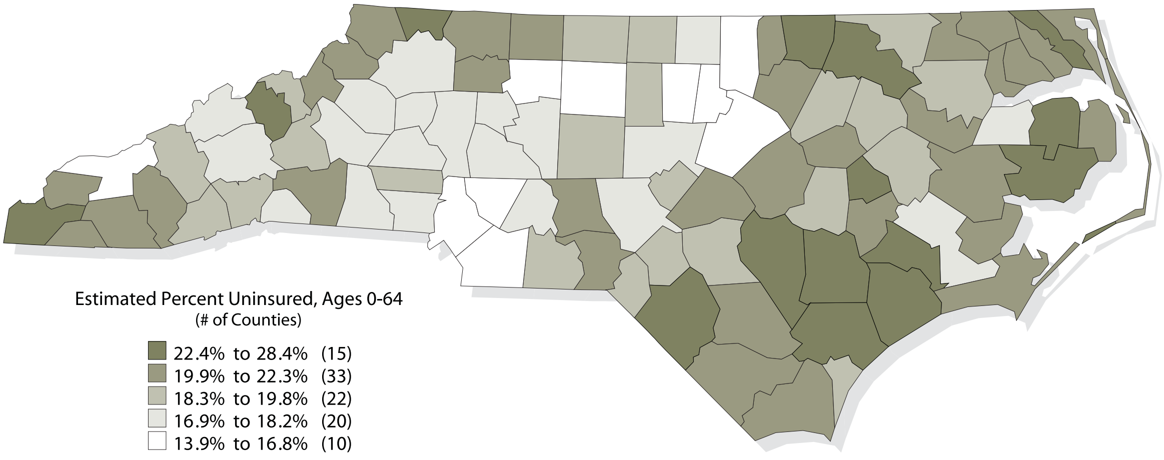
From the Cecil G. Sheps Center for Health Services Research at the University of North Carolina at Chapel Hill
http://www.shepscenter.unc.edu

The Uninsured in North Carolina, 2004

Estimating the number of uninsured at the county level is not a straightforward process because there are no direct surveys at the local level. Analysts at the Cecil G. Sheps Center for Health Services Research have used data from the United States Census Bureau's Current Population Survey (CPS) March Supplements from 1995-2005 to create county-level estimates of the numbers of persons under 65 years of age who were without insurance for each year starting in 1999. The maps displayed here summarize the results for 2004.

This estimation process identified the factors associated with being uninsured in the state-level sample then extrapolated those data using full population data for each of the counties. Those data indicate that, in general, people who lack health insurance in North Carolina are more likely to be poor, younger, or employed in small business. These factors, among others, were then used to create local estimates. For example, if 20% of males and 10% of females working in service industry jobs in North Carolina are uninsured, then these rates can be applied to county level employment and age-gender characteristics to generate an estimate of the rate of uninsured in a particular county The complete report, including a listing of counties with numbers and percent of population uninsured, is available at http://www.shepscenter.unc.edu/.

Percent of North Carolinians Aged 0-64 without Health Insurance
Estimates for 2004



Produced by: Program on Health Economics and Finance, Cecil G. Sheps Center for Health Services Research, University of North Carolina at Chapel Hill.

Source: Synthetic estimates based on Annual Social Economic Supplement, US Census Bureau, 2004-2005.

Full report available at http://www.shepscenter.unc.edu.

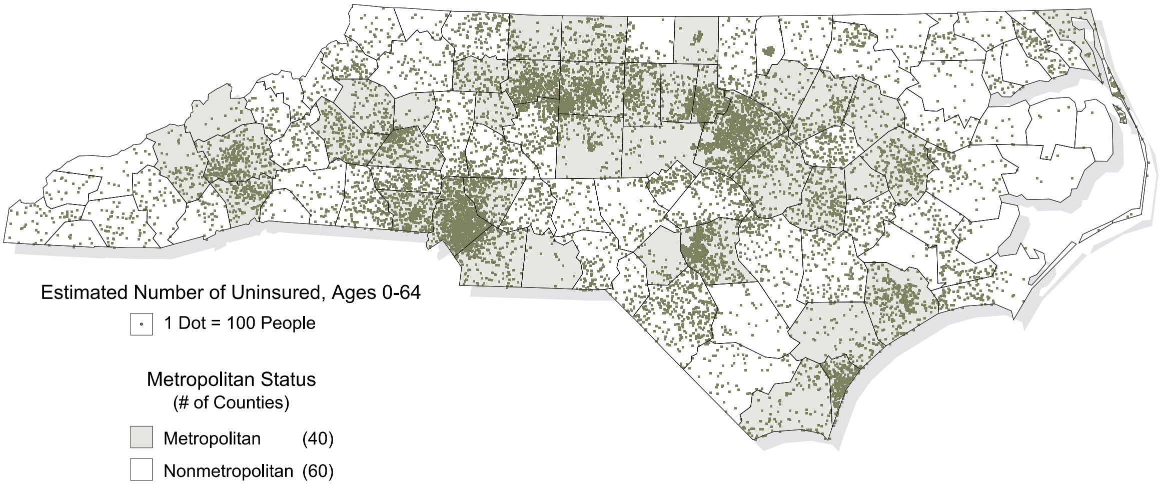
RTN—continued on page 236

RTN—continued from page 235

The maps show that higher proportions of the population in the more rural areas of the eastern part of the state and the northern and southern mountain counties are more likely to be uninsured with a notable "cluster" of high rates in the region including Onslow, Jones, Duplin, Sampson, and Pender counties. The second map indicates that the absolute numbers of uninsured are concentrated in the urban counties. The problem of uninsurance is a statewide phenomenon with rates and numbers showing slightly different effects across the state. Since some areas of the state have lower average incomes or more employees of small businesses, these areas will generally have more uninsured people. Policymakers may wish to focus efforts in areas with particularly low insurance coverage rates. Local healthcare providers may better demonstrate the extent of their need for government and philanthropic support using estimates of local uninsured populations.

Number of Residents Aged 0-64 without Health Insurance

North Carolina, 2004



Produced by: Program on Health Economics and Finance, Cecil G. Sheps Center for Health Services Research, University of North Carolina at Chapel Hill.

Sources: Uninsured Data—Synthetic estimates based on Annual Social Economic Supplement, US Census Bureau, 2004-2005. Metropolitan Status—US Census Bureau and Office of Management and Budget, 2003.

Full report available at http://www.shepscenter.unc.edu.

Note: Dots are scattered randomly throughout zip code areas and are not intended to locate a particular place or population.

Contributed by Thomas C. Ricketts III, PhD, MPH, and G. Mark Holmes, PhD
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Readers' Forum

To The Editor:

As Chief of the North Carolina Division of Social Services' (DSS) Family Support and Child Welfare Section, I value the commitment and efforts of our university and medical partners and sister agencies in the North Carolina Department of Health and Human Services. We all diligently strive to achieve the safety, permanence, and well-being of children and their families. The commentary written by Dr. Adam J. Zolotor, Dr. Desmond K. Runyan, Ms. Brenda Motsinger, and Ms. Catherine Sanford published in the September/October 2005 volume of your Journal, entitled "Building an Effective Maltreatment Surveillance System in North Carolina" had several points that I agree with and support. One of these is that "coordinated efforts and a variety of data sources from multiple sectors" are critical to developing a child maltreatment surveillance system. The North Carolina Division of Social Services supports this endeavor through participation in the Families Accessing Services through Technology (NC FAST) program. When fully implemented, it will provide for efficient, effective assessment; comprehensive case management; and better evaluation information through its comprehensive outcomes data and capacity to ensure accountability across programs. As a result, I agree that this system will "improve the consistency of data collection and allow data to be compared more easily among counties."

The commentary continues to state that "for each report that is accepted to the department of social services for a family or investigative assessment, the family's needs are now assessed using a standardized risk assessment tool," which leads the reader to believe the use of standardized assessment tools is a new development. The Division implemented the use of Structured Decision Making tools in the county Departments of Social Services on April 1, 2002. These tools were adopted to achieve greater consistency among our child welfare staff in providing on-going safety and permanence for children and families. Our use of those tools over almost four years has guided our case decision-making and helped us better achieve the outcomes of safety, permanence, and well-being of children.

The authors are correct that domestic violence is a risk factor for child abuse. Their statement that "…DSS has recently implemented a policy to accept all reports of witnessed domestic violence for investigation" seems to infer this is new to our system. Our Structured Intake policy guides our intake and screening decisions and became effective June 1, 2003.

We believe that child maltreatment and adult domestic violence often occur together. In September 2004, we established a separate section of our Child Protective Services (CPS) policy manual to provide the specific information and protocol that addresses the intersection of child safety, permanence, and well-being and domestic violence. This policy was developed in collaboration with the state's domestic violence community. It establishes the primary focus of child protection intervention in cases involving domestic violence as the ongoing assessment of the risk posed to children due to the presence of violence in their families. It, in combination with our Structured Intake policy, establishes that the DSS does not accept all reported cases involving domestic violence. A CPS report in which the *only* allegation is domestic violence does not meet the statutory criteria for child abuse, neglect, and dependency.

This article's statement also leads one to believe that workers make CPS assessment case decisions independently. This is not accurate or supported by policy that has guided CPS practice for many years. Policy clearly states, "the CPS assessment case decision must be a shared decision, including at a minimum, the worker and the workers' supervisor or supervisor's designee or staffing team."

I appreciate the authors' efforts in serving children and their families. Without them, and others like them, North Carolina's children would be much less safe than they are today. I am honored to partner with them in our continued collaborative efforts. Thank you for the opportunity to offer some insight on some of our policy and practice points. I am available to answer questions or further explain our CPS system.

Jo Ann Lamm, Chief
Family Support and Child Welfare Services Section
North Carolina Division of Social Services
North Carolina Department of Health and Human Services

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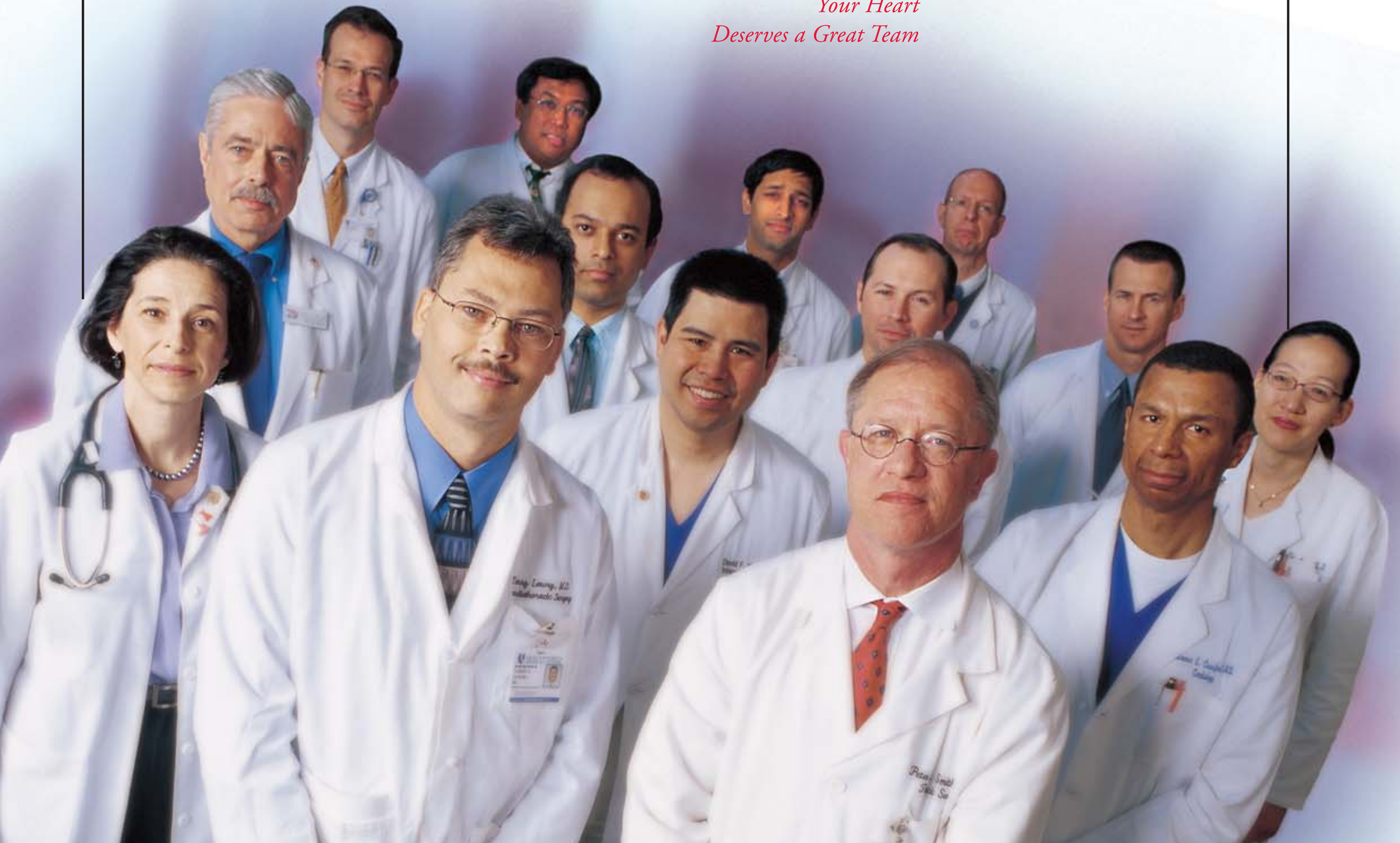

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Confronting the **Problems** of **Overweight** and **Obesity**

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How a team of heart specialists helped Hugh McColl make the best investment of his life.

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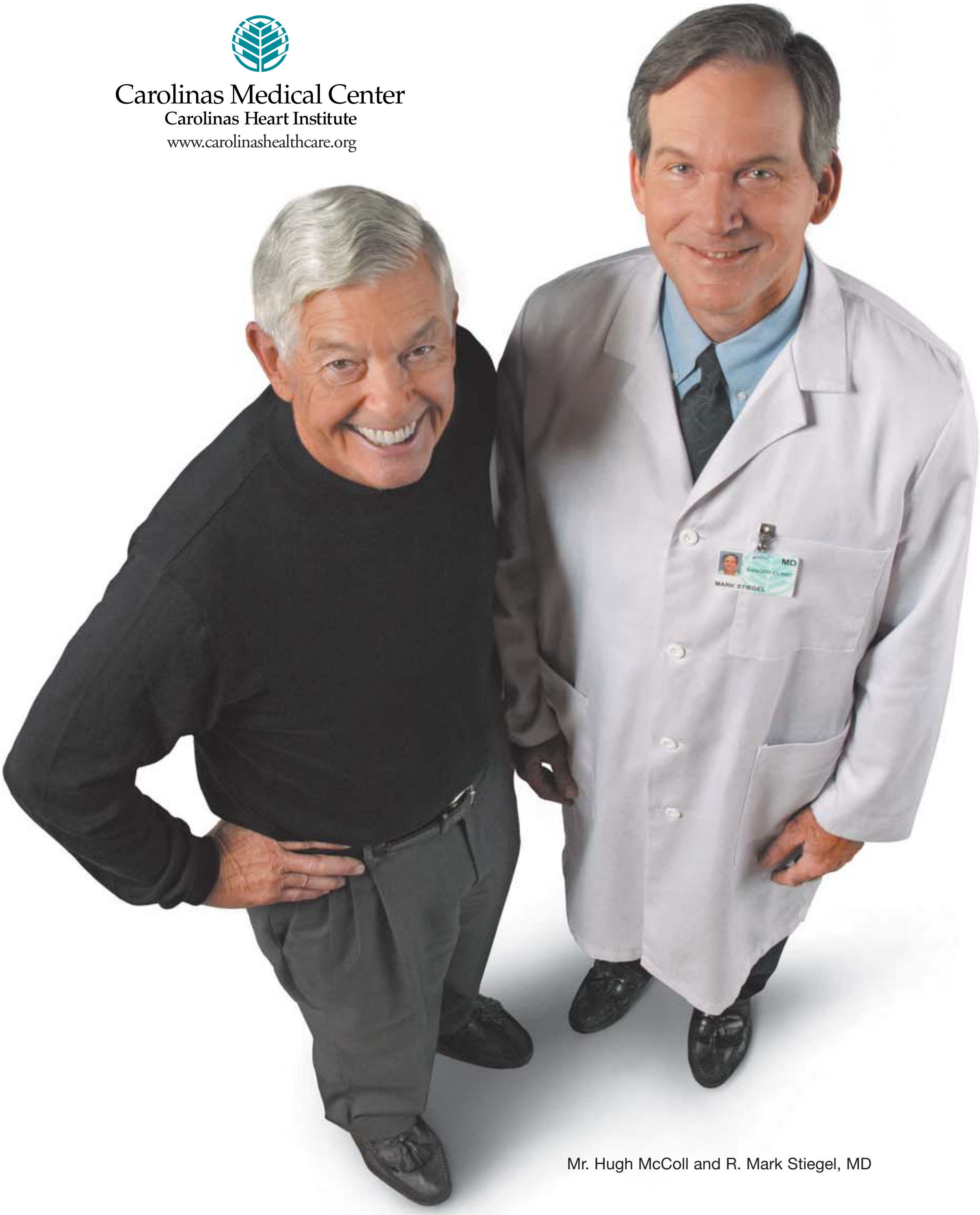

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Tarheel Footprints in Healthcare

Recognizing unusual and often unsung contributions of individual citizens who have made healthcare for North Carolinians more accessible and of higher quality

Recognizing Tom Vitaglione, MPH
Senior Fellow, Action for Children North Carolina

(formerly known as the North Carolina Child Advocacy Institute)

Tom Vitaglione, MPH

Anyone who has worked on statewide issues related to child health in North Carolina over the past thirty-five years could not have gone without some contact or communication with Tom Vitaglione. He has played a key role in shaping a host of programs that have made a tremendous impact on the health and well being of North Carolina's children and youth.

Tom chose to start his professional career in North Carolina after receiving his master's degree in public health from Columbia University and spending time in Malawi with the Peace Corps. Over his more than three decades of state service through the Children and Youth Section in the Division of Public Health, his leadership and accomplishments are widely recognized. For example, he was a principal architect of North Carolina's Children's Health Insurance Program (NC Health Choice) and helped to assemble a task force of 75 leading experts with the North Carolina Institute of Medicine to prepare an outline of the proposed program. The result was legislation eventually enacted to extend coverage to over 75,000 previously uninsured children. This number has since been extended by the North Carolina General Assembly to include more than 125,000 children.

Tom was also one of the leaders whose vision created the North Carolina Child Fatality Task Force. He continues to play a strong role as Co-Chair, a position to which he was appointed by Governor Michael Easley. In this role he has brought public, media, and legislative attention to a number of child mortality issues. The Child Fatality Task Force compiles annual statistics on a wide spectrum of risks to child health and safety, then partners with the North Carolina Institute of Medicine and Action for Children North Carolina to release them each year. The *North Carolina Child Health Report Card*, a visual measure of our progress on key health indicators, has been released for a decade thanks to Tom's leadership.

Further, Tom has been a tireless advocate for stricter automobile child restraint laws, for the regulation of child safety in the operation of all terrain vehicles, for graduated driver's licenses, the dangers of home fires for children and infants, the reduction of child exposure to lead, programs to address the problems of child maltreatment and abuse, and the active role of state government in the collection, analysis and publication of child health, injury, and fatality statistics.

Leah Devlin, North Carolina State Health Director, comments that "Tom Vitaglione has always been a fearless champion for improving children's health and well being. He has been a strong leader for many years from within the public health system and he brings that same energy and advocacy in his current role in the private sector. Generations of children and their families in North Carolina continue to be well served by the passionate and committed Tom V."

Since his retirement from state government, Tom Vitaglione has been a Senior Fellow at Action for Children North Carolina. In addition to his role as a Fellow and as Co-Chair of the Child Fatality Task Force, Tom and his wife have found time to invest their energy and talents in developing (and fundraising for) the Malawi Children's Village, a multifaceted program serving more than 3,500 AIDS orphans in 37 villages in the southern region of this small country in East Africa.

Dr. Jonathan Sher, former President of the NC Child Advocacy Institute, had this to say about him: "Tom is the most universally respected and beloved person that I ever have known personally (having only met the Dalai Lama in passing). This is even more impressive given that, as an Italian Catholic from New York City, he started with three strikes against him in the North Carolina of three decades ago. When I grow up, I'd be delighted to turn out just like the real-life Tom Terrific!"

The *North Carolina Medical Journal* is proud to recognize the career and continuing accomplishments of this tireless child health leader in our state. We celebrate our good fortune that Tom Vitaglione chose North Carolina as "home" and thank him for his ongoing efforts on the part of the children of our state.

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MEDICAL JOURNAL
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July/August 2006, Volume 67, Number 4 **Published by the North Carolina Institute of Medicine and The Duke Endowment**

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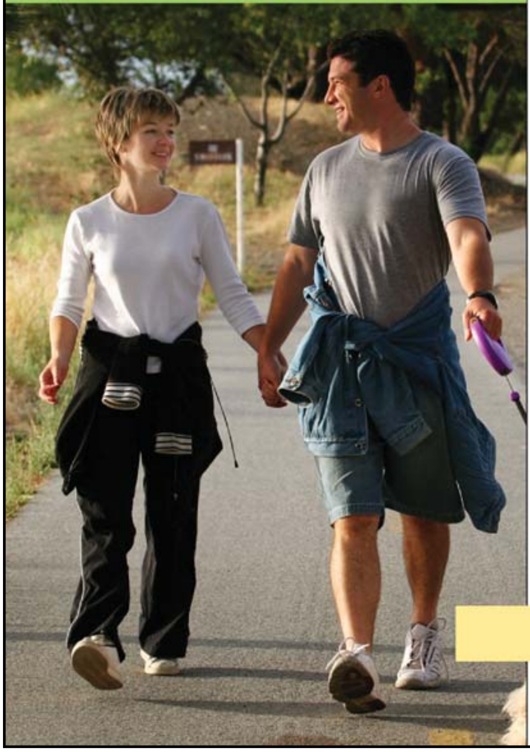

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In 1983 the North Carolina General Assembly chartered the North Carolina Institute of Medicine as an independent, non-profit organization to serve as a non-political source of analysis and advice on issues of relevance to the health of North Carolina's population. The Institute is a convenor of persons and organizations with health-relevant expertise, a provider of carefully conducted studies of complex and often controversial health and healthcare issues, and a source of advice regarding available options for problem solution. The principal mode of addressing such issues is through the convening of task forces consisting of some of the state's leading professionals, policy makers and interest group representatives to undertake detailed analyses of the various dimensions of such issues and to identify a range of possible options for addressing them.

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ARTICLE

Feasibility of a Primary Care Intervention to Decrease Oral Antibiotics for Acute Upper Respiratory Tract Infections:

A Pilot Study

Meera Kelley, MD; Mark W. Massing, MD PhD; Joshua Young, BS; Anne Rogers, RN, BSN; Renee Taylor, MPH and Robert Weiser, BA

Abstract

Background: *Antimicrobial resistance in common respiratory tract pathogens is a growing public health threat, especially in the southeastern United States. The excessive use of antibiotics for common infections is a major contributing factor in the emergence of antibiotic resistance. We report results from a multi-site outpatient pilot project in North Carolina to reduce antibiotic prescriptions for acute nonbacterial upper respiratory tract infections (URIs).*

Methods: *Primary care practices were provided education and symptom therapy kits for patients with URIs, as an alternative to antibiotics, in a project to reduce the overuse of antimicrobial therapy. The feasibility of this approach was evaluated with interviews and surveys. A methodology for claims-based evaluation of intervention efficacy in reduction of antibiotics use was developed as part of this project.*

Results: *Of eight contacted practices, four agreed to participate and three participated fully. Physicians reported that symptom therapy kits were useful for patients with URIs and resulted in a meaningful change in antibiotic prescribing behaviors. A claims-based approach is a feasible and promising method to evaluate efficacy in subsequent post-pilot large-scale implementations.*

Limitations: *Due to the small number of outpatient practices and the lack of controls in this pilot study, the efficacy of the intervention in reducing antibiotic use could not be determined.*

Conclusions: *Education combined with symptom therapy kits as an alternative to oral antibiotics is a feasible intervention that warrants additional studies to evaluate the efficacy of this approach in the reduction of antibiotic use for URIs.*

Keywords: *antibiotics, upper respiratory tract infection, outpatient care.*

Introduction

Resistance to antimicrobial agents is a growing public health threat, especially in the southeastern United States.[1-6] Antibiotic overuse contributes to resistance, yet antibiotics are commonly administered to treat conditions such as nonbacterial acute upper respiratory tract infections (URIs) for which they are not proven effective.[7-11]

The American College of Physicians-American Society for Internal Medicine, American Academy of Family Physicians, Infectious Diseases Society of America, and the Centers for Disease Control and Prevention have endorsed a campaign to promote appropriate antibiotic use for the treatment of acute respiratory tract infections in adults. Clinical Practice Guidelines providing evidence-based recommendations have been published.[12] They provide practical strategies for limiting antibiotic use to the patients who are most likely to benefit.

Among the frequently cited causes for antibiotic overuse are physician perceptions of patient expectations, patients' actual expectations, lack of knowledge of the dangers and limitations

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of antibiotic therapy, and inadequate communication during physician-patient encounters.[13-17] To maximize effectiveness, interventions to reduce antibiotic use will need to address as many of these factors as possible.

We developed a multi-pronged approach to reduce the outpatient use of antibiotics for URIs that focuses on patient and physician education and understanding while enhancing patient-physician communication through the use of symptom therapy kits. In this report, we describe a pilot project to evaluate the feasibility and uptake of this approach. We report promising findings supporting the need for a large scale study to evaluate the effectiveness of educational interventions combined with symptom therapy kits to reduce the use of antibiotics for URIs.

Methods

Pilot Project Overview

Internal medicine, general practice, and family medicine providers treating large numbers of patients were identified as potential project participants. Of eight invited practices, one practice declined because the physician felt that patients seen at the practice were particularly high-risk and likely required antibiotics for treatment of URIs. Three other practices declined due to time constraints. Of the four practices that entered the project, one failed to complete the intervention because the practice physically relocated and intervention materials were misplaced. Three practices successfully completed the project interventions.

Physicians in four participating practices received a project introduction consisting of training related to antibiotic resistance and current treatment guidelines provided by a physician specializing in infectious disease. Intervention materials provided in January 2002 to each practice included 100 symptom therapy kits, 15 posters, and 10 symptom relief prescription pads. Symptom therapy kits and symptom relief prescriptions offered patients the alternative of symptom control with reassessment in consultation with their physician should symptoms not improve.

Physicians and their staff were contacted routinely throughout the cold and flu season of early 2002 to identify problems and successes related to the project, assess practice adherence with project protocols, and identify the need for additional intervention materials. A formal interview and questionnaire were administered to participating providers in April 2002.

Because this was intended to be a pilot project for the development of the intervention, the number of participating practices was limited and no controls were identified. Thus, intervention efficacy could not be determined. However, in anticipation of a large-scale implementation of the intervention, this project also included a component to develop an evaluation methodology using administrative claims.

North Carolina Medicaid outpatient and pharmacy claims were reviewed to characterize antibiotic use for acute nonbacterial URIs. Methods and results are described in detail elsewhere.[18] Data were provided by the Division of Medical Assistance of the North Carolina Department of Health and Human Services, the administrators of the state's Medicaid program.[19] Pre-intervention analyses of Medicaid claims revealed high levels of antibiotic use, justifying the development of this pilot project to reduce outpatient antibiotic use for acute nonbacterial URIs.

This project was sanctioned by the North Carolina Medicaid program due to its potential to prevent drug-related adverse events, protect public health, and reduce costs. It was approved by the Institutional Review Board of the University of North Carolina School of Medicine.

Interventions

Educational materials were distributed to participating physicians at no charge. Some materials were obtained from the Campaign for Appropriate Antibiotic Use in the Community sponsored by the Centers for Disease Control and Prevention.[20] These included an educational poster for examination and waiting rooms, a prescription pad for symptomatic relief of URIs,[21] and "A new threat to your health: Antibiotic Resistance" pamphlet.[22] Clinical practice guidelines were distributed to all participating practices. These were adapted from "Principles of Antibiotic Use for Treatment of Acute Respiratory Tract Infections in Adults" created by the American College of Physicians-American Society of Internal Medicine.[12] The guidelines included information concerning the syndrome, etiology, course of illness, and treatment recommendations for common adult URIs including nonspecific URIs, acute pharyngitis, acute rhinosinusitis, and acute bronchitis.

In addition to the above materials, The Carolinas Center for Medical Excellence developed a symptom relief kit known to patients and providers as the "self-care kit." This kit consisted of an assortment of items used for education and symptomatic relief in a custom-designed 6x4x1.5 inch box (Figure 1). Each kit cost approximately $6. Providers were encouraged to distribute the kit and other intervention materials, in place of antibiotics, to patients with URIs. Practices were encouraged to distribute these materials to all patients with URIs regardless of insurance status and payer. The kit included a postcard survey returned via mail to assess patients' impression of the usefulness of kit contents. The response rate (2.6%) was too low to be meaningful, and the patient survey results are, therefore, not reported here.

It was recognized that recommended treatment approaches for URIs may differ among professional societies. Although the American College of Physicians guidelines were distributed, the adoption of these guidelines versus others was not specifically requested. The main focus during educational meetings with physicians was to describe and encourage the use of the symptom therapy kit as an alternative to antibiotics when, in the physician's judgment, the likelihood of a bacterial infection was low.

Project Evaluation

Interviews and surveys completed by participating physicians were used to evaluate the feasibility of this approach. The prevalence of filled prescriptions for oral antibiotics following index patient-physician encounters for URIs occurring during baseline (January 1, 2001-March 31, 2001) and intervention (January 1, 2002-March 31, 2002) measurement periods was determined from Medicaid pharmacy claims as a model for the evaluation of a large-scale implementation of this intervention beyond the pilot phase. Antibiotics were identified using the *Physician's Desk Reference and the National Drug Code (NDC) Directory*. NDC numbers for oral antibiotics in the Medicaid pharmacy claims database were obtained from the Multum Lexicon™ database (Multum Information Services, Inc., Denver, CO, 2001). The number of days from the date of the index patient-physician encounter for URIs to the first pharmacy service date for an oral antibiotic prescription was evaluated as a potential indicator of intervention efficacy.

Patient Populations

Patient populations for this project consisted of all adult patients with nonbacterial URIs seen at any of the participating practices. Complete information regarding these populations is not available. Medicaid administrative claims were used for limited practice characterization.

According to our claims-based evaluation protocol, a Medicaid recipient must have had at least one face-to-face outpatient encounter with a family medicine, general practice, or internal medicine physician for acute nonbacterial URIs during the measurement period. Qualifying outpatient physician-patient encounters were identified based on *Current Procedural Terminology (CPT)*[23] and *International Classification of Disease, 9th Revision, Clinical Modification (ICD-9-CM)*[24] codes in Medicaid claims.

In our claims-based evaluation protocol, the conditions and diagnosis codes for acute nonbacterial URIs were acute nasopharyngitis (460), acute pharyngitis (462), acute upper respiratory infections (465.9), acute bronchitis (466.0), and influenza (487.1). Index encounters must have occurred in the baseline or intervention measurement periods. Patients with acute nonbacterial URIs encounters less than 90 days prior to the index encounter were excluded. Patients with chronic respiratory conditions were also excluded: chronic bronchitis (491), emphysema (492), asthma (493), and chronic obstructive pulmonary disease (496). These conditions were identified from claims for outpatient services occurring during an observation period beginning 90 days prior to the index visit. To exclude a patient for chronic conditions, there must have been two or more claims at least six days apart specifying at least one of the chronic respiratory condition diagnosis codes.

Analysis

All analyses were performed at The Carolinas Center for Medical Excellence. Data from physician interviews and surveys were recorded and analyzed using electronic spreadsheets. Our pilot methodology for claims-based evaluation used Medicaid data provided by the North Carolina Department of Health and Human Services Division of Medical Assistance. Statistical and claims analyses were performed using SAS v9.1 statistical software (SAS Institute, Inc., Cary, NC).

Figure 1.
Self-Care Kit

- Chicken Soup
- Tea
- Saline nasal spray
- Lozenges
- Chest Patch
- Thermometer
- Facial Tissues
- CDC pamphlet
- Survey

Results

Intervention Uptake

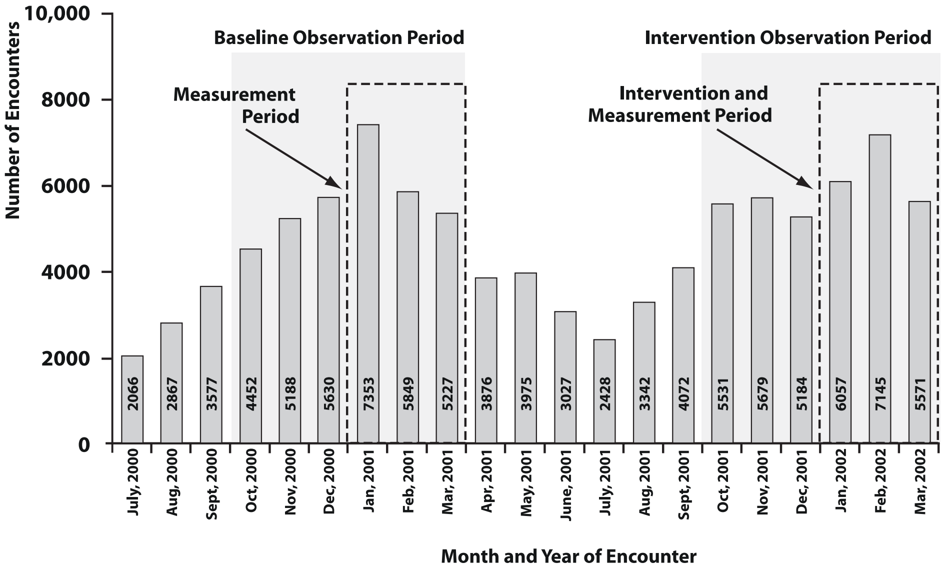
Surveys completed by all participating physicians (n=14) in late April and early May 2002 indicated an overall positive view of project interventions and their effect on prescribing patterns. Results suggest that most physicians frequently felt pressured to prescribe antibiotics. On average, physicians reported that they would prescribe antibiotics for acute nonbacterial URIs 39% of the time before the intervention and 20% of the time after the intervention. All physicians surveyed thought the kits were helpful, and most believed their patients also found the kits useful. On average, physicians reported they had given kits to 44 patients, and about a third of patients who received the kits were enrolled in Medicaid. Posters and printed guidelines were also used by almost all physicians. In contrast, the symptom relief prescription pads were used by less than half the physicians.

Claims-based Findings

A claims-based approach is a feasible method to characterize patient populations and to assess efficacy of this intervention in large-scale studies designed for this purpose. Statewide in the Medicaid population 18 to 64 years of age, there were 98,096 patient-physician encounters for acute nonbacterial URIs from July 1, 2000 through March 31, 2002. These involved 55,614 patients seen by 1,739 providers. The number of encounters varied seasonally, as expected (Figure 2), with the highest monthly counts occurring in January 2001 and February 2002. During the baseline measurement period there were 18,429 encounters involving 14,960 patients and 1,210 providers. During the intervention measurement period there were 18,773 encounters involving 15,439 patients and 1,269 providers. The distributions of specific URIs diagnoses were similar during the baseline and the intervention measurement periods, with approximately 2% of encounters for acute nasopharyngitis; 17-18% for acute pharyngitis; 32-33% for acute upper respiratory infections; 43% for acute bronchitis; and 4-5% for influenza.

The state population was mostly female (78%) and Caucasian

Figure 2.
Number of patient-physician encounters by month and year for acute nonbacterial upper respiratory tract infection among Medicaid recipients 18 to 64 years of age in North Carolina.



(59%). African Americans were the largest minority group (31%). Almost three quarters (73%) were less than 50 years of age. Participating practices differed substantially from the state and among each other with respect to Medicaid patient population size, age, sex, and race/ethnicity composition (Table 1).

In the Medicaid claims analysis for this pilot project, there were 15,628 and 16,020 pharmacy claims for oral antibiotics during the baseline and intervention measurement periods, respectively, in the statewide population of Medicaid patients seen for URIs. Among patients filling an antibiotic prescription for URIs, about 79% of pharmacy claims occurred by the day following the patient-physician encounter, and 84% occurred within 5 days. More than half of the statewide population filled a prescription for antibiotics within 5 days of seeing a primary care provider for acute nonbacterial URIs. The prevalence of pharmacy claims for antibiotics declined slightly, from 59% to 58% statewide, comparing baseline and intervention measurement periods. Rates also decreased in the intervention practices (Table 2). The extent to which these declines were related to the intervention cannot be determined due to limitations in the study design in this pilot study. Nevertheless, these effectiveness measures can be readily determined from administrative claims supporting a claims-based methodology for the evaluation of an efficacy study.

Discussion

Antimicrobial resistance has increased at an alarming rate, both in hospitals and in the community. During the five-year period from 1994–1995 to 1999–2000, penicillin susceptibility decreased from 76% to 66%, and erythromycin susceptibility from 90% to 74%.[25] The overall proportion of penicillin non-susceptible pneumococci within a population-based surveillance program across the United States in 1997 was 25%.[3] The southeastern United States has demonstrated the lowest susceptibility of all regions, with up to one third of pneumococci isolates demonstrating antibiotic resistance.[3,4,26]

The excessive use of antibiotics in the outpatient setting has contributed to the increase in antimicrobial resistance.[5,27] In one study, antibiotics were prescribed for 51% of patients diagnosed with colds, 52% with upper respiratory tract infections, and 66% with bronchitis.[9] The progression of antimicrobial resistance can be reversed. For example, in Finland, nationwide reductions in the use of macrolides resulted in a significant decline in resistance among Group A streptococci.[8]

Table 1.
Characteristics of Medicaid patients with acute nonbacterial upper respiratory tract infection during the intervention period for North Carolina and participating practices.*

	State	Intervention Practice		
		1	2	3
Jan 1, 2002-March 31, 2002	n=13,295	n=41	n=25	n=128
Age				
18-34	41	54	16	55
35-49	33	32	32	34
50-64	27	15	52	11
Sex				
Female	78	85	84	82
Race/Ethnicity				
African American	30	34	12	11
Caucasian	59	46	88	81
Other	11	20	0	8

*All numbers are a percent of the column-specific total.

Table 2.
Percent of patients filling antibiotic prescriptions within 5 days of index encounter for acute nonbacterial upper respiratory tract infection among Medicaid recipients without chronic respiratory conditions during the baseline and intervention measurement periods in participating practices.*

	Intervention Practice % (total Number of Patients with URI)		
	1	2	3
Baseline Period Jan 1, 2001-March 31, 2001	62 (40)	67 (33)	64 (101)
Intervention Period Jan 1, 2002-March 31, 2002	39 (41)	60 (25)	60 (128)

*These descriptive data are not useful for evaluation of intervention effectiveness due to limitations in study design and statistical power.

Results from our pilot project suggest that physicians respond favorably to interventions aimed at reducing antibiotic use for nonbacterial URIs. The symptom therapy kits were especially well received. An expanded study to test the efficacy of this approach could be supported by our findings. Furthermore, the claims-based evaluation methodology created as part of this project appears to be a feasible method to evaluate intervention efficacy in a study designed for this purpose. The availability of Medicare pharmacy benefits starting in 2006 offers the potential for expansion of this evaluation into the Medicare population.

We have reported that the North Carolina Medicaid program paid more than $1.5 million for 33,061 oral antibiotic prescriptions filled for acute nonbacterial URIs from October, 2000- March, 2001.[18] The average prescription cost of $45 during this period well exceeds the $6 cost of the self-care kit. Healthcare payers may find such kits a cost effective alternative to antibiotics. Providers interviewed during the project suggest that, when the kit is offered during outpatient office visits, it serves as a catalyst to foster better patient-physician communications, promotes increased knowledge, and enhances awareness of expectations.

Important strengths of this study include a multi-site implementation, pre-post quantitative evaluations, qualitative evaluations, and the inclusion of diverse patient populations commonly seen by primary care providers throughout North Carolina. The extent to which project practices represent the "typical" North Carolina practice is not known. Characteristics of Medicaid patient populations for some project practices differed substantially from those of the state. This should be considered when evaluating the generalizability of our findings. Patient populations seen in these practices include Medicaid and minority populations common to other practices throughout the state. In this respect, the project practices may share similar barriers related to URI treatment with other practices statewide. A limitation is the low response rate to patient surveys. As a result, the acceptability of this intervention to patients could not be directly determined.

Medicaid claims-based evaluation of efficacy may be limited by several factors. Medicaid patients generally have good access to medications through the program's pharmacy benefit, and information about this access is readily available through the Medicaid program; however, these patients are not necessarily representative of the overall patient population. The effect of interventions cannot be determined for patients not in Medicaid. Our inability to distinguish between patients who were not prescribed medications from those who were prescribed but did not fill prescriptions is another limitation of claims-based evaluation.

In conclusion, our multi-pronged approach to reduce antibiotic use for URIs in the outpatient setting by targeting barriers related to understanding and communication shows much promise. We have found that these efforts are feasible and welcome in outpatient practices. We have also shown that physicians are very receptive to symptom relief kits, especially when combined with patient education. Unfortunately, a statistically rigorous proof of effectiveness was not possible, nor was it our goal, given the limited nature of a pilot project. Nevertheless, it is reassuring to find that antibiotic use rates declined for all participating practices. These findings suggest that an expanded study to test the effectiveness of this approach is warranted. **NCMedJ**

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Public Health News Frames in North Carolina Newspaper Coverage of the 100% Tobacco-Free Schools Campaign? Sometimes

Suzanne DePalma Morrison, MPH; Sonya F. Sutton, MA and Felicia E. Mebane, PhD

Abstract

Objective: *News organizations are an important and influential part of the social environment. They identify certain issues by the extent and nature of their coverage. To help explain what public health policy messages may have influenced school policy decisions, this content analysis provides an examination of newspaper coverage of North Carolina's 100% tobacco-free schools campaign.*

Data Collection Methods: *Researchers searched LexisNexis for articles published in North Carolina newspapers between January 1, 2001 and December 31, 2004 that included variations of "North Carolina tobacco-free schools." Researchers then conducted a descriptive analysis of 138 stories from nine North Carolina newspapers (approximately 4% of all the state's newspapers) and used page placement and story type to examine the level of importance placed on the issue. Finally, frames for and against tobacco-free school policies were tracked, along with the presence of key messages presented by 100% TFS advocates.*

Principal Findings: *The volume of news coverage changed throughout the study period, with peaks and valleys closely associated with external "trigger" events. In addition, a majority of the newspaper articles did not include key public health messages.*

Conclusions: *The results suggest an opportunity for public health experts and officials to work more effectively with local journalists to increase the use (and impact) of public health messages in news coverage of tobacco policies affecting youth.*

Introduction

Tobacco use is a tremendous public health burden in North Carolina, particularly among youth. The results of tobacco prevention research in schools show that school districts with a 100% Tobacco-Free School (TFS) policy in place (one that bans all tobacco use, everywhere on campus, by everyone, at all times) have a lower rate of tobacco use among youth.[1,2]

North Carolina state law prohibits tobacco use inside school buildings, but permits local school boards to establish policies for outdoor tobacco use by students, school staff, and school visitors.[3] In 2000, 90% of North Carolina's 115 school districts had policies that permitted school staff, visitors, and/or students to use tobacco on campus and at school-related events.[4] In response, the North Carolina Tobacco Prevention and Control Branch (TPCB) of the North Carolina Department of Public Health initiated a statewide campaign to encourage all school districts to adopt a 100% TFS policy.[5] This initiative has relied on advocacy strategies to draw attention to the issue and promote public health frames intended to influence how the public and policymakers respond to the proposed policy changes. As of January 2006, 65 districts were 100% tobacco-free.[6,7]

As public health leaders and advocates focus their efforts on 100% TFS policy adoption in the remaining North Carolina school districts, it is important to understand what information on this issue is available to policymakers and to consider the kinds of messages or data needed to inform these debates. The primary aim of this study is to describe whether key public health messages, sources, and data related to 100% TFS policies are being presented in print news media. Following this analysis, recommendations are offered for how existing media advocacy strategies promoting public health messages can be improved

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or expanded so 100% TFS policy debates are informed by public health goals and evidence.

An Overview of North Carolina's 100% Tobacco-Free Schools Campaign

North Carolina's 100% TFS campaign was spurred by former Governor Jim Hunt's Teen Tobacco Use Prevention Summit in January 2000. The Summit was organized by state leaders in response to the high tobacco usage rates among North Carolina's youth reported in the 1999 Youth Tobacco Survey.[8] The initiative gained momentum in 2002 with the creation of the 100% TFS Program within the TPCB. In June of the same year, the State Board of Education passed a resolution encouraging, but not requiring, all North Carolina school districts to adopt this policy. Finally, in July 2003, the North Carolina General Assembly passed Senate Bill 583 (SB 583) entitled "Tobacco Use in Schools."[9] This new law joined federal legislation in banning tobacco use in school buildings and gave school districts the authority to adopt 100% TFS policies that are more restrictive than the state law. By December 2005, 57% (65) of North Carolina school districts had adopted this policy. This paper focuses on how some of the key public health messages, sources, and data were reported in newspapers by North Carolina journalists from 2000 through 2004.

The Significance of News Frames in Public Policy Debates

News reports, analyses, and commentaries comprise the principal arenas within which scientific, medical, and public health controversies are defined as public problems and are brought to the attention of decision makers, interest groups, and the general public.[10] News coverage (in print and other media) affects the shape and outcome of health policy debates in two key ways: agenda setting and story framing.

First, agenda setting theory shows that the capacity of the public's or policymakers' agendas is limited.[11] At any time, only a few major issues—out of the hundreds that can be reported each day—are of concern to the general public or policymakers. Journalists' and editors' story selections focus a spotlight on issues that are reported. The spotlight can be enhanced by the relative prominence of placement of news reports.[12-14] By emphasizing some issues with repeated and prominent coverage, the news legitimizes and increases the salience of highlighted problems, leading people to seek solutions for highly visible issues, often to the exclusion of unpublicized ones.[11,15-20] In sum, journalists may influence health policy by highlighting issues and policies that then become more likely than other issues to find a place on the public agenda.

Second, journalists use frames, a central organizing idea or story line, to tie information together or provide emphasis and to quickly convey the essence of an issue.[21] By emphasizing a specific component of an issue or policy solution over another, news frames can influence which considerations are deemed most accessible or most important when the public is making policy choices.[22,23] Frames within news articles provide direction for audiences by assigning relative importance to particular problem definitions, causal interpretations, moral evaluations, or preferred courses of action.[24,25]

Thus, by presenting particular interpretations of problems and policies, issue frames presented in the news can become a key basis for public policy decisions.[26,27] And, once an issue is framed by news coverage, it can be very difficult for policymakers and other interests to shift the image of the issue to another perspective.[10]

Key Research Questions

This analysis evaluates news coverage about 100% TFS policies in North Carolina with regard to agenda setting and framing. The time period, 2001-2004, represents the first key phase of the 100% TFS campaign. This analysis examines the volume and prominence of the North Carolina newspaper coverage of 100% TFS schools as well as the tobacco control frames and messages that were reported.

Methods

This study analyzes newspaper coverage of the 100% TFS issue in North Carolina from January 1, 2001 to December 31, 2004 in major daily newspapers in the state. Reports on this topic were identified by performing a key word search using phrases related to "North Carolina tobacco free schools." We collected all of the reports with the key terms anywhere in the full text of the article from the sources listed for North Carolina in the LexisNexis news archive between November 2004 and February 2005. The resulting nine English language newspapers were from the North Carolina news outlets in the LexisNexis archive and represent 4% of the state's newspapers. Initially, we retrieved and reviewed 192 articles against our inclusion criteria, leaving 138 in our final sample.

Outcomes Measures: General

Each article was coded for the newspaper that published it, the date of publication, and whether 100% TFS was the focus of the report or part of a broader discussion. The inverted pyramid style of journalism calls for the most important information of the article to be placed at the beginning or lead.[28] Consequently, 100% TFS was considered to be the focus when it was mentioned in the headline or lead sentence or discussed in at least one-third of the article. In addition, each story was coded for whether it was a regular news report, a news brief, an editorial or letter to the editor, or commentary. Hard news stories (the regular reports and news briefs) are expected to report the who, what, when, where, and how of a news event with no explicit opinion.[28] A newspaper's editorial page, letters to the editor, or commentary pieces are intended to convey the views or opinions of the editorial board of a newspaper or the author. This variable allows for a better understanding of the sources of the public health frames.

Outcome Measures: Agenda setting

The extent of the 100% TFS coverage was measured by counting the volume of news coverage over the study period. In addition to reporting significant issues more often than other issues, editors and reporters give information they consider important more prominent placement.[29] Because prominent stories are more likely to have an impact on audiences, each article was coded for whether it was published on the front page of the first section of the newspaper, on the front page of the local news section, or in other sections.

Outcome Measures: Framing

A preliminary review of the North Carolina news articles confirmed reliance on two, prominent policy frames on each side of the tobacco policy debates. The primary frame supporting 100% TFS, that tobacco in schools is a children's health problem, uses a public health frame implying that 100% TFS is necessary to provide a healthy school environment. The primary opposing frame, that adults have a right to use tobacco as they see fit, consolidates the argument around infringement on the personal rights of adults who work in schools or attend school functions. Each article was coded for whether it mentioned either of these issue frames.[27,30]

Regardless of the frame through which the story was told, each report was also coded as to whether it contained two messages about tobacco use that are offered as an underlying rationale for 100% TFS policy and are based on public health research. We measured whether the articles included (1) information that secondhand smoke is dangerous to youth and (2) that role modeling of tobacco use by peers and adults is associated with an increase in youth tobacco use. Each article was also coded as to whether specific data, such as youth tobacco use rates, were mentioned.

Coding

Each outcome measure was based on published analyses of news coverage of health or health policy topics and a review of prior debates of tobacco free schools.[27,36-37] A codebook was developed and the coding for each variable was pre-tested. Coding reliability was tested on a 25% probability sample of the population of articles. Coder agreement, calculated as the percentage of agreement between the two coders, was 94% across 54 variables. Data were analyzed using a combination of Microsoft Excel and SPSS software.

Results

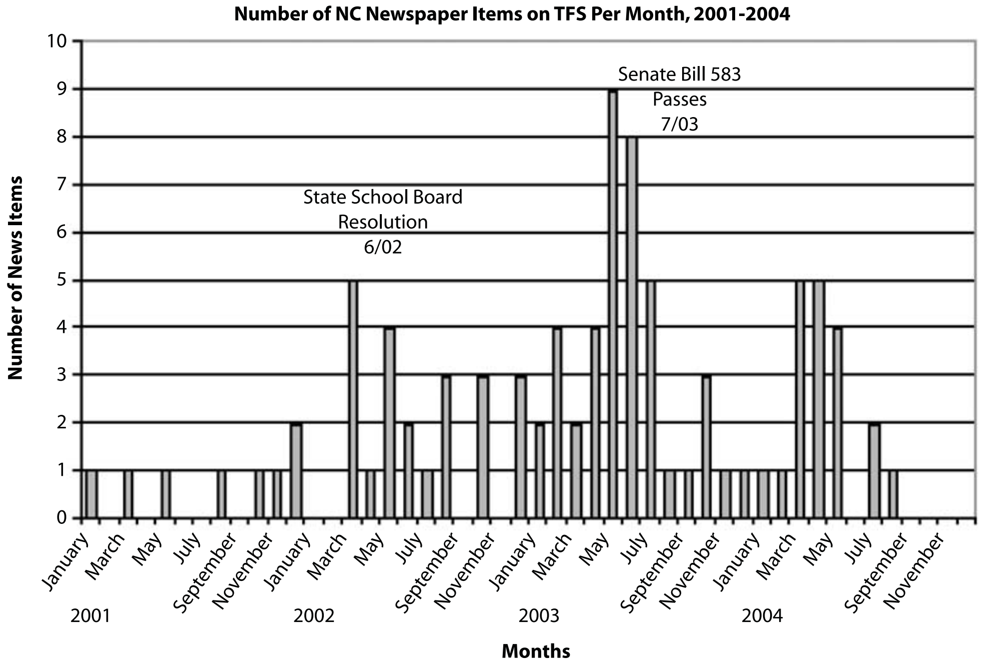
General

A majority of the 138 articles identified in our search came from North Carolina's largest daily newspapers, with the greatest percentage of articles (23%) came from the *Raleigh News & Observer*, which serves the state capital and covers state government issues closely. Eighty-eight of these news items (64%) were focused on 100% TFS in either the headline, lead or at least one-third of the article. Regular news reports accounted for more than half (55%) of the articles analyzed. Thirty-five percent were news briefs and 10% were opinion pieces (i.e., commentary or editorials/letters to the editor).

Agenda Setting

Figure 1 shows that there were several peaks and valleys in the volume of 100% TFS newspaper coverage in the time period. Events such as the State School Board Resolution and the debate and passage of SB 583 are associated with an increase in news coverage. Following these events, the coverage level dropped to previous levels. As another indication of the prominence of these reports, one quarter of the articles appeared on a front page of a newspaper section; 7% appeared on the front page of the entire

Figure 1.
Monthly Distribution of 100% TFS News Items in North Carolina Newspapers, 2001-2004, n = 90



newspaper, and 18% appeared on the front page of the second section of the newspaper, which is usually devoted to local news.

Framing

Slightly less than half (47%) of the news items included at least one of the two dominant policy frames. The children's health frame was used in 33% of the news items, while 19% of the stories framed the issue around individual rights (see Table 1). The messages about dangers of secondhand smoke and the importance of role modeling for school staff were apparent in the coverage. Thirty percent of the reports included the secondhand smoke message, and 28% included the role-modeling message. Fifty-seven percent included neither of these messages.

Table 1.
Distribution of Public Health Policy Frames and Messages in 100% TFS Coverage in North Carolina Newspapers, 2000-2004

Frames	**% of News Items n = 138**
Children's Health	33%
Individual Rights	19
Neither of these	53
Messages	
Danger of second hand smoke and smoking for youth	30
Impact of role modeling on youth	28
Neither of these	57

Discussion

The results of this analysis provide the first systematic description of the extent and content of newspaper coverage of North Carolina's 100% TFS movement from 2001-2004. First, the volume of reports from these newspapers appears to reflect coverage of "trigger" events, such as adoption of the statewide school board resolution on 100% TFS, rather than continued interest in the local processes considering 100% TFS across the state. While this trend is not surprising given journalists' reliance on events as a catalyst for news reports, it also highlights the fact that proponents of 100% TFS will likely have to continue their advocacy campaigns to provide incentives for continued coverage.

Second, the prominence of these stories provides another view of what priority newspapers placed on reporting the 100% TFS policy. Very few (7%) of the 100% TFS articles in this study made it onto the front page of the newspaper. While newspaper coverage is not the only indicator of the public policy agenda, it is an important indicator of how the public perceives an issue.

Several factors may have influenced the extent and prominence of this newspaper coverage of the debate. First, newspaper editors may consider 100% TFS debates a community news story, one more likely to be covered by a local newspaper. Second, debates about 100% TFS in a newspaper's market may not have been controversial and reporters and editors may not have believed they merited attention or prominence in the news coverage. This explanation suggests that advocates wanting to raise the salience of 100% TFS in school districts should spend some advocacy efforts on finding ways to connect 100% TFS to values, consequences, and conflicts that are newsworthy or connect with the communities' top priorities. Getting more front page coverage about 100% TFS could help move this policy onto or up school boards' agendas. Third, reporting on the issue may be especially challenging for North Carolina newspapers. Editors may hesitate to take on a topic that has the potential to alienate some of their readers, for example, those who use or make their living from tobacco. Fourth, there is also a tendency for news items to naturally run out of steam, especially if not refreshed by new information or story lines. Finally, editors may have chosen to feature other tobacco-related stories during the study period, including the proposed tobacco tax and the tobacco buyout.

A third key finding is that although these newspapers' reporters used the children's health issue frame in nearly twice as many articles as the rights frames, a large majority of the articles did not contain this public health frame. These results suggest that public health frames in connection with 100% TFS may not be getting through to news audiences.

This study has several limitations. One drawback of this type of evaluation is the lack of consensus in the broader public health and journalism communities about what constitutes high quality coverage for 100% TFS and related policies. For assessments of news coverage to be most effective, they should be guided by a normative standard incorporating the goals and constraints of news reporting and the information needs of the general public. Further discussion and analysis is needed to determine and apply a policy news reporting standard to tobacco free schools policy coverage.

Another limitation is that the newspapers included are only a small proportion of the newspapers in North Carolina. Because LexisNexis is a key news archive and is often used as the basis for this type of analysis, we believe our findings highlight important insights that warrant further investigation with a more representative sample of North Carolina news. This study points to the need for research that identifies the full scope of reporting on the issue and examines in detail why local journalists report on tobacco-free school policy issues as they do (or do not) and the impact those choices have on local and state level debates.

Finally, though this study reported on the use of data and sources in articles related to tobacco free schools, it did not assess the accuracy or balance of the information presented. News stories that contain inaccurate information or portray circumstances with an obvious bias can result in opinions or views about policies that are misinformed and not truly reflective of public preferences.

Conclusions

Based on these results, additional public relations events and promotions from state leaders may help raise 100% TFS on journalists' agendas. At the same time, providing opportunities for journalists to report proactively, rather than focus on event-driven coverage, may help to increase the number of 100% TFS articles. For example, public health advocates may arrange to meet with reporters and editors to discuss the benefits of the policy to students and school districts. They may provide other reporting angles, such as education, business, or economics, that might broaden its appeal to news audiences and convince reporters that the issue is important because of its statewide scope. Reporting frames that link 100% TFS with other tobacco-related stories, such as those on hospitals, worksites and universities considering a tobacco-free policy, may also help raise the salience of 100% TFS. Finally, for public health framing to gain traction in news coverage, public health advocates should consistently promote several public health angles, including the one that moved public policy in early tobacco control debates, specifically the notion that tobacco kills.

In sum, news organizations have an important role to play in public health policy development in all types of settings, including schools. While news professionals make the decisions about how to write a story, advocates and public health leaders who work with journalists can help inform and shape the views of the public and policymakers. For the 100% TFS policy, improved news coverage could help the issue garner more attention from North Carolina residents and policymakers. **NCMedJ**

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ARTICLE

Skin Problems Related to the Occupation of Commercial Fishing in North Carolina

William A. Burke, MD; David C. Griffith, PhD; Christopher M. Scott, MD and Eric R. Howell, MD

Objective: *Commercial fishing is one of the most dangerous professions with many of the occupational health problems related to the skin. This study elucidates the types of occupational skin disorders that occur in commercial fishermen in North Carolina.*

Study Design/Settings: *Booths were set up offering free skin cancer screenings at various seafood festivals, a "blessing of the fleet" event and commercial fishing shows, which were located throughout eastern North Carolina from 2002-2004. When commercial fishermen were screened, they were asked about significant skin problems that they had experienced and were related to their occupation. They were specifically asked about their history of (1) cancerous and precancerous skin lesions, (2) eczemas, (3) superficial fungal infections, (4) bacterial infections of the skin, (5) traumatic injuries related to the skin, (6) bites and stings, (7) shocks from fish, and (8) skin problems related to environmental extremes.*

Results: *Eighty-one North Carolina watermen were screened: seven of the fishermen (9%) had at least one basal cell carcinoma, five (6%) had at least one squamous cell carcinoma, and no melanomas were detected. Many occupationally related skin disorders were noted on the historical survey, and some of the more dangerous of these included traumatic injuries related to fishing equipment, cutaneous cancers, fish bites, infections, stingray injuries, and man-of-war stings.*

Limitations: *The sample population was comprised of volunteers, which limits generalizability, and some diagnoses were established retrospectively.*

Conclusions: *There are a wide variety of skin disorders among commercial fishermen in North Carolina and healthcare professionals should be aware of these when working with watermen.*

Key Words: *Fishermen, fishing industry, occupational health, skin diseases.*

Introduction

North Carolina is usually ranked amongst the nation's top ten seafood producing states and has approximately 4,000-7,000 active full-time commercial fishermen harvesting catches from its 4,000 miles of marine and estuarine shoreline.[1-3] Situated where the cold-water Labrador Current meets the warm tropical waters of the Gulf Stream, North Carolina waters offer an especially wide and diverse variety of seafood.

Commercial fishing is well-known to be one of the most hazardous of all occupations.[4] A significant proportion of work-related health problems in this industry affect the skin.[5,6] The skin of fishermen is often exposed to high levels of wetness; to a variety of potential cutaneous pathogens; to estuarine and marine flora and fauna that can bite, sting, shock, or otherwise cause contact/irritant skin reactions; to multiple types of traumatic injuries; and to extremes of heat and cold.

Currently, very little data exist related to cutaneous diseases in the workforce of watermen in our region. The commercial fisherman is usually a stoic, independent, and hard-working individual who is often distrustful of institutions such as medicine.[7] As such, watermen often don't seek medical attention for perceived minor skin ailments. In addition, many can't afford to see a physician even for more serious problems due to a lack of personal funds as well as often having no health insurance.

The purpose of this study is to gather data about cutaneous problems related to the occupation of commercial fishing in North Carolina. In addition, an effort was made to educate the watermen and their families about some of the well-known risks of their occupation as well as some preventive measures.

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Materials and Methods

From 2002-2004, multiple seafood festivals, commercial fishing shows, skin cancer screening sessions, and a "blessing of the fleet" event, all taking place in eastern North Carolina, were attended by our faculty group at ECU (see Table 1). At these events, a booth offering free skin cancer screenings to all interested individuals (including commercial fishermen) was set up. While the vast majority of people who presented themselves for screening were not watermen, those who were fishermen (and who agreed to a short survey) were questioned about their previous history of skin problems related to their work in commercial fishing. A skin examination of their scalp, face, ears, neck, and upper extremities was performed by an experienced board-certified dermatologist. Impressions of clinical lesions were recorded, but biopsies were not done.

Table 1.
List of events/places where screenings and study took place.

Event Attended	Date(s)	# Fishermen Screened
North Carolina Commercial Fishing Show (New Bern, NC)	February 23-24, 2002	20
Engelhard Seafood Festival (Engelhard, NC)	May 18, 2002	6
Blessing of the Fleet (Hobucken, NC)	June 15, 2002	7
Swansboro Mullet Festival (Swansboro, NC)	October 12, 2002	0
Mill Creek Oyster Festival (Mill Creek, NC)	November 2, 2002	2
Carteret Skin Cancer Screening (Beaufort, NC)	February 18, 2003	6
North Carolina Commercial Fishing Show (New Bern, NC)	February 22, 2003	12
North Carolina Commercial Fishing Show (New Bern, NC)	February 28, 2004	19
Pitt County Memorial Hospital/ECU clinics (Greenville, NC)	various, 2002-2004	9
Total		**81**

The survey instrument was designed by the authors and included the current skin cancer screening results as well as the historical information related to previous skin problems the dermatologist obtained through interviewing the participating fishermen. This information included previous personal histories of precancerous and cancerous skin lesions, eczematous (including allergic) conditions, superficial fungal infections, bacterial infections, traumatic injuries, bites and stings, fish shocks, and problems related to environmental extremes. In addition, questions were asked related to demographics, including zip code of the domicile, age, sex, full-/part-time work; where they fished (inshore/offshore/both); and whether they had insurance. Skin phototype[8] (ranging from skin type I through skin type VI) was also assessed by the dermatologist. A person with skin type I has extremely fair white skin that never tans and always burns with even minimal sun exposure. In contrast, an individual with skin type VI has very dark brown skin that pigments extensively and almost never burns. The research protocol was approved by the East Carolina University Brody School of Medicine Institutional Review Board.

Table 2.
An overview of the 81 commercial fishermen in this study.

Mean Age (years)	52	(range 24-79)
Sex	N	(%)
Male	81	(100)
Female	0	(0)
Time Commitment	N	(%)
Full-time (currently or retired)	73	(90)
Part-time	6	(7)
Disabled (previously full time)	2	(2)
Fishing Location	N	(%)
Inshore	46	(57)
Offshore	11	(14)
Both inshore and offshore	24	(30)
Health Insurance	N	(%)
Yes	49	(60)*
No	32	(40)
Skin Phototype[8]	N	(%)
I	1	(1)
II	76	(94)
III	4	(5)
IV – VI	0	(0)

* includes 13% over 65 on Medicare

Results

A total of 81 North Carolina commercial fishermen were screened, a sample representing approximately 1-2% of all licensed watermen in the state. All of the watermen who presented to the researchers and were asked to participate in the study consented to the survey. Background information collected on these individuals is summarized in Table 2.

These fishermen lived from as far north as Moyock

(Currituck County), North Carolina to as far south as Southport (Brunswick County), North Carolina (see Figure 1). A summary of the clinical data is listed in Table 3.

Figure 1.
Map of Eastern North Carolina Showing Hometowns (dots) of Fishermen Participating in this Study.

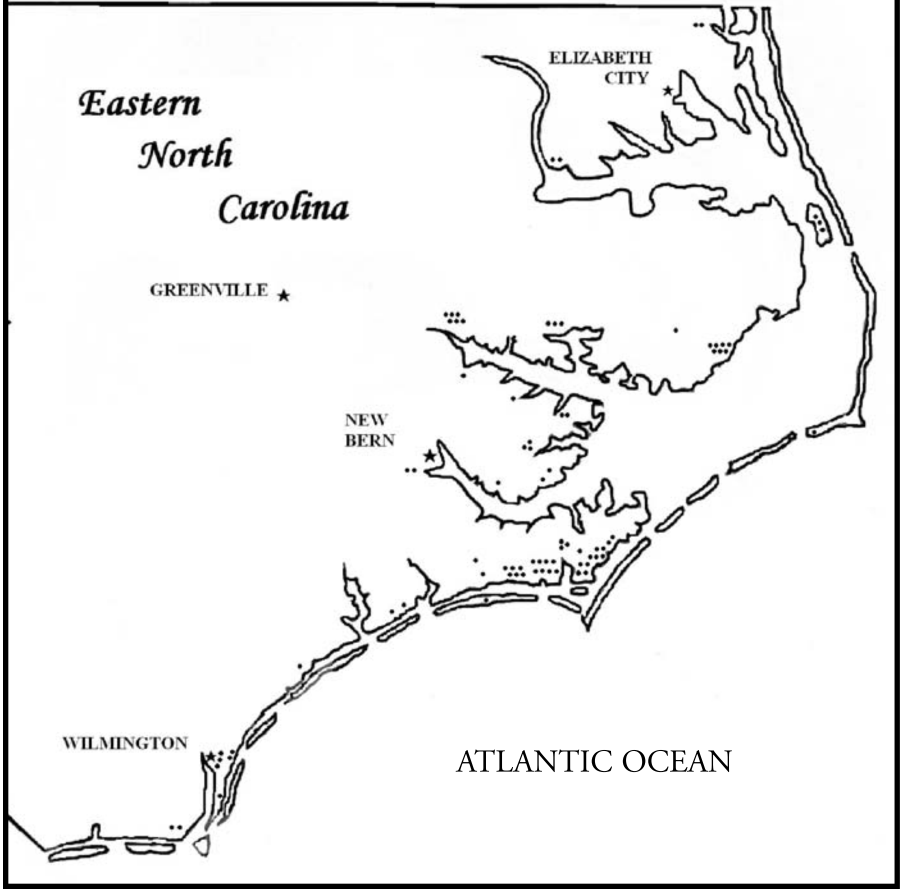

Table 3.
Clinical data on the 81 commercial fishermen in this study.

Skin Problem	# Fishermen in "Live" Screening	# with History of Problem
Actinic Keratosis	49 (60%)	27 (33%)
Actinic Cheilitis	12 (15%)	1 (1%)
Basal Cell Carcinoma	7 (9%)	15 (19%)
Squamous Cell Carcinoma	5 (6%)	7 (9%)
Malignant Melanoma	0 (0%)	3 (4%)
Eczema		30 (37%)
Superficial Fungal Infection		24 (30%)
Bacterial Infection		47 (58%)
Traumatic Injury		25 (31%)
Bites/Stings		69 (85%)
Fish Shocks		12 (15%)
Heatstroke/Frostbite		0 (0%)

Cancerous/Precancerous Skin Lesions

Of the 81 fishermen screened, only one (1%) had skin type I (fair-skinned white individual who burns extensively and never tans), 76 (94%) had skin type II (fair-skinned white individuals who usually have lighter hair and blue eyes and who burn easily and tan with difficulty), and four (5%) had skin type III (average white individual with darker hair and brown eyes who burns moderately, but tans well). Forty-nine (60%) of the fishermen had a total of 269 precancerous actinic keratoses. Individuals had between 1 and 45 actinic keratoses, Of these individuals, one had skin type I with the remainder having skin type II. Twelve watermen (15%) had actinic cheilitis (all skin type II). Seven fishermen (9%) had a total of 14 basal cell carcinomas (one with type I skin and six others with skin type II). Five fishermen (6%) had a total of seven squamous cell carcinomas (all skin type II). There were no malignant melanomas found in the limited skin screening in this group of watermen.

Twenty-seven (33%) of the fishermen reported a previous history of having been treated for actinic keratoses, and one (1%) had previously diagnosed actinic cheilitis. All of these men had skin types I and II, and their average age was 58 (range = 40-79). Fifteen (19%) reported having had a total of 28 basal cell carcinomas. The mean age of these watermen was 59 (range = 48-79) and all had skin type II. Seven (9%) of the 81 total fishermen reported having had ten squamous cell carcinomas. The mean age of those reporting a previous history of squamous cell carcinomas was 64 (range = 48-79), and all had skin type II. Three (3.7%) of the overall group gave a history of having had malignant melanoma. All of them had skin type II, and their mean age was 63 (range 59-72).

Eczemas

A total of 30 fishermen (37%) reported a history of "eczema," with hand eczema and eczema of the forearms accounting for all of these cases. It was generally reported by the fishermen that the problem was worse in the winter months. Although there may be others, three of this group reported having had rashes that suggested a history of an allergic contact dermatitis: one who was allergic to rubber/latex gloves, one who reacted only when handling shrimp, and one who reacted only after handling squid.

Superficial Fungal Infections

Of the entire group of watermen studied, 24 (30%) gave a history of having had superficial fungal infections. The majority of them gave a history of "athlete's foot" (tinea pedis), with others giving a history of hands, legs, groin, and nails being involved (often combined with their feet). One individual gave a history of a fingerweb "fungus infection" when working in gloves, and this was likely due to *Candida* (erosio interdigitale blastomycetica).

Bacterial Infections

Commercial fishermen are exposed to many disruptions of the epidermal barrier to skin infections due to the minor cutaneous traumatic injuries in their day-to-day work in handling fish/crustaceans with spines, sharp shells, pinch injuries, and fish bites. A total of 47 fishermen (58%) described having had a bacterial infection that was serious enough to warrant seeking medical care, and many of them described multiple episodes.

The largest numbers of cases of infection were described by individuals as "fish poison," "shrimp poison," "crab poison," or "scallop poison," and were reported by 25 fishermen (31%). These are common names for the usually transient and self-limited cellulitis known as erysipeloid due to the organism, *Erysipelothrix rhusiopathiae*. True cases of erysipeloid may, however, be difficult to sort out from fish envenomations in this historical study. Many fishermen reported not seeking medical attention except for the most serious episodes of erysipeloid, and yet, *Erysipelothrix rhusiopathiae* can disseminate and cause endocarditis as well as other sequellae.[9]

The next most common infection where medical attention was sought was abscess formation in eight fishermen (10%) and cellulitis in seven fishermen (9%). These infections were often related to a puncture wound (fish/crab/shrimp spine or splinter injury) or a laceration (crab pinch, fish bite or other traumatic injury).

Three (4%) of the fishermen reported seeking medical attention for cases of *Mycobacterium marinum* infection. This slow-growing aquatic organism causes granuloma formation in tissue with a tumorous or verrucoid lesion enlarging over many weeks to months and usually following (and at the site of) a traumatic injury to the skin.

Other less common infections requiring medical attention were folliculitis (two fishermen; 2%) where the infection was occurring under or at the margins of rubber gloves, and an acute paronychia infection of a proximal nail fold (one fisherman; 1%). One fisherman (1%) also reported that he had been treated for the infestation commonly known as "creeping eruption" or "catworms" (cutaneous larva migrans).

Traumatic Injuries

Most fishermen laughed when initially asked about traumatic injuries to the skin: "It happens every day," they answered. However, when asked about the more serious traumatic injuries to their skin where medical attention should have been sought, 31% reported in the positive. Lacerations, skin avulsions, severe puncture injuries, and crush injuries (with injury to the skin) related to boats or boat equipment occurred in eight fishermen (10%). Injuries ranged from a hatch falling, a hand crushed between two boats, a bulkhead injury, a fall on the boat, and a drill bit injury while working on the boat, to a hand caught in a boat's steering chain with loss of digits/fingertips. Lacerations, skin avulsions, or crush injuries (with injury to the skin) due to the larger fishing equipment were reported to have occurred to nine fishermen (11%). Injuries ranged in this category from a trawl door falling on a foot, a net dropping on a foot, winch injuries, block injuries, a crab pot-pull injury, a gill-netter pulley tearing a waterman's hand open, to lacerations from metal oyster gear equipment. Serious fishhook lacerations/injuries occurred in five fishermen (6%) with these occurring most commonly in the offshore/finfish fishermen. Serious knife laceration injuries occurred in three watermen (4%), and serious, deep lacerations from an oyster shell injury occurred in one fisherman (1%). Several of the fishermen reported more than a single serious traumatic event.

Bites and Stings

Virtually all of the commercial watermen interviewed were very familiar with the day-to-day exposure to minor fish bites, crab pinch injuries, shrimp spine injuries, minor jellyfish stings, minor shell cuts, minor fish stings, etc. Out of the 81 total fishermen interviewed, there were only 12 who reported never having had what they would consider a "significant" or "serious" bite/sting related to their occupation.

Serious or extensive exposure to jellyfish stings was the most common exposure occurring in 22 individuals (27%). Nettles falling from nets led to extensive and severe stings in some individuals. Indeed, 21 fishermen (26%) reported being stung by jellyfish in the eyes with temporary blindness, "blistering" of the eyes, severe conjunctivitis, and pain/edema causing temporary ocular closure. Nine fishermen (11%) reported at least one serious sting by a Portuguese man-of-war. One individual reported such a severe sting to his chest and face that he "went into shock." He recovered without medical attention as he was offshore and couldn't get to a medical facility.

Potentially one of the most severe and common sting injuries to which commercial fishermen in North Carolina are exposed is from the stingray. The injury usually occurs on the limbs, and these injuries account for many of the visits to doctors' offices in this occupational group. Twenty-six (32%) of watermen surveyed reported at least one stingray sting (range 1-13 stings). Fifteen (19%) had suffered multiple stings. Smaller sting injuries were referred to as "pin cushion" stings whereas the larger lacerations, deep puncture injuries—injuries with retained spines or those leading to infection—were those requiring medical attention.

Serious puncture injuries necessitating extraction or causing infection from fish fins/spines/bones or crab/shrimp spines/ "prongs" occurred in 16 commercial fishermen (20%). Severe fish stings (other than those due to stingrays) were reported in five individuals (6%), with the more severe stings reported due to the spiny dogfish and sea catfish.

Fish bites can also lead to severe injuries, and the more severe injuries were reported by ten watermen (12%). In North Carolina, fish reported to cause these more severe bite injuries included sharks, barracuda, mackerel, and bluefish.

Severe crab pinch injuries were more common in the inshore fishermen and were reported by nine commercial watermen (11%). These resulted in lacerations that required suturing, resulted in tendon exposure, or were crush injuries.

Fish Shocks

Some fish have specialized cells known as electrocytes, which are capable of producing an electric current strong enough to shock individuals coming in contact with them. Fish known to cause electric shocks in North Carolina waters include the stargazer (Family Uranoscopidae) and torpedo ray (Family Torpedinidae). Eleven fishermen (14%) reported shocks from stargazers and one (1%) from a torpedo ray. There were no serious sequellae, and only transient anesthesia and paraesthesias were noted.

Environmental Extremes

Fishermen often continue to work in extremes of heat, cold, and wetness. No cases of "immersion foot" were reported. There were also no cases of heat stroke although two reported "heat prostration" (with loss of consciousness in one). There were also no cases of frostbite reported, although two watermen reported frostnip injury.

Discussion

Skin cancers as well as precancerous lesions have been shown to have an increased incidence in commercial fishermen and have been found to be correlated with age and fair skin types.[10] In addition, actinic cheilitis and squamous cell carcinoma of the lip have also been shown to have a high incidence in this occupational group.[11] Sun-protective clothing, sunscreens (PABA free, waterproof, at least SPF 15), lip balm containing sunscreens, and wide brimmed hats will all lower the potential for skin cancers in watermen. It must be emphasized that even "waterproof" sunscreens will wash off with the extremes of wetness and perspiration that occur in fishermen, and frequent reapplications are needed.

A history of eczematous rashes was commonly reported by our study group with the majority fitting into the category of irritant/xerotic/atopic with only a few having allergic contact dermatitis. Allergic dermatitis to latex/rubber products is well known,[12] as are allergic reactions to seafood.[13,14]

Exposure to wetness, humidity, and perspiration likely explains the high incidence of superficial fungal infections in commercial fishermen. Interestingly, in a previous study of watermen (in Germany), there was an even higher preponderance of tinea infections than that reported by the fishermen in our study.[15]

Fishermen are occupationally subject to infections not commonly seen in persons working in terrestrially-based occupations. In addition to the more usual Staphylococcal or Streptococcal infections, aquatic organisms such as *Vibrio* species, *Aeromonas hydrophila*, and *Pseudomonas*, need to be considered when treating infections in these individuals. Very serious and life-threatening infections due to *Vibrio vulnificus* and *Aeromonas hydrophila* need to be considered in fishermen who have liver disease, are immunosuppressed, or who have chronic diseases, such as kidney failure or diabetes.[16]

Traumatic injuries to the skin in commercial fishermen were often due to the vessel, fishing equipment, or knives/hooks. Deeper as well as crush injuries may need radiologic evaluation as well as consultation with a surgical sub-specialist, both of which are often hard to arrange at the time these injuries occur among watermen.

Bites and stings were a common injury to the watermen in our study, and treatment of these injuries usually depends on the type of injury incurred. If spine/foreign body retention is possible, a radiologic examination may reveal it, and a surgical consultation should be considered. Consideration of antibiotic coverage and attention to tetanus prophylaxis is also warranted.

Fishermen in our study were the recipients of shock injuries from both the stargazer and torpedo ray. These fish can deliver shocks anywhere from 14 to 220 volts depending on the species.[17,18] No serious complications are generally noted in these injuries and no treatment is usually indicated.

Working in the hot summer heat without taking sufficient breaks, coupled with insufficient fluid intake, historically accounted for the few cases of heat prostration in our study. No cases of frostbite were recorded in this study, but prolonged exposure to cold without protective clothing/gloves accounted for the two cases of frostnip noted. It is recommended that protective survival suits be carried on commercial fishing vessels as they may be life-saving in the event of a vessel capsizing or sinking.

Conclusions

It is easy to conclude from this study that North Carolina commercial watermen are exposed to a large variety of risks to their skin including: (1) high levels of ultraviolet rays of sunlight causing development of cancerous and precancerous skin/lip lesions; (2) traumatic injuries from fishing equipment, boats, boating repairs, as well as sharp spines/shells in sea critters; (3) skin irritants and allergens, wet/dry cycles, and chapping cold exposure that all can lead to eczematous conditions; (4) wetness, humidity, and sweaty conditions leading to cutaneous fungal infections; (5) traumatic injuries to the epidermal barrier to infection as well as exposure to a variety of aquatic pathogens leading to bacterial infections, including life-threatening ones; (6) bites, stings, and shocks from marine fauna that can, at times, be severe; and (7) extremes of wetness, heat, and cold potentially leading to injury.

The most serious concerns raised by this study include the high incidence of skin cancer, especially melanoma, where 3.7% of North Carolina watermen surveyed had a history of this potentially metastatic and life-threatening form of skin cancer (as compared to a lifetime risk of 2.2% in white males in North Carolina[19] or the typically accepted 1.3% in the general population in the United States[20]). Other concerns about skin cancer relate to the high numbers of uninsured watermen, which can lead to delays in seeking medical attention.

There are several concerns when interpreting the results from this study. First, with the exception of the skin cancer screening of this group, the study is largely retrospective, relying on memories of events by the fishers themselves. The results are not proven by biopsies, microscopic tests or cultures, but rely on visual recognition and historical claims. One could make the argument that many of the accounts are embellished and magnified. However, in the opinion of our group, this is probably not a significant factor and, if anything, the stoicism and fierce independence of these individuals lends them to tend to diminish and belittle even potentially life-threatening events.

Second, some of the fishermen talked of other peers who had life-ending infections or severe disabling traumatic injuries. Obviously, the individuals who had these events were not able to present themselves for our study. Indeed, watermen coming to festivals and events likely represent the healthier and higher end of the financial spectrum of watermen. We could observe many out working in the sounds during these festivals/shows. Finally, since the commercial fisherman in our region tends to be an independent individual, lacking in finances or insurance to pay for medical care, and at times distrustful of the healthcare system, many fishermen probably did not present to our booth for a screening. It was often the spouse of a waterman who coerced him over to our booth to get screened for concerning lesions. As the participants in this study were volunteers, it is unclear whether the data collected here can be extrapolated to the entire population of watermen.

In conclusion, we have presented a study of 81 commercial fishermen in eastern North Carolina who have had a large variety of cutaneous problems related to their occupation. While this group of watermen has had severe economic pressures in recent decades, they have unique healthcare needs. Concerning issues in this group of North Carolina workers include: (1) the need for affordable health/disability insurance; (2) first aid/emergency supplies on vessels; (3) protective gear and equipment for fishermen; and (4) better access to healthcare (including specialty access) in rural fishing communities. As the economy becomes more global with its concomitant local economic pressures on this group of watermen, a more global approach both to fishing regulations and fishing safety should be pursued. **NCMedJ**

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POLICY FORUM

Confronting the Problems of Overweight and Obesity

Introduction
Gordon H. DeFriese, PhD

Issue Brief: The Epidemic of Overweight and Obesity: A Challenge to Medicine, Public Health and Public Policy
Don W. Bradley, MD, MHS-CL

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The Public Health Challenge of Obesity in North Carolina
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Sidebar: Integrating A Focus on Overweight and Obesity in Clinical Practice: Practical Suggestions
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The Clinical Nutritional Implications of Obesity and Overweight
Kathryn M. Kolasa, PhD, RD, LDN; Kay Craven, RD, LDN; Sarah Henes, MA, RD, LDN and Catherine Sullivan, MPH, RD, LDN, IBCLC, RLC

> *"Mirroring the 53% increase in obesity over the last 10 years, the self-reported prevalence of diabetes, elevated cholesterol, and hypertension has increased (in North Carolina) 89%, 52% and 41%, respectively..."*

Addressing the Problems of Overweight and Obesity

Tipping the Scales of Prevention Advocacy with $10,000 and a Notebook
Jennifer Hastings, MS, MPH; Meg van Staveren, MPH, RD; Rachel Biloff; Julie Knaack, RD and Meg Molloy, DrPH, MPH, RD

Sidebar: The Active Living by Design Program of the Robert Wood Johnson Foundation
Sarah Strunk, MHA

Coordinating School Efforts to Help Address the Obesity Epidemic in North Carolina
Paula Hudson Collins, MHDL, RHEd

Yes, Virginia, Bariatric Surgery Works…and It is Safe
Walter J. Pories, MD, FACS

Addressing Disparities in the Obesity Epidemic
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Private Sector Responses to Overweight and Obesity

Empowering Consumers and Employees to Lead Active, Healthy Lifestyles
Steven S Reinemund

Obesity in (Corporate) America: Large Employer Concerns and Strategies of Response
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Why Does the Private Sector Underinvest in Obesity Prevention and Treatment?
Eric A. Finkelstein, PhD and Derek S. Brown, PhD

The Payer Perspective: Blue Cross and Blue Shield of North Carolina's Approach to the Obesity Epidemic
Robert T. Harris, MD

SPECIAL ARTICLE

The Kate B. Reynolds "Smoking Education Lifestyle Fitness" (SELF) Improvement Program: Preventing and Reducing Chronic Disease in Low-Income North Carolina Communities
Margaret L. Sauer, MS, MHA; John H. Frank, MBA; J. Lloyd Michener, MD; Susan D. Yaggy, MPA and Truls Østbye, MD, PhD

INTRODUCTION

Policy Forum:
Confronting the Problems of Overweight and Obesity

Most of us have had the embarrassing (and sometimes horrifying) experience of seeing photographs of ourselves taken some 25 or 30 years ago, only to realize that "back then" we were but a mere fraction of our present body size and shape. We wonder "What happened?" When this experience occurs just after end-of-year holidays, it can be the stimulus for numerous resolutions to address these parts of our personal lifestyles in the effort to return to a shape and size we once were.

In recent years, those of us who have devoted our lives and careers to the health and health-related professions have become increasingly aware, as have all who are exposed to the national news media, that Americans (and North Carolinians) collectively are gaining weight at an alarming pace. Recent analyses of data from the National Health and Nutrition Examination Survey (NHANES) indicate that as many as 17% of U.S. children and adolescents are overweight and 32.2% of adults are obese. Others have estimated that as many as 65% of American adults are either overweight (BMI of 25-29.9) or obese (BMI of 30 or higher). And, it is the velocity of these increases which is of even greater concern. Most of us have seen the maps produced by the Centers for Disease Control and Prevention (CDC) which, when rapidly viewed in sequence, seem to show the nation becoming "heavier" with each successive picture.

There is some good news in that the rate at which average weight in our population has been increasing over the six-year period from 1999 to 2004 is somewhat lower for women than for men, children and adolescents. From the perspective of most highly respected organizations and individuals in the field of public health, we are facing a substantial "epidemic" of overweight and obesity in this country, and North Carolina is a state where these trends are most evident.

There have been efforts to "account for" and "explain away" some of the extent, if not the likely health consequences, of these trends. One paper gaining substantial interest this past year, by Flegal and colleagues, argues that obesity, as a cause of death is far less significant than many have estimated. But the fact remains, that the percentage of our population who meet the criteria for overweight and obesity has increased significantly, and we know that there are health and healthcare costs associated with these trends.

The *North Carolina Medical Journal* has assembled in this issue a number of commentaries addressing various aspects of this epidemic in an attempt to underscore the significance of these trends for our state and our healthcare arena. We are grateful to all our contributors, particular Dr. Don Bradley of Blue Cross and Blue Shield of North Carolina, who has provided the overview Issue Brief. We are also pleased that three of our state's largest private philanthropies (The Duke Endowment, the Kate B. Reynolds Charitable Trust, and the NC Health and Wellness Trust Fund Commission) have each contributed descriptions of programs and initiatives they have funded to assist in addressing these issues. We are also pleased that some of the authors in this issue bring important "national" perspectives to bear on these topics. We appreciate the contributions of Steven Reinemund, CEO of PepsiCo and LuAnn Heinen of the National Business Group on Health, as well as Donald Hensrud of the Mayo Clinic, who have helped us put many aspects of these trends into a broader perspective.

We are aware that there are those who have resisted the use of the term "epidemic" to describe the trends we highlight in this issue of the Journal. But, few can argue that these trends are not occurring, and at an alarming pace. Addressing these issues will require the concerted efforts of healthcare professionals and healthcare organizations, voluntary organizations, employers, public schools, and local civic organizations. We hope that these commentaries will help illuminate the many ways in which these problems can (and are) being addressed in our state.

Gordon H. DeFriese, PhD
Editor-in-Chief

The Epidemic of Overweight and Obesity:
A Challenge to Medicine, Public Health and Public Policy

Don W. Bradley, MD, MHS-CL

The National Institutes of Health (NIH) and National Heart Lung and Blood Institute (NHLBI) define adult overweight as a body mass index (BMI) between 25 and 29.9, and adult obesity as a BMI greater than 30.[1] By those definitions, the United States is in the midst of a dramatic obesity/overweight epidemic with data being quoted from a variety of perspectives and timeframes. North Carolina is representative of national trends, with the Behavioral Risk Factor Surveillance System (BRFSS) reporting 52.3% of adults as overweight or obese in 1995 and 62.6% in 2005.[2] The prevalence of overweight amongst children (6-11 years) and adolescents (12-19 years) rose from 11% to 19% and 11% to 17%, respectively, between the 1988-1994 and 2003-2004 National Health and Nutrition Examination Surveys (NHANES).[3]

In this issue of the *North Carolina Medical Journal*, staff of the NC State Center for Health Statistics have provided recent data on the extent of the overweight and obesity epidemic in our population,[4] along with data on trends in the behaviors of youth putting them at risk of these conditions.

Some critics argue that not everyone who has a BMI >25 is overweight, that the health and economic impacts of overweight/obesity are greatly exaggerated,[5] and/or that all the hype about the obesity epidemic is a ploy by the weight-loss industry, pharmaceutical companies and some researchers to create business.[6] Actually, their arguments have some validity, which suggests several caveats as the reader "digests" the following diverse compendium of well-reasoned articles by a distinguished set of authors.

First, the critical issue is control of obesity's comorbid conditions, not weight per se. A singular focus on weight or BMI misdirects both clinician and patient regarding the importance of lean versus fat body composition or distribution of fat. BMI is a correlate, though not a direct measure of body fat and fat distribution. Rather, weight/BMI should be considered a vital sign, giving the practitioner an objective, but non-specific metric that relates to potential underlying conditions.

Two commentaries in this special issue of the *North Carolina Medical Journal* offer specific advice to clinicians regarding how discussion of overweight and obesity can be handled in the context of conventional clinical encounters with patients with or at-risk for these conditions. The first of these by Dr. Donald Hensrud of the Mayo Clinic in Minnesota outlines a broad, but specific, approach to how these issues may be addressed as part of clinical practice routine.[7] The second, a sidebar commentary by Dr. Suzanne Lazorick of the NC Division of Public Health, gives further illustrations of how BMI and other related measures can be integrated with normal practice procedures.[8]

> *"It is much easier to maintain a healthy weight (and lifestyle) than it is to remediate unhealthy eating and sedentary habits. For this reason, a key focus should be prevention and treatment of childhood obesity."*

The underlying conditions of importance include diabetes, hyperlipidemia, hypertension, coronary artery disease, osteoarthritis, obstructive sleep apnea, gall bladder disease, asthma, depression, and some cancers (e.g., colon and breast).

Simply removing body fat by abdominal liposuction will not significantly improve metabolic parameters such as insulin

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sensitivity and lipid concentrations.[9] More recent evidence suggests visceral fat has a far greater impact on obesity-related metabolic disease.

Second, lifestyle change, not weight loss, is critical. Enduring weight loss requires sustained behavioral change, with or without pharmacologic support. It is those lifestyle changes—lower and improved caloric intake and increased physical activity—that impact obesity comorbidities. Multiple authors note that loss of as little as 5-10% of body weight through lifestyle changes improves metabolic parameters of diabetes and cardiac risk factors.[10,11]

Third, successful treatments of obesity-related conditions will require a different medical paradigm than is in place now. Given the need for ongoing support for lifestyle changes, obesity should be considered a chronic condition, followed by clinicians using an integrated, multidisciplinary Chronic Care Model.[12] The model is described in more detail later, and presumes involvement of the patient, the clinical team, decision support and information systems, and the community.

Fourth, prevention rather than treatment is the preferred method to deal with obesity-related conditions. It is much easier to maintain a healthy weight (and lifestyle) than it is to remediate unhealthy eating and sedentary habits. For this reason, a key focus should be prevention and treatment of childhood obesity. The complexity of prevention-oriented initiatives addressing the problem of overweight and obesity are described more fully by Jennifer Hastings and her colleagues from NC Prevention Partners in this issue of the *North Carolina Medical Journal*[13] and by Drs. Leah Devlin and Marcus Plescia of the NC Division of Public Health.[14] Dr. Alice Ammerman and colleagues from the UNC Center for Health Promotion and Disease Prevention describe the extent and the problems of addressing the epidemic of obesity among NC's racial and ethnically diverse population.[15]

Impact

Caveats given, North Carolina is in the midst of an epidemic of obesity-related conditions. Mirroring the 53% increase in obesity over the last 10 years, the self-reported prevalence (BRFSS-NC) of diabetes, elevated cholesterol, and hypertension has increased 89%, 52% and 41%, respectively, over the last ten years (see Figure 1). Notably, obesity is more prevalent in eastern North Carolina over the last four years (see Figure 2), and the rate is increasing more quickly than in the rest of the state. If comorbid conditions follow the rates of obesity, then one may assume they are more prevalent down east.

Figure 1.
North Carolina BRFSS 1995-2005 Obesity and Related Comorbidities

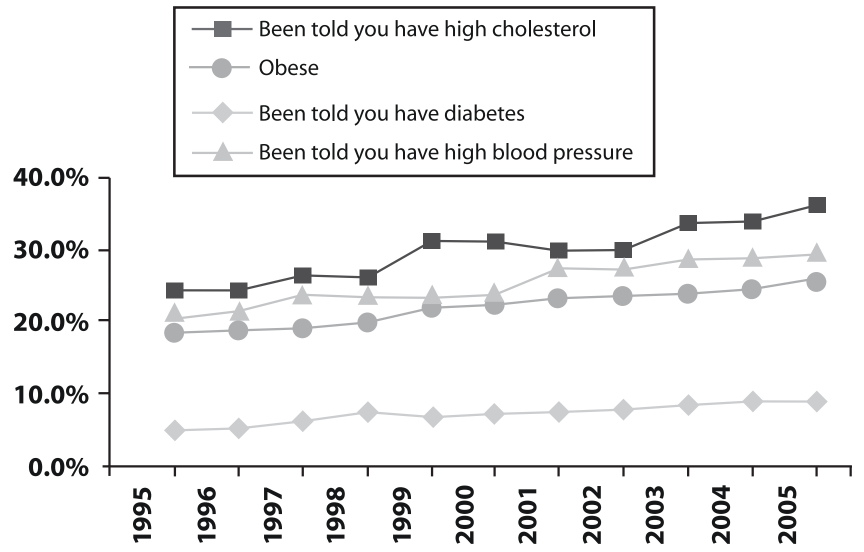
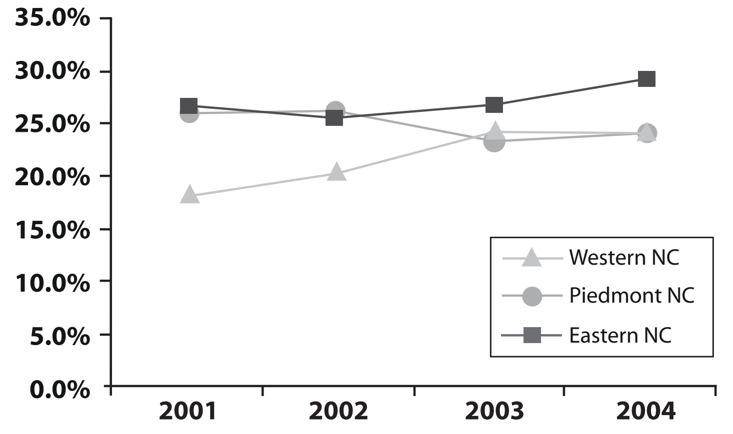


Figure 2.
North Carolina BRFSS 2001-2004 Obesity by Region



This increase in obesity-related chronic illness creates a significant burden for North Carolina primary care practitioners because care for chronic illness requires more time and practice resources than treatment of acute illnesses, especially if the conditions are not well controlled. Ostbye, et.al.[16] estimated that a 2,500-patient primary care practice caring for 10 chronic diseases (seven of ten related to obesity) per national practice guidelines would require 3.5 hours a day if the conditions were well controlled. If the chronic conditions were not well controlled, then the estimated time increased by a factor of 3, or 10.6 hours a day. Add to the practicing physician's day another 7.4

hours a day to deliver nationally accepted (and recommended by the US Preventive Services Task Force) preventive care guidelines,[17] and the primary care practice would need to stay open 18 hours per day, not including any acute care visits.

Even if practices chose to remain open 24 hours a day, it is abundantly clear that it is difficult to deliver all recommended care for chronic conditions. McGlynn[18] estimates that only 45% of recommended care is provided for diabetes, 49% for hyperlipidemia, 57% for osteoarthritis, 65% for hypertension, and 68% for coronary artery disease.

The quality issue identified by McGlynn is not caused by the obesity epidemic, but it is certainly exacerbated by it. Fortunately, there are sources of assistance for overweight or obese patients to whom physicians can make referrals when needed. These are described by Dr. Kathryn Kolasa and colleagues in this issue of the *North Carolina Medical Journal.*[19]

Obesity is a Chronic Condition

The Institute for Healthcare Improvement (IHI) advocates the Chronic Care Model developed by Wagner and colleagues at the Group Health Cooperative of Puget Sound[20] as a paradigm for delivering care for chronic conditions including obesity comorbidities (www.ihi.org). This paradigm focuses on productive interactions between a well-informed, highly motivated patient and an integrated, multidisciplinary healthcare team that anticipates patient needs and addresses them not only during individual physician visits, but also at individual or group meetings with other healthcare team members, outbound phone calls, emails, or mailings, and referral to a variety of informational resources.

Obesity treatment requires that the patient be supported in making self-management decisions based on his/her current preferences and readiness to change. The goal is to have the patients assume primary responsibility for their own health and hopefully make healthy clinical and lifestyle choices. The healthcare system should include incentives for patients (and physicians), adequate reimbursement for necessary services, and accurate, accessible, relevant and timely information that the patient and doctor can use to make decisions, and information systems that automatically remind providers and patients what services are needed and when.

The context for interactions between the patient and the healthcare system in the Chronic Care Model is the community, and it plays a significant role in the management of obesity-related conditions. Obesity is impacted by the quantity, quality and cost of food available, marketing and packaging of food, the safety and availability of environments to be physically active, competing priorities for time to be active (e.g., school curriculum, television/video games/internet "tube time", work and sleep), cultural and faith-based ethnic beliefs regarding body habitus, physical activity and eating behaviors, and regulatory and legislative mandates.

Payors (employers, insurance companies, Medicare and Medicaid) have historically been reluctant to cover treatment of obesity because of controversy regarding evidence that obesity directly contributes to medical and business costs, the lack of evidence that treatment is effective, and the lack of demonstrable short-term financial return.

The data shown above speak to the impact of obesity (as a marker of sub-optimal nutrition and physical activity) on medical conditions.

The Evidence is Mounting

Fortunately, there is a mounting body of evidence that the Chronic Care Model is effective in managing obesity-related conditions such as diabetes,[21,22,23] and emerging literature suggests that obesity itself is amenable to treatment.

One well-designed study, for instance, suggests that specific meal replacement as a mechanism to reduce caloric intake was effective in attaining and maintaining modest weight loss over four years.[24,25] Another systematic review[26] recommends dietary, physical activity, and behavioral approaches. And recently, preliminary studies suggest sleep deprivation plays a role in obesity.[27,28]

In addition, the magnitude of preventable disease attributable to obesity is increasingly well documented.[29,30] Thompson and Finkelstein estimate that 5% of all medical spending is attributable to obesity, and that the average annual medical spending for obese patients is 26-39% higher than for normal weight adult patients. This is consistent with Blue Cross and Blue Shield of North Carolina data (2003), which showed 32% higher medical expenditures for obese patients.

At issue from a financial perspective is the belief of some employers and insurers that they will not recognize a return on investment for obesity treatment, especially with younger employees/members. As a chronic condition, the medical sequelae of poor nutrition and lack of activity do not become apparent for several years. Some payors are concerned that they may pay for expensive treatment (especially bariatric surgery), only to have the patient leave their employ or plan well before reduced medical expenses are realized.

In this issue of the *North Carolina Medical Journal*, Drs. Eric Finkelstein and Derek Brown of Research Triangle Institute address the reasons why private sector organizations are reluctant to invest in obesity prevention and treatment for their employees.[31] But, commentaries by Steven Reinemund, CEO of PepsiCo,[32] and LuAnn Heinen of the National Business Group on Health,[33] point out the way in which American business and industry have undertaken to address these issues as matters of concern to their consumers and their own employee populations.

More recent and sophisticated economic models[34] confirm that time required to break even and possibly realize a financial benefit of bariatric surgery is considerable, estimated at five years. Strategies to mitigate the prolonged return on investment time, though, may include incentives to use centers of excellence for bariatric surgery, employee cost sharing, and incentives to retain the patient with the employer or insurance plan after surgical intervention. Further evolution of economic models will help influence payor coverage decisions for treatment of obesity. Of note, Medicare recognized obesity as a condition (eligible for reimbursement) in 2003, and began limited coverage for bariatric surgery in 2006. In this issue of the North Carolina Medical Journal, Dr. Walter Pories of East Carolina University's Brody School of Medicine, one of the pioneers in bariatric surgery in the U.S., offers a detailed overview of current progress and efficacy in this mode of treatment for morbid obesity.[35]

The key to ongoing reimbursement for the treatment of obesity will be the results of studies and pilot programs currently being launched. A variety of stakeholders are involved in these efforts, including the Centers for Disease Control and Prevention, the North Carolina Health and Wellness Trust Fund, the State of North Carolina, public school systems, private insurers and foundations, and employers. We are fortunate to be able to include in this issue of the *North Carolina Medical Journal* descriptions of programs addressing the childhood obesity epidemic by Paula Hudson Collins of the NC Department of Public Instruction[36] and Lt. Governor Beverly Perdue on behalf of the NC Health and Wellness Trust Fund Commission.[37]

The physician's role in combating the obesity epidemic is multi-faceted and critical. As the most trusted source of medical information, the doctor can identify, assess, and make recommendations for prevention and treatment of obesity and obesity-related conditions. Efforts by Blue Cross and Blue Shield of North Carolina to give physicians (and their patients) access to the best medical and behavioral therapies for addressing the problem of overweight and obesity are described in this issue of the *North Carolina Medical Journal* by Blue Cross and Blue Shield Senior Vice President Robert Harris.[38]

Within a Chronic Care Model, he/she may not provide direct behavioral counseling or nutritional advice, but extends medical legitimacy to other healthcare team members (nurses, nutritionists, trainers, counselors, community programs, on-line programs, health plan programs, etc.). The primary care practitioner helps coordinate and direct care, especially if the patient has (and many patients do have!) multiple chronic conditions. The physician should seek multiple communication channels to work with patients, including printed materials, referral to on-line resources, group sessions, inbound and outbound phone lines, and e-mail. The practice should keep patient registries for chronic conditions, automate care reminders, and track clinical performance.

A proactive physician may work outside the office setting, collaborating with the school system, faith-based or community organizations, or government-sponsored programs.

Of no small importance, physicians can model healthy behaviors, including demonstrating healthy nutrition in the office, being physically active in a public manner, and maintaining a healthy weight. Modeling health behaviors not only increases physician credibility with patients, but provides insight into the practicalities and options being recommended to the patient.

Finally, physicians can serve as potential advocates for public policy change, planning for active communities, and changes to employer-based programs. The more evidence-based the advocacy, the more powerful it is.

Since obesity is as much of a social issue as it is a medical issue, the role of stakeholders outside the healthcare system cannot be underestimated. Several North Carolina initiatives are described in this issue of the *North Carolina Medical Journal*, and are excellent examples of the multi-pronged approach that is needed to stem the rising tide of obesity as a population health issue. Among these are programs supported across North Carolina by The Duke Endowment[39] and the Kate B. Reynolds Charitable Trust,[40] the NC Health and Wellness Trust Fund Commission, and the national program of the Robert Wood Johnson Foundation based in Chapel Hill known as "Active Living by Design."[41] Since the backgrounds and needs of North Carolinians are unique (as they are in any state), and there does not appear to be any approach that has demonstrated superior results, it is highly appropriate that multiple initiatives be undertaken. What is critical, however, is to coordinate separate efforts as much as possible, and to carefully document outcomes so that we know where best to invest resources going forward.

Federal assistance for combating obesity is directed primarily through the Federal Trade Commission (marketing and advertising, particularly to children and adolescents), and the Food and Drug Administration (food labeling).[42] The Federal Trade Commission is mired in technical complications in identifying and regulating advertising to children,[43] while the Food and Drug Administration has had somewhat more success in promoting food labeling. We in North Carolina must recognize that federal efforts are but one more piece of an extensive medical/social/economic puzzle. **NCMedJ**

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Overweight and Obesity:

A Clinician's Perspective

Donald D. Hensrud, MD, MPH

In recent years, much has been published in the medical and lay literature on overweight and obesity. The most current United States data show that in 2003-2004, 32.2% of adults were obese and 66.3% were overweight or obese.[1] The increasing prevalence over the past three decades, the associated disease comorbidities, and the attributable healthcare costs of obesity have been well documented. Various etiologic factors for the relatively recent increase in weight have been described, many of which involve a permissive environment that promotes a sedentary lifestyle and increased energy intake. For these reasons, obesity is one of the major public health challenges the United States is facing.

If overweight and obesity are a public health problem, does it not require a public health solution? What can healthcare providers do in their office to make a meaningful impact on a problem that affects two-thirds of their adult patients? Compounding the challenge to clinical treatment of overweight and obesity are the limited appointment time and reimbursement available to most clinicians. While the impediments to effective treatment of obesity are real, healthcare providers can stimulate individual and collective changes in their patients by following a specific, efficient, and systematic plan. Listed below are elements of a general plan to treat overweight and obesity for the busy clinician.

1. Perform a Brief Assessment

A. Classification

Measure height, weight, and waist measurement (or estimate by inspection) and determine body mass index (BMI) from a table or by calculation. Review the established comorbidities from obesity that are present (Table 1). Health risks, and therefore the need to lose weight, increase with increasing BMI, increasing waist measurement, and a greater number of established comorbidities (Table 2).[2] The initial classification of obesity can help guide treatment recommendations.

Table 1. Medical Comorbidities of Obesity

Type 2 diabetes mellitus
Hypertension
Dyslipidemia (high triglycerides and low HDL cholesterol)
Cardiovascular disease
Coronary artery disease
Stroke
Congestive heart failure
Nonalcoholic fatty liver disease (steatosis, steatohepatitis, cirrhosis)
Respiratory diseases
Obstructive sleep apnea
Obesity-hypoventilation syndrome
Asthma
Restrictive lung disease
Many cancers
Osteoarthritis
Cholelithiasis
Gastroesophageal reflux disease (GERD)
Gynecologic abnormalities
Infertility
Abnormal menses
Venous stasis
Skin problems
Intertrigo
Cellulitis
Increased risk of complications during surgery or pregnancy
Increased overall mortality

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B. Patient Readiness

Is the patient interested in increasing their efforts to lose weight? If not, just providing a brief motivating message and educational material may be all that can be accomplished at this time. Administering treatment recommendations will probably not be effective. Questions based on the stages of change model can be used to help determine patient readiness. Examples of patient readiness questionnaires are available, some of which target general readiness,[3] while others focus on specific diet and physical activity habits.[4]

Table 2.
Classification of Overweight and Obesity.[1]

			DISEASE RISK	
	BMI[2] (kg/m2)	Obesity Class	Low Waist Cir	High Waist Cir[3]
Underweight	< 18.5		-	-
Normal	18.5 – 24.9		-	-
Overweight	25.0 – 29.9		Increased	High
Obesity	30.0 – 34.9	I	High	Very high
	35.0 – 39.9	II	Very high	Very high
Extreme obesity	≥ 40	III	Extremely high	Extremely high

1 The Practical Guide to the Identification, Evaluation, and Treatment of Overweight and Obesity in Adults. NIH Pub. No. 00-4084, 2000. Available online at: http://www.nhlbi.nih.gov/guidelines/obesity/practgde.htm/, accessed July 10, 2006.

2 Body mass index (BMI) can be calculated as wt(kg)/ht^2(m), or wt(lb)x703/ht^2(in). Tables of weight, height, and BMI are also available.

3 High waist circumference is defined as > 40" in men and > 35" in women

C. History

Much of the medical history and weight-related assessment of obesity can be performed most efficiently with a written questionnaire. The items listed in Table 3 are relevant to the assessment of obesity and may influence treatment recommendations. A questionnaire based on these items can be prepared, tailored to the physician's practice, and administered to patients undergoing assessment for weight management. If it is not possible to provide a questionnaire to patients ahead of time, asking a few brief questions, even in a busy practice, can provide a reasonably good snapshot of baseline diet and activity habits (Table 4).

2. Order Appropriate Laboratory Studies

Consider obtaining a fasting blood glucose, lipid screen, TSH, and AST. Further testing should be guided by the clinical evaluation. For example, if there is a history of snoring with possible apneic periods or overnight oximetry, an appointment in a sleep disorders center should be obtained.

3. Use a Positive Approach

This is an area that is often under appreciated and difficult to document, but can be extremely important. Patients are often discouraged by lack of results in weight management. Physician recommendations can have a strong influence on patient behavior. The physician can prepare the patient by providing motivation and encouraging a positive attitude when initiating and following through on weight loss efforts. A typical approach toward weight management is to go 'on a diet', which is often overly restrictive, has a negative connotation, and is therefore likely to be temporary. On the other hand, people often say they feel better when they are more active. By focusing on the beneficial aspects of lifestyle changes in diet and physical activity, weight management efforts are more likely to be enjoyable, sustainable, and effective.

4. Determine a Tailored Plan

The plan for weight loss should be individualized based on the initial classification of obesity and factors in the patients' history. The aggressiveness of the approach should be guided by the degree of obesity and number and extent of comorbidities. All patients should initially receive specific recommendations for diet, physical activity, and lifestyle behavior changes. If there is no response to initial therapy, some patients may be candidates for pharmacotherapy or possibly surgery (Table 5), in addition to continuing efforts with lifestyle therapies. Physicians should obviously be familiar with medications to treat obesity if they are going to use them. Referrals for possible surgery should be made to medical centers experienced in this modality.

The plan for weight loss should include specific treatment recommendations for diet, physical activity, and lifestyle changes. Suggestions for dealing with individual challenges of managing weight that were uncovered in the assessment should be included. Rather than overwhelm someone with too much to address, a few main items can be targeted. For example, if eating at restaurants occurs frequently, a plan for making appropriate choices as well as monitoring of calorie intake should be developed. Encouraging patients to use problem-solving techniques can help them confront challenges more effectively. First, the problem is identified. Barriers to change followed by benefits to change can be written down. Potential solutions to the problem can then be explored, and a specific plan for addressing the problem designed. Goals should be determined (see below) and follow up appointments arranged.

5. Outline a Dietary Program

Many different dietary plans and programs are available including low carbohydrate, low fat, counting calories, meal replacements, very-low calorie diets, and popular diets, of which some have little basis in known physiology. The

Table 3. Items to Assess in the Medical and Weight History for Evaluation of Obesity.

Medical History
Comorbidities of Obesity
Medications and dietary supplements (some medications, e.g., corticosteroids, some antidepressants, and others may adversely affect weight)
Family history of obesity
Weight History
Reasons/expectations for weight loss
Available support
Previous methods of weight loss and results (including why results were not successful)
Potential barriers to weight loss and maintenance (time, finances, established habits, physical limitations)
High School graduation weight, minimum and maximum adult weight
Periods of increased weight gain (e.g., pregnancy, smoking cessation, stressful life periods)
Current (and past) diet
Triggers to eating
Current (and past) exercise and general activity
Type, frequency, and duration of exercise
Amount of nonexercise activity
Factors the patient believes are responsible for weight
Binge eating, purging, laxative or diuretic use

approach used should be practical, enjoyable, healthful, and sustainable. If tracking calories are used, an initial goal of 1,000 to 1,200 kcal/day for women and 1,200 to 1,600 kcal/day for men can be recommended.[2] Increasing the intake of low energy dense foods including vegetables and fruits can lower overall energy intake, yet maintain bulk that contributes to satiety.[3] Including foods such as whole grains and small amounts of unsaturated fat while restricting saturated fat, refined carbohydrate and processed foods can help promote health while managing weight. This approach is also consistent with other dietary guidelines recommended to decrease the risk of chronic diseases. Specific areas to target that have been identified as contributing to increased caloric intake or obesity are portion control, skipping breakfast, eating away from home—particularly fast food, and consuming refined carbohydrate, particularly sugar.[5]

6. Incorporate Exercise/NEAT

Increasing total energy expenditure can be accomplished through increasing exercise and non-exercise activity thermogenesis (NEAT). Patients should be encouraged to start a regular aerobic exercise plan slowly, yet gradually and progressively increase the frequency, duration, and intensity of exercise, in that order. Patients may need individual instructions from a physical therapist or other qualified healthcare provider on the appropriate exercises based on their fitness level and physical limitations.

While exercise is the most efficient way to burn calories, the potential for increasing total energy expenditure is just as great by increasing NEAT throughout the day. Many people exercise an hour or two of the 168 hours in a week. Increasing NEAT may increase total energy expenditure more than exercise, because of the multiple opportunities available in the rest of the waking hours of the week. Lists of potential activities and strategies are available,[3] but the bottom line is any activity is good activity. The more excuses people can make to get activity during the day by performing activities such as walking during a work break or parking farther from a destination (instead of 'taking the shortcut'), the better chance they'll have at managing weight.

7. Formulate Realistic Process Goals

The goal in weight loss is obviously a lower weight. However, many people focus too much effort on this outcome goal and not how to reach that goal. This is analogous to having a goal to make $100,000 without putting sufficient thought and effort into a plan on how to make it. It's been reported that the vast majority of people have unrealistic outcome goals for weight loss,[6] which eventually results in frustration, abandonment of efforts, and regain of any weight that was lost.

Process goals help to focus on the day-to-day activities that result in weight loss and, more importantly, sustaining that weight loss over time. Goals should be SMART—specific, measurable, attainable, realistic, and trackable. Examples of SMART process goals include eating one more serving of vegetables daily or starting to walk 10 minutes four times per week (and increasing by one session and 5 minutes per session each week to a goal of 40 minutes 6 times per week).

Challenges and problems should be expected and a plan to deal with them should be utilized, using problem-solving techniques. For example, everyone hits a weight plateau eventually. Two basic options for addressing this are to further increase physical activity or decrease calorie intake. If it is not possible to implement further changes in these areas that are sustainable, then continuation of current lifestyle habits is much preferred over

Table 4. Brief Questions to Assess Diet and Physical Activity Habits.

Diet
What do you eat in a typical day for breakfast, lunch, dinner, and snacks?
How much meat and how much vegetables and fruits do you eat in a typical day or week?
How often do you eat outside the home?
Physical Activity
How much exercise do you get in a typical week?
How much physical activity do you get in a typical day?

> *“The most current United States data show that in 2003-2004, 32.2% of adults were obese and 66.3% were overweight or obese.”*

stopping existing efforts and regaining weight.

Self-monitoring is an important aspect of adherence to change and achieving goals. People who keep diet and activity records are more likely to manage weight successfully.

8. Provide Resources

Time is limited in the office setting. Verbal recommendations should be supplemented by a written recommendations and resources such as office handouts, pamphlets, or a book. In addition, there are many websites related to weight loss, some of which are interactive, but the quality may vary. Telephonic coaching is becoming more popular. Patients should generally be referred to a Registered Dietitian who can take the time to obtain a detailed dietary history, provide education and recommendations, and follow patients over time, often in a group setting. Reputable commercial weight management programs can follow people over time and provide social support. For patients with significant behavioral issues related to weight management such as binge-eating disorder, referral to a Clinical Psychologist is indicated.

9. Arrange Follow up

Ongoing follow up is important in that it can help maintain motivation and provide an opportunity to ask questions, give feedback, refine recommendations, and revise process goals. Patients often appreciate the support and accountability a follow up visit offers. Patients can follow up in various ways and with different types of people. Similar to the rest of the plan, follow up should be tailored to the individual.

10. Outcome Measures

A comprehensive lifestyle modification program may result in weight loss of approximately 10% in 16 to 26 weeks.[7] While weight loss is an obvious primary objective, success can be defined in many additional ways. Long-term weight maintenance after weight loss is more important than rapid, short-term weight loss followed by weight regain. Inches lost and body composition changes are important intermediate markers. Improvement in the comorbidities of obesity and quality of life are important additional goals that can be realized. These goals can result from weight loss and from sustained health-promoting lifestyle changes in diet and physical activity, independent of weight loss.

Barriers to Clinical Treatment of Obesity

In addition to genetics and the environment, barriers to effective implementation of the clinical plan outlined above can be due to patient, healthcare provider, and health system factors. Patients often don’t appreciate the strength of the connection between their obesity and health comorbidities. In fact, patients who are overweight or obese often don’t recognize themselves or their children as such.[8] In addition, many people have tried to lose weight, often with an ineffective approach, and realize the difficulty of losing and maintaining weight loss. Healthcare providers are not exempt from challenges with managing their own weight and have experienced how difficult it is to achieve lasting weight loss in their patients. In addition, healthcare providers may not have adequate training or resources to help them adequately treat obesity. Insurers do not generally reimburse for obesity as a diagnosis. An exception to this is Blue Cross Blue Shield of North Carolina, which has instituted a plan for addressing obesity as part of a healthy lifestyle program that covers a limited number of office visits for physicians and registered dietitians, as well as pharmacotherapy when indicated.[9] Further education for healthcare providers and patients, implementation plans to treat obesity and document outcome, and resources to support these efforts are needed.

Table 5.
Treatment Options for Obesity.[1]

	BMI				
Treatment	**25-26.9**	**27-29.9**	**30-34.9**	**35-39.9**	**≥40**
Diet, physical activity, and behavior therapy	with comorbidities	with comorbidities	Yes	Yes	Yes
Pharmacotherapy		with comorbidities	Yes	Yes	Yes
Surgery				with comorbidities	Yes

1 The Practical Guide to the Identification, Evaluation, and Treatment of Overweight and Obesity in Adults. NIH Pub. No. 00-4084, 2000. Available online at: http://www.nhlbi.nih.gov/guidelines/obesity/practgde.htm/, accessed July 10, 2006.

Conclusion

The causes of the recent rise in the prevalence of overweight and obesity are multiple, diverse, collectively powerful, and pervasive. Multidisciplinary action with interventions from government, academia, public health, private industry, and healthcare institutions will be necessary to reverse the rising trend in obesity. The healthcare providers' office is one part of this massive effort and while efforts by clinicians may not solve the problem of obesity, they may help many individuals to improve not only their weight, but their health and quality of life. **NCMedJ**

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The Public Health Challenge of Obesity in North Carolina

Leah Devlin, DDS, MPH and Marcus Plescia, MD, MPH

Obesity is one of the most important public health issues of our time. Just as infectious diseases threatened the health and well being of communities in the early 20th century, chronic diseases are now the greatest threat of the 21st. The risk factors for obesity, physical inactivity and poor nutrition have begun to approach the public health impact of tobacco use.[1] The resulting rise in chronic diseases that is directly attributed to these three risk factors threatens to undo much of the progress made to improve health in the last century and worsen existing health disparities. At no other time in our history have we had the majority of our population affected or threatened by an epidemic; over 67% of American adults are overweight.[2]

As with any public health epidemic, we must take aggressive steps. Progress in containing infectious disease epidemics of the past occurred when epidemiologists shifted focus from identifying afflicted individuals to resolving the underlying environmental causes of infectious outbreaks by ensuring adequate access to clean water supplies and appropriate disposal of sewage. The same approach must be taken with obesity. While physical inactivity and poor quality dietary practices are the immediate causes of obesity, our society must shift from a focus on individual responsibility and look to the root factors in our societal environment that have led to this unprecedented increase.

Responsible public health practice is based on population-based surveillance and the use of evidence-based interventions. Much can be learned from our experience with tobacco control. After evidence emerged that tobacco use could best be controlled through societal and environmental approaches, interventions were implemented to make the product less available, more expensive, and less appealing. Rates of tobacco use and worksite exposure to second-hand smoke are now declining across the nation, including in North Carolina.[3,4] Evidence-based approaches for obesity are also emerging. Using the same approach as the *Guide to Clinical Preventive Services*,[5] *The Guide to Community Preventive Services*[6] has convened a scientific committee to review the evidence for effective community-based interventions (www.thecommunityguide.org). In 2005 the national Institute of Medicine (IOM) convened an expert task force to make recommendations on how to control childhood obesity based on scientific reports, review of previously successful public health campaigns, and expert testimony.[7] The recommendations of these two expert groups (the US Preventive Services Task Force and the CDC Task Force on Community Preventive Services) require complex approaches to impact obesity in multiple sectors of our society. An emphasis is placed on policy and environmental change as more efficient and sustainable approaches than focusing solely on personal responsibility.

> *"The risk factors for obesity, physical inactivity and poor nutrition have begun to approach the public health impact of tobacco use."*

Eat Smart, Move More...North Carolina is an ambitious statewide initiative to encourage healthy eating and physical activity wherever people live, learn, earn, play, and pray. The North Carolina Division of Public Health provides staff support and funding for the Eat Smart, Move More leadership team, a

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group of over 100 public and private partners. The focus of the initiative is on seven evidence-based strategies:

- reducing time spent watching television;
- increasing physical activity;
- increasing fruit and vegetable consumption;
- decreasing sugar-sweetened beverage consumption;
- decreasing portion sizes of foods and beverages;
- preparing and eating more meals at home; and
- breastfeeding.

Consistent with national recommendations, Eat Smart, Move More…North Carolina is a comprehensive, multi-level initiative to effect policy and environmental change across the state, within organizations and among communities and to support interpersonal and individual changes in health behavior.

Across the State: Public Policy and Social Norms

An educational campaign through television, radio, and print presently targets mothers aged 25 to 54 with all seven Eat Smart, Move More messages. The campaign is running currently in the Raleigh-Durham and Charlotte media markets, and will expand statewide in the late fall. The re-designed Website, *www.EatSmartMoveMoreNC.com*, was re-launched in January 2006 with a new consumer-focused Website, MyEatSmartMoveMore.com. The Website features tools and resources for professionals, news tips for journalists and helpful information for individuals trying to make simple lifestyle changes.

Based on the work of the North Carolina Health and Wellness Trust Fund Obesity Study Group, legislation was passed in the 2005 session to implement nutrition standards for school meals and vending machines as well as a state Board of Education policy to make physical activity mandatory for grades K through eight. North Carolina has recently been identified as a national leader for its use of federal Preventive Health and Health Services Block grant funds to support policy and environmental change interventions through every local health department in the state. Local progress in effecting such change has been well documented. Legislation has been introduced this year to fund a community grants program to make neighborhoods, towns, and cities more pedestrian friendly. In August 2006, the NC Division of Public Health will host an obesity summit in collaboration with the Trust for America's Health with the goal of committing prominent leaders to support a public policy approach to obesity prevention and control.

Organizations: Policies and Environments

The Health*Smart* Worksite Wellness Tool Kit has been developed for state employee worksite wellness committees in collaboration with the North Carolina State Employee's Health Plan. Employee groups across the state have been trained in how to organize an effective committee to develop policies and resources that will improve nutrition, physical activity, tobacco cessation, and stress management among the state employee workforce. A demonstration project has been started in the Department of Health and Human Services. Policy and environmental changes in the Division of Public Health include availability of healthy vending machine snacks, a stairwell project, local walking routes and a breastfeeding room.

Eat Smart: North Carolina's Recommended Standards for All Foods Available in School and Move More: North Carolina's Recommended Standards for Physical Activity in School are curriculums available to all school districts and have been implemented at varying levels to incorporate healthy eating and physical activity in the academic environment.

A partnership with the North Carolina Cooperative Extension Service provides preschools with *Color Me Healthy*, a nutrition and physical activity education program for four to five year-olds that has been implemented in 5,500 child care centers across North Carolina. Through the use of color, music, and exploration of the senses, *Color Me Healthy* teaches children that healthy food and physical activity are fun. The Nutrition and Physical Activity Self-Assessment for Child Care (NAP-SACC) is a pilot intervention in child care centers aimed at improving nutrition and physical activity policies and practices. Center staff complete self-assessments and receive consultation on improving the center's feeding and physical activity programs. This program will be expanded statewide in the coming year.

African American Churches Eating Smart and Moving More: A Planning and Resource Guide is designed to create healthy eating policies and physical activity programs among church congregations. This tool builds on the existing Black Churches United for Better Health program and is helping churches form wellness committees, start walking clubs, and institute healthy food potlucks. Statewide train-the-trainer workshops are helping interested church members become agents for change in their church communities.

Communities: Policies and Environments

All local health departments receive capacity funding for health promotion efforts focused on policy and environmental change. Local Physical Activity & Nutrition Coalitions (LPANs) promote physical activity and healthy eating opportunities at the community level. Currently, 68 out of 100 North Carolina counties have an LPAN, usually as a subcommittee of their Healthy Carolinians partnerships.[a] These coalitions initiate and coordinate local programs and interventions to increase opportunities for physical activity and healthy eating. Coalitions are encouraged to focus on policy and environmental approaches. *Winning with ACEs! How You Can Work Toward*

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[a] Healthy Carolinians, a network of public-private partnerships representing public health, hospitals, schools, churches, businesses, community members, and elected officials, address North Carolina's 2010 health objectives through a collaborative planning process.

Integrating A Focus on Overweight and Obesity in Clinical Practice: Practical Suggestions

The U.S. Preventive Services Task Force found good evidence to support assessment of Body Mass Index (BMI, weight in kilograms divided by the square of height in meters) of all adults when primary care visits occur. The task force recommended that if BMI is greater than 30, healthcare providers should arrange for, or provide, intensive counseling about nutrition and physical activity.[1]

Measuring BMI

Accurate BMI measurement requires an office *system* that supports regularly obtaining accurate heights and weights (e.g., shoes off, stadiometer, calibrated scale) and includes one of the easy-to-use tools to calculate and record the BMI (e.g., table, wheel, website, PDA, or by hand calculator). Making room for these measurements in the routines of a busy primary care practice requires special attention to staff orientation and the scheduling of intake procedures.

As a practice routinely begins to document BMI for all of its patients, it is important to plan or identify appropriate patient follow-up recommendations depending on the results obtained from these measures. One very simple office protocol is shown in Table 1, but this can be modified to a practice's particular level of counseling ability and local resources.

Table 1.
Basic Office Protocol Based on Patient BMI Calculation

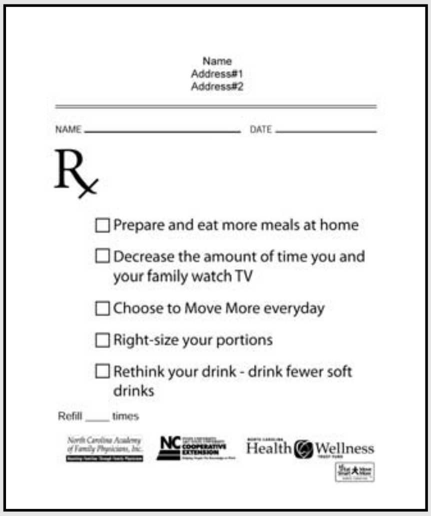
BMI Result	Action Plan
Underweight BMI < 18	• Communicate the BMI result, • Schedule follow up for further work-up as indicated
Healthy 18 < BMI < 25	• Communicate the BMI result, • Reinforce healthy behaviors
Overweight BMI = 25-30	• Communicate the BMI result, • Provide introductory counseling, • Plan follow up
Obese BMI > 30	• Communicate the BMI result, • Schedule any appropriate lab work, • Plan follow-up for more intensive counseling or refer for further intervention

Introducing Brief, Targeted Counseling about Nutrition and Physical Activity

With access to the Internet, a great place to start is the newly redesigned website: *www.eatsmartmovemorenc.com*. This site includes an entry portal that takes one to a site for professionals that includes a drop-down menu of downloadable, ready-to-use tools. There are several handouts for patients that provide practical strategies to address each target behavior in the Eat Smart Move More program. Office staff could prepare a few packets ready for specific issues, or customize packets that will best fit specific patient populations. Although handouts by themselves are not likely to be effective, they do facilitate discussion of a patient's motivation to make changes and focus on one or two behaviors that they may be most successful at changing. If available time does not allow for personalized messages at each visit, it may be best to focus on one behavior at a time for several weeks, and simply discuss that issue with all patients, with a goal over a year of reaching many patients with different, but important, messages.

Another way to reinforce behavior change messages is the "Big Five Prescription Pad" available as a customizable pdf from the tools menu. (Figure 1) This tool can be used as a take-home prescription for patients to emphasize the behaviors discussed, or perhaps to contract with them on 1-3 behaviors on which they may agree to focus after the visit. The key is not to overwhelm the patient with what may appear to be expectations of sweeping changes that must be made all at once, but support them in the idea they can target their efforts to selected issues.

Figure 1.
Example Blank "Big Five Prescription" Pad, modifiable PDF available at www.eatsmartmovemorenc.com/



Name
Address#1
Address#2

NAME ______________ DATE ______________

℞

☐ Prepare and eat more meals at home

☐ Decrease the amount of time you and your family watch TV

☐ Choose to Move More everyday

☐ Right-size your portions

☐ Rethink your drink - drink fewer soft drinks

Refill ____ times

Additionally, a computer for patient education use in the office can be an advantage, and it can be set to this site for easy patient access.

More ideas

If the goal is to provide more than the simple handouts discussed above, an individualized, but still brief, tool is "Starting the Conversation," available for a modest price through NC Prevention Partners (*www.ncpreventionpartners.com*). This tool can be completed by the patient while waiting for the provider. The tool helps illustrate to both patient and provider which behaviors may be problems and provides suggestions as to how to support the behavior change which can be reinforced by the provider. Therefore, this easy to use, brief, "handout" also serves as an *interactive*, individualized counseling tool.

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Active Community Environments (referred to as the ACEs Guide) is a tool specifically developed to help community coalitions promote changes in community design that make opportunities and facilities for physical activity more available and accessible.

Funding for specific physical activity and nutrition programs has been available through the Eat Smart, Move More…North Carolina Community Grants program, which has funded approximately 15 counties each year for the past six years to implement evidence-based programs in their communities. These grants, together with grants from the Kate B Reynolds SELF project, and the Fit Together Initiative of the NC Health and Wellness Trust Fund and Blue Cross and Blue Shield of NC (both programs described elsewhere in this issue of the *North Carolina Medical Journal*) provide resources for communities to adopt evidence-based policies and practices that improve access to and increase opportunities for healthy eating and physical activity in various settings.

Interpersonal and Individual: Lifestyle Changes

Families Eating Smart and Moving More is an interactive curriculum offered in communities and through physicians' offices to help families find simple solutions to eat more nutritious meals and be more physically active. Community health professionals and para-professionals use this formal curriculum to teach families the skills to eat more meals at home, make healthy food choices when eating out, incorporate exercise in their everyday routine, and watch less television.

Traditional public health programs also promote healthy lifestyles. The Women, Infants and Children (WIC) program serves over 230,000 individuals across North Carolina to assure that pregnant women and infants have access to healthy foods. WIC nutritionists instruct families about good nutrition and promote breastfeeding. Recent expansion of the North Carolina School Nurse program has provided opportunities to identify children who are overweight and counsel their families about healthy physical activity and nutrition practices.

Future Directions

Obesity is a complex problem that will require complex solutions. Changing the societal and institutional factors that have contributed to this problem will also require strong political will and the investment of significant resources. Three areas need particular attention if we are to continue to make progress.

1. Statewide capacity for health promotion.

Competitive grants for community-based obesity prevention have increased significantly over the last few years from a variety of North Carolina funders. Interest in preventive interventions remains high among local philanthropies. However, recent reductions in federal funding have decreased the baseline level of general health promotion funding that has traditionally been made available to every local health department in the state. This may ultimately undermine the capacity of local health departments in lower wealth counties to pursue competitive funding, resulting in increased geographic disparities within the state. The North Carolina Public Health Improvement Plan from the Public Health Task Force 2004 is now being updated for 2006. The plan recommends a health promotion coordinator in every local health department to assure a basic level of health promotion capacity across the state.[8] State and local funding strategies must be identified to reach this goal.

2. Social Marketing to Change Social Norms

Community-wide campaigns are evidence-based approaches to increase physical activity when combined with local interventions.[9] This is an integral component of the Eat Smart Move More…North Carolina initiative and local and regional efforts have shown that these campaigns have great promise in North Carolina communities. The Centers for Disease Control and Prevention's *Best Practices for Comprehensive Tobacco Control Programs* recommended spending between $1.00 to $3.00 per capita on tobacco prevention and control public education campaigns to obtain a meaningful result.[10] Applying this same formula to a comprehensive obesity prevention campaign would cost the state a minimum of $8.25 million. While this is a significant sum, it represents only 1.2% of the $600 million annual cost to the North Carolina Medicaid program that has been attributed to the treatment of obesity related illnesses.[11]

Land Use and Transportation Policy

The connection between land use, transportation policy, and physical activity is one of the most compelling evidence-based opportunities to impact obesity.[7] Much of the current effort to create better infrastructure for physical activity has focused on regional and local programs. Efforts should also focus on transportation policy and planning at the state level. Assessments of traffic performance and environmental impact must be prepared for most transportation projects. Assessments could also be required to document the impact of state and local transportation plans on pedestrian access and potential use. Less than four percent of North Carolina students currently walk or ride a bicycle to school one or more days per week.[12] Safe routes to school projects have been implemented in other states by assessing and improving sidewalks and road crossings. Similar projects should be developed and funded across North Carolina. Placing greater priority on pedestrian and bicycle improvements in the State Transportation Improvement Plan would increase resources available to fund local projects. However, transportation changes will not be effective without supportive land use changes. People are more likely to walk or ride a bicycle if popular destinations can be reached safely and efficiently. Local land use planning is highly variable, and often dismissed or ignored. Efforts should be made to set land use planning performance standards across the state and local health departments must begin to be more involved in the planning process.

The complexity and multi-dimensional nature of the overweight and obesity problems will require a multitude of approaches and collaborative efforts across multiple sectors of society. Using the framework of the Eat Smart, Move More…North Carolina initiative, NC public health agencies and programs are working closely with foundations, media and policy makers, business and industry, schools and preschools, faith-based organizations, communities, and individuals to reverse the rising rates of obesity in North Carolina. We must continue to focus our efforts and resources on this important public health problem. Public health is a public responsibility. **NCMedJ**

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The Clinical Nutritional Implications of Obesity and Overweight

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Introduction

It can be argued that our unstated national policy, until recently, has been that a person's weight is his/her "personal responsibility." Until 2005, the unspoken philosophy of our Dietary Guidelines was to encourage consumption of the variety of our national food supply. This policy coupled with limited, if any, reimbursement for non-pharmacological and non-surgical obesity treatments remain a major deterant for adults and children in receiving appropriate preventive and treatment counseling. Only recently has obesity been recognized as a disease that has both medical and economic sequelae.

Adults, too, report that they know "what to do" but just don't do it.[1] However, there is little evidence that Americans know how to estimate their caloric need or select a health promoting diet. Only one third of Americans report obtaining nutrition advice from physicians and even fewer (13%) receive counseling from a nutrition professional.[2] The American food supply is very complex, and stereotypes and myths of "healthful eating" are pervasive.[1] That shouldn't be surprising considering consumers receive most of their nutrition information from the media.[2] And though the United States government publishes evidence based dietary guidelines, it has virtually no budget for their promotion. As a result, few Americans have the knowledge, skill or motivation to embrace a diet that is health promoting and leads to a healthy weight. Nutrition knowledge alone does not guarantee healthy eating behaviors, but consumers cannot make informed food choices without it. Nutrition professionals have the education and experience to aid adults and children in developing eating plans that are personally satisfying and health promoting. For this paper, "nutritionist" refers to a licensed dietitian/nutritionist (RD/LDN).[3]

> *"Only recently has obesity been recognized as a disease that has both medical and economic sequelae."*

Additionally, RD/LDNs contribute to the nutrition education of physicians and other care providers. They work in coalitions toward environmental and policy changes to improve opportunities for physical activity and healthy eating.

Nutrition Education of and by the Physician

Nutrition and obesity education of medical students, residents and practicing physicians is uneven but generally inadequate.[4-6] The specialty of Family Medicine has led the way by requiring nutrition training.[4,5] As an example, medical students and Family Medicine residents at the Brody School of Medicine at East Carolina University (ECU) analyze their personal diets, learn to routinely include nutrition assessment in their history taking, practice counseling overweight patients with standardized patients, develop a relationship with a skilled clinical dietitian, and learn evidence based guidelines for treatment of

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overweight. Unfortunately, the inclusion of nutrition and obesity training in North Carolina medical schools is not assured. This led the Fit Families North Carolina Study Committee to recommend that "North Carolina based medical schools should teach the basic principles of prevention including the benefits of healthful eating and physical activity, the importance of breastfeeding, and how to effectively counsel people to change health behaviors as part of the core curriculum."[7]

Kahn[6] suggested that even if medical students receive good training, their interest and enthusiasm for nutrition assessment and counseling rapidly diminishes if they do not receive reinforcement from their clinical house officers and faculty mentors. It seems paradoxical that primary care physicians agree that providing nutrition counseling to their patients is their responsibility, even when they are not entirely comfortable and confident with the advice they give for life style change.[4] Kahn confirms that few take advantage of CME opportunities.[6] Too often we observe physicians who have embraced the concept of evidence-based practice for their specialty but either are unaware or ignore nutrition evidence when counseling patients. Physicians need to determine the nutrition and obesity prevention and treatment messages they have the time and skill to provide to their patients. They should follow practice guidelines (not dietary fads or trends) that include practices such as annually monitoring weight of patients, plotting the BMI of children on growth charts, measuring waist circumference, encouraging the DASH diet for patients with pre-hypertension, pre-diabetes, or metabolic syndrome. Physicians who choose to counsel their patients about weight should be guided by the National Heart, Lung and Blood Institute (NHLBI) guidelines.[8] Tools for office practice developed by NHLBI Nutrition Academic Award are available at http://www.nhlbi.nih.gov/funding/training/naa/products.htm. "Practical Advice for Family Physicians to Help Overweight Patients" describes implementation of a systematic and practical approach to management of obesity in practice.[9] Physicians who find time, reimbursement or skill as barriers to providing this type of care, can still serve their patients by reinforcing the messages of the North Carolina Eat Smart Move More campaign which are to: 1) decrease sugar-sweetened beverages, 2) decrease TV time, 3) prepare and eat more meals at home, 4) decrease portion sizes, 5) increase physical activity, 6) increase fruits and vegetables, and 7) breastfeed your baby (www.myeatsmartmovemore.com).[10] They should refer their patients to an RD/LDN or to a weight loss program that conforms to the North Carolina safe weight control program regulations.[3]

Referral to Weight Control Programs.

The Federal Trade Commission's "Voluntary Guidelines for Providers of Weight Loss Products or Services" encourages consumers to protect themselves from programs that do not adhere to standards.[11] North Carolina seeks to further protect consumers from unsafe weight loss programs by requiring annual review of programs, which are not provided by an RD/LDN. The regulations require that the client's level of health risk should be identified as low, moderate, high, or inappropriate for participation in a weight loss program. Patients at "low risk" can obtain nutrition education about the Dietary Guidelines for Americans and the Food Guide Pyramid from health educators and nurses. Patients of higher risk require physician clearance and a nutrition prescription and consultation from an RD/LDN. Key features of the standards include: 1) the program should not promise weight loss in excess of the safe two pounds per week; 2) plans should have at least 1,000 calories per day; adequate protein (0.8-1.8 grams/kilogram of goal weight) and no less than 100 grams carbohydrate/day; 3) participants receive nutrition education that encourages permanent change; 4) a maintenance component is provided; and 5) appropriate staff is available. Any supplements should not exceed 100% of the Recommended Dietary Allowances and neither formula products nor appetite suppressants should be used with low risk clients. Although these regulations became effective in 1995, the North Carolina Board of Dietetics/Nutrition has very limited resources for promotion or enforcement. Complaints can be filed with the Board at www.ncbdn.org.

Referral to a Licensed Dietitian/Nutritionist (RD/LDN).

There is adequate evidence that weight loss can be achieved with a variety of dietary approaches.[12] The RD/LDN has the education and skill to assist patients with the selection of an approach that not only leads to a healthy weight but is health promoting. The RD/LDN can assist patients with the most difficult aspect of weight loss treatment—adherence. North Carolina has licensed nutrition professionals[3] since 1991. The Dietetics Practice Act is to protect the citizens of North Carolina from harmful nutrition practices. Anyone who holds a valid license from the North Carolina Board of Dietetics/Nutrition can legally practice in the state. Additionally, those who are exempt (e.g., doctors, physician assistants, nurses, dentists, dental hygienists and psychologists) from the Act (NCGS 90-368) can offer nutrition education, but cannot use the title "registered dietitian," "licensed dietitian" or "nutritionist."[3] Additionally, federal, state and local government employees, herbalists, and weight control service providers are among those who are exempt as a function of their employment (e.g., sales person in a health food store). In 2005, Blue Cross Blue Shield of North Carolina (BCBSNC) invited about 700 North Carolina RD/LDNs to become credentialed and listed in their provider network (www.bcbsnc.com). The weight loss interventions offered by these RD/LDNs are guided by "Adult Weight Management Evidence-Based Nutrition Practice Guidelines."[13] Recently BCBSNC began reimbursing up to four doctor's office visits and up to 6 credentialed RD/LDN visits for weight assessment and counseling to adults enrolled in their "Healthy Lifestyle Choices."(www.bcbsnc.com/health-wellness/mhp/healthylifestyle.cfm) Although the reimbursement is very modest, the action by BCBSNC is a laudable first step to improving access for weight management services.

North Carolina RD/LDNs in partnership with BCBSNC have launched a study to evaluate the cost and clinical outcomes of Medical Nutrition Therapy (MNT) provided by RD/LDNs.

Physicians can assist by referring patients to this 24-month prospective study. There already are published trials demonstrating lifestyle change occurs with intensive therapy. For example, the Diabetes Prevention Program (DPP) trial[14] showed that nutrition and physical activity interventions were superior to pharmacological interventions. In that study, participants had multiple interactions with nutrition professionals including culturally sensitive training in diet, exercise, self-monitoring, goal-setting, and problem-solving as part of a 16-session core-curriculum. Monthly individual or group sessions, phone or mail contacts were provided. Unfortunately, the significant barrier to translating the DPP findings into real life practice is the lack of reimbursement for this intervention and lack of willingness or inability of the patients to pay for these services.

Facilitating a Successful Referral to the Dietitian.

RD/LDNs report that the success of their patients, including their "show rate" for MNT visits, is dependent on the physician setting strong expectations. This should not be the "referral of last resort" that occurs only after medicines have been maximized. Physician need to tell patients the dietary intervention is integral to their treatment and is best provided by a nutrition specialist. The RD/LDN will tailor the dietary prescription to the patient's lifestyle and preferences. Physicians who inform their patients that they will monitor progress increase the patient's likelihood of success. And when the change occurs, the physician needs to note changes and as appropriate adjust medications. Physicians can explain that the cost of the consultation, if not reimbursed, is reasonable and will more than likely save the patient time and money in planning healthy eating and reducing medications. A directory of RD/LDNs can be found at www.eatright.org/find.html. While consumers can refer themselves to a dietitian they are best served when their physician offers the opportunity.

The Special Case of Medical Nutrition Therapy for Gastric Bypass Patients.

Since most third party payers began requiring a nutrition assessment prior to gastric obstructive procedure (GOP) the opportunity for RD/LDNs to counsel GOP patients has dramatically increased. The authors of this paper provide assessment and counseling to patients from multiple surgical practices. At the pre-surgical assessment, some patients are well informed. Others see the surgery as a quick fix or "magic pill". The RD/LDN helps the patient understand the mechanisms of the surgery and its short and long term impact on both nutritional and overall health. Some surgical candidates have attempted many weight loss programs, but many have not experienced a structured nutrition intervention. While traditional diet and exercise programs may not be sufficient to help most morbidly obese patients, some lose significant weight and elect not to pursue surgery. Unfortunately, the requirement for the pre-GOP nutrition assessment is often without reimbursement, contributing to wide variations in the comprehensiveness of the MNT patients receive. Since little is known about the natural history of nutrient status and eating habits of these patients, it is prudent for all GOP patients to have access to MNT both pre- and post- their gastric obstructive procedure . Many GOP patients who were not provided MNT peri-surgically, self refer to an RD/LDN when weight re-gain begins, about two years post-surgery. Currently clinical experience rather than evidence guides most nutrition recommendations made for GOP patients.

Surgery remains the most effective means currently available to induce and sustain substantial weight loss in these morbidly obese patients, however, experience suggests that too few patients have the opportunity, while they are gaining the excess weight, to receive the MNT they need about portion sizes, calories, carbohydrates, fat, and protein. In addition to lack of reimbursement, barriers include lack of physician referral as well as physicians' negative attitudes about potential success.

The Special Case of Treating Children, Adolescents, and Their Families.

Children, adolescents, and their families would benefit from assessment and nutrition intervention by a RD/LDN. In the absence of national guidelines in 2004, RD/LDNs associated with the Pediatric Healthy Weight Research and Treatment Center at ECU developed a seven visit MNT protocol (www.ecu.edu/pedsweightcenter). Pitt Memorial Hospital Foundation funding supported a dietitian providing MNT in eight pediatric and family medicine offices. A retrospective chart review of 129 at-risk or overweight youth who received multiple sessions with the RD/LDN was completed. It typically took four visits, over five months, for patients to make lifestyle changes impacting their BMI. Strategies such as increasing the number of days of physical activity, reducing the number of times eating out per week, increasing servings of fruits and of vegetables, decreasing consumption of fried foods, and reducing total amount of sweetened beverages consumed made a difference. These changes resulted in a decrease in BMI. To some, the effect size appears small, but those children who had abnormal laboratory values for lipids or blood sugar generally normalized them.

Based on experience with more than 800 overweight children, single visits seem to be of limited value. At least one visit is needed to "sell" the patient and family that eating healthy and being physically activity is for everyone in the household, including part-time care providers like grandparents and "weekend parents." The RD/LDN empowers the family to set realistic goals. The patient is told in follow up that the RD/LDN will provide a structured plan and non-judgmental support. We are surprised by the prevalence of emotional eating by children. Youth who are singled out in their family often "sneak" "hoard" or "binge" on restricted foods. Our first strategy is to help the family switch from sugar sweetened beverages (e.g. sweet teas, colas, kool-aid and juices) to sugar free drinks, plain and flavored water, and low fat milk. Much work is needed in this area as families often only switch from one sugar sweetened beverage to another without instruction. It is particularly important to help pre-teens and teens become accountable for their food and beverage choices through skill building including label reading, portion size recognition, and recognition of internal hunger cues.

The challenge remains that medical nutrition therapy for overweight children is not reimbursed, except at health departments. In 2005, The North Carolina Study Committee for Childhood Overweight/Obesity proposed that "the State Health Plan, Medicaid, Health Choice and Special Health Services should include coverage in North Carolina to include prevention and treatment services for children, youth, and their families who are overweight or at risk for overweight, and to allow RD/LDN practicing in both public and private settings to be reimbursed for medical nutrition therapy."[7]

There are many different lifestyle change programs to help parents and children with weight management. However, a systematic literature review found that the limited evidence conclusions about the effectiveness of these interventions was not conclusive.[15] It is not clear what criteria should be used to call a group weight management program for youth "a success."

We find that youth taking part in the eight to ten week, age specific programs at ViQuest Center—Greenville (www.uhseast.com) have varying outcomes. In 2005, 68% of the school age participants maintained or reduced their BMI percentile for age. But these results vary from session to session, in no predictable way. Defining success, providing appropriate follow-up, and making these programs affordable to overweight North Carolina youth remain unresolved challenges for those providing group classes.

Moving Outside the Clinical Setting: Environmental and Policy Changes to Support Healthy Eating

More than a skilled clinician and a motivated patient is required to achieve lifestyle changes that support healthy weights. Environmental and policy changes are needed to make it easier for people to make healthy food choices. North Carolina has a variety of plans available to allow citizens to begin to make these changes. Healthcare providers and persons in healthcare leadership positions should review these plans and identify objectives that can be incorporated into their own work and community environments.

The North Carolina Division of Public Health has championed the development of plans and tools to address obesity including "Moving Our Children to A Healthy Weight"[16] as well as "Blue Prints for Changing Policies and Environments in Support of Healthy Eating and Physical Activity."[17] North Carolina published achievable standards for all foods available in schools.[18] North Carolina's plan to prevent obesity and reduce chronic diseases is expected in August, 2006. The North Carolina Health and Wellness Trust Fund (HWTF) supported the development of recommendations to address Childhood Obesity in its Report of the Fit Families' Study Committee.[7] HWTF, also, in partnership with Blue Cross Blue Shield of North Carolina has tools for healthier weight and lifestyle at www.fittoghernc.org.

The experts note that solutions to the obesity epidemic need to be "local." The Eat Smart Move More web site (www.eatsmartmovemorenc.com) includes a catalogue of success stories. Nutrition education resources in North Carolina's rural areas are limited. Food Literacy Partners Program (FLPP) is an example of a successful program where RD/LDNs in Pitt County have trained more than 240 community volunteers who share their new health and food literacy with others at schools, churches, clinics, health fairs, and other events. Most graduates, who are required to provide 20 hours of community service in return for the free training, report changing their own food choices and finding themselves talking about nutrition to their families, friends and co-workers. Finding the resources to sustain successful local nutrition education initiatives like FLPP remains a challenge.

Bottom line

North Carolinians have limited access to evidence-based food and nutrition information to help prevent or treat overweight and obesity. RD/LDNs are uniquely qualified to train others to provide nutrition education and to deliver medical nutrition therapy directly to patients.

Physicians can find a dietitian by using the Blue Cross Blue Shield of North Carolina list of credentialed dietitian or Find A Dietitian at www.eatright.org. **NCMedJ**

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Tipping the Scales of Prevention Advocacy with $10,000 and a Notebook

Jennifer Hastings, MS, MPH; Meg van Staveren, MPH, RD; Rachel Bikoff; Julie Knaack, RD and Meg Molloy, DrPH, MPH, RD

A nationwide glance reveals that North Carolina has some of the best health insurance coverage and benefits for obesity. Examples include health coaching and lifestyle improvement programs offered by the State Health Plan of North Carolina; reimbursement and tools for primary care providers to address obesity, nutrition counseling, and weight loss medications through Blue Cross Blue Shield of North Carolina; and medical nutrition therapy for children and adolescents provided through the NC Division of Medical Assistance. Unfortunately, more than 1.3 million nonelderly people in North Carolina lack health insurance coverage, and these resources are not available to them.[1] Furthermore, access to these policies and resources in other settings are critical in the fight against obesity and overweight.

NC Prevention Partners' (NCPP) collaboration with the Kate B. Reynolds Charitable Trust addressed this issue in five low-income community health centers (CHC) throughout the state. Over the last three years, this partnership enabled NCPP to work closely with these CHCs to establish systems to improve health. In addition, this funding along with funds from the NC Division of Public Health facilitated the creation of the *Prevention Rx* system for healthcare clinics, the *NC Good Health Directory*, and the *Starting the Conversation* series. With these tools, the CHCs have built strong, sustainable systems, including those that support nutrition and tobacco cessation in their communities.

Imagine a community health center has been given a check for $10,000 to be used over two years. With this money, they've hired a part-time, 15-hour a week nutritionist. Then, imagine the funding disappears or comes to an end. Would the nutrition program be gone, too? This amount of money, given to one CHC, helped to start an effective nutrition counseling program. Thanks to system-level changes the CHC made, the program is still in operation and is now sustainable even after the funding period ends.

Here is what one CHC did. First, the CHC hired a part-time dietitian to counsel both patients and staff. However, the CHC did not just hire a nutritionist for the life of the grant. Instead, to be able to retain the services of a nutritionist after the grant, they began filing for reimbursement for the nutrition services they offered. The nutritionist worked closely with the billing and coding departments to set up a system to reduce the number of rejected claims. In addition, she worked with the CHC's staff providers to educate them about the services she

> *"If the familiar adage, 'An ounce of prevention is worth a pound of cure,' was restated using units of time, it might read as: 'A brief preventive healthcare intervention can add up to years of quality, healthy living.'"*

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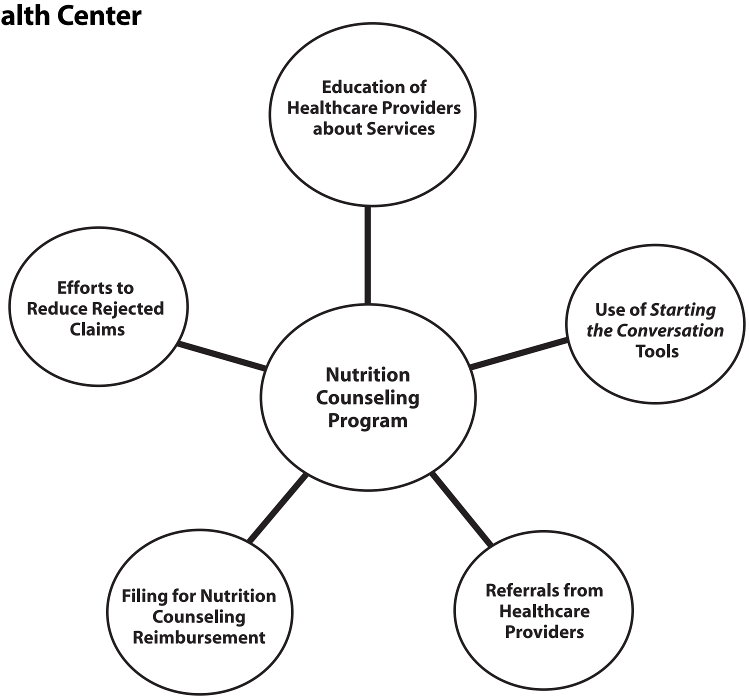
Figure 1.
Sustainable System for Nutrition Counseling at the Community Health Center



offered and to increase patient referrals. These system-level changes, as seen in Figure 1, are critical components of the CHC's ability to impact obesity and overweight in the local community.

Many motivated health professionals attend trainings to learn about how to combat obesity and chronic disease. Unfortunately, many of the notebooks and resources provided often return to offices only to sit unused on bookshelves. What made the difference for the community health center described above was that the nutritionist and other staff who attended the Prevention Partners *Prevention Rx* training session made it a priority to use those resources and newly-aquired tools and skills. A measure of their nutrition program's success can be seen in the number of patients helped—nearly 400 in less than two years. One patient seen during that time had been obese for years and was able to lose over 100 pounds, dramatically improving her quality of life.

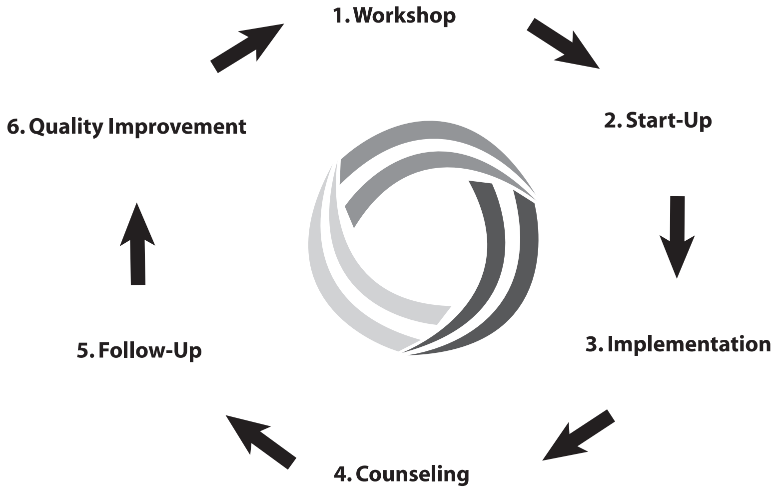
This story exemplifies the way NC Prevention Partners approaches problems in public health. We want the notebook to come off the shelf. We look for ways to make it easier for individuals to do simple things like make good food choices, receive preventive healthcare, and find support for healthy behaviors. We focus on system, policy, and environmental changes because, as Malcolm Gladwell, author of *The Tipping Point: How Little Things Can Make a Big Difference*, states,[2] "Human beings and their behavior are highly-sensitive to their environment." The environments highlighted in this article are healthcare settings, schools, and worksites.

Where People Receive Healthcare

If the familiar adage, "An ounce of prevention is worth a pound of cure," was restated using units of time, it might read as: "A brief preventive healthcare intervention can add up to years of quality, healthy living." NC Prevention Partners created the *Prevention Rx* system to facilitate the process of routinely addressing physical activity, nutrition, and tobacco use in healthcare interactions. As shown in Figure 2, *Prevention Rx* workshops give healthcare providers working in any setting the necessary tools, resources, and skills to do this.

Through the one-day workshop, healthcare professionals learn how to use the *Starting the Conversation* series—tools that help providers conduct brief screening and counseling for nutrition, physical activity and tobacco. In addition, information is provided about modifying patient history forms, documenting prevention encounters, and filing for reimbursement. Finally, an on-line referral database called the *NC Good Health Directory* gives providers a collection of local resources to which they can refer their patients. *Prevention Rx* is a healthcare office system that takes the guesswork out of how to help patients practice healthy behaviors, such as those that support a healthy weight.

Figure 2.
The *Prevention Rx* System



Where People Learn

There has been substantial controversy surrounding the nutrition and physical activity environment in the school system. Along with the recent release of the "School Foods Report Card" from the Center for Science in the Public Interest, there has been a strong push for national and state system-wide changes. Reaching children through schools is logical because children spend so much time there. However, differences between school systems at the local level mean that policy or programmatic changes need to incorporate flexibility to allow for district specific adaptations. It is these smaller modifications that will tip the local scales in favor of a generation of healthier youth.

Since 2004, North Carolina has taken a step forward in addressing the health of children through "Eat Smart: North Carolina's Recommended Standards for All Foods Available in Schools," and "Move More: North Carolina's Recommended Standards for Physical Activity in Schools." Additionally, national legislation now requires schools participating in any reimbursable meals program to develop district-level wellness policies by the start of the 2006-07 school year.

NC Prevention Partners' *Zone Health* pilot program, supported by GlaxoSmithKline Community Partnerships, provides schools with toolkits to take local policies from the notebook to practice. Recognizing that obesity is a multi-factorial problem, *Zone Health* guides schools through an assessment of their school health environments and policies. Through the program, schools receive assistance and resources to make changes and to begin drafting quality prevention policies to support the health of their students and staff. Once their policy development is complete, schools are given training and tools to do ongoing evaluation and policy revisions. Even schools that have completed and adopted wellness policies at the school level can benefit from the *Zone Health* program because it allows them to assure the steps they have taken are comprehensive and meet or exceed district-level policy requirements.

The *Winner's Circle Healthy Dining Program* is another collaborative initiative between NC Prevention Partners, local and state public health and school leaders. This program offers tools and training for schools to promote healthy foods and beverages on their campuses using the *Winner's Circle* purple star and gold fork logo. One of the organizational goals for DPI set by the Section Chief of Child Nutrition Services is for all NC elementary schools to implement the *Winner's Circle* program. Eventually, middle and high schools will also be targeted for *Winner's Circle* implementation. This will help schools meet the health and nutritional policies detailed in the state publication, "Eat Smart: North Carolina's Recommended Standards for All Foods Available in School." Since 2002, eighty-one NC Local Education Areas (LEAs) have received *Winner's Circle Healthy Dining Program* training through the NC Division of Public Health (DPH) and the NC Department of Public Instruction (DPI). To date, *Winner's Circle* has been implemented in approximately 1,600 schools.

Schools participating in the *Winner's Circle* program develop their own promotional campaigns to engage and encourage students to think about healthy eating. The schools also have the flexibility to adapt the program to their school-community culture by selecting from a variety of *Winner's Circle*-qualified foods and beverages to include in their offerings. Any food substitutions can be incorporated over time to avoid potential financial losses from a complete system overhaul. In addition, incremental meal service modifications will lead to well-balanced menus and will tip the scales for obesity prevention in North Carolina.

Where People Work

The typical American spends well over half of his or her life at work, establishing the work environment as a significant factor in individual health. For example, access to nutritious foods at work can increase the likelihood that healthy food choices are made; physical activity incentives for employees can increase the likelihood that employees are more active; and health insurance options that include covered physical activity and nutrition benefits can help overweight and obese employees reach and maintain a healthy weight.

Every year, medical care and lost productivity from obesity, poor nutrition, physical inactivity, and tobacco use cost employers an average of $5,000 per employee.[2] To help businesses improve employee health and reduce healthcare costs, NC Prevention Partners created the *Prevention 1st Challenge*. One of the goals of this program is to facilitate the creation of policies and environments that support individual health in worksites throughout the state.

The *Challenge's* main tool—the *Prevention Audit*—provides businesses the opportunity to assess their physical activity, nutrition, and tobacco use policies and environments. The audit and resulting *Prevention Report Card*[3] can then be used to identify priority issues and to assist in the development of a strategic prevention plan to create policies and environments that support employee health. The *Prevention 1st Challenge* can similarly be used by counties. County health directors and Healthy Carolinian coalitions can use their county *Prevention Report Card* to create awareness and leverage support from their local and state public policy makers and community leaders.

Be an Advocate

All of these programs require that simple changes in policy and environment are made. Taken together, these changes can significantly influence obesity and overweight. Using the premise of Gladwell's book that, "little things can make a big difference," it stands to reason that in public health, simple changes and actions will determine whether we win or lose the fight with obesity and overweight in this state. Advocacy is about doing something and doing something that makes sense. In his book, Gladwell[2] mentions three factors that drive social change. They are:

- **The Law of the Few**—Exceptional people who spread the word through social connections, energy, enthusiasm, and personality.

- **The Stickiness Factor**—Simple changes that can make a big difference in how much impact a message makes.
- **The Power of Context**—Human beings and their behavior are highly-sensitive to their environment.

With these three factors in mind, imagine if just 10 readers of this journal—that's 0.03% of the *North Carolina Medical Journal's* readership—made simple changes that led to sustainable system-level changes in their clinic, school or place of work. Now, like the clinic in the vignette above, imagine that each of those system-level changes affected 400 people over two years. Even with less than 1/10 of a percent of the journal's readership causing these small changes, as many as 4,000 of the overweight or obese individuals living in this state could be helped.

As the CHC in the vignette showed, tipping the scales in favor of prevention could start with as little as $10,000 and a notebook.

What else can we do? Be an advocate for sustainable systems in North Carolina to support healthy weight and consider the many additional opportunities described in Table 1. **NCMedJ**

Table 1.
Advocacy Opportunities for Addressing Obesity

☐ Strengthen your own clinic, hospital, school, or work environment by establishing the *Prevention Rx* system and linking with other resources in your community. Support one another, benefit from the expertise and experience of those around you, and avoid re-inventing the wheel.

☐ Advocate for local policy changes in your community's schools and work sites. Advocate for increased availability of quality resources in your area to help people reach and maintain a healthy weight. Consider volunteering with a local task force or as a speaker to the school board.

☐ Advocate for state and federal policy changes to support improved nutrition and increased physical activity in schools and communities.

☐ Publicize resources and programs available in your area and share your success with others around the state on the *Healthy County Profile* (located under Quick Links) at www.ncpreventionpartners.org.

☐ Find and use local physical activity and nutrition resources in the *NC Good Health Directory* at www.ncgoodhealthdirectory.com, and submit resources not found there to let others know what is available in your area.

☐ Visit the *Preventive Benefits Watch* (located under Programs at www.ncpreventionpartners.org) to learn about what preventive benefits are offered for physical activity, nutrition, and obesity by the private and public NC health insurers. North Carolina is the only state in the nation that makes this information publicly available, thanks to all of the health plans voluntarily sharing and annually updating their preventive benefits profiles and to the NC Division of Public Health, NC Department of Health and Human Services.

☐ Attend a training session to obtain the tools and skills to implement *Prevention Rx*, *Winner's Circle*, *Zone Health*, or the *Prevention 1st Challenge*. For current offerings, go to www.ncpreventionpartners.org.

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Active Living by Design

Active Living by Design (ALbD), a $15.5 million national program supported by the Robert Wood Johnson Foundation (RWJF), was launched in late 2001. Located in Chapel Hill and part of the North Carolina Institute for Public Health at the UNC School of Public Health, ALbD helps communities increase physical activity and healthy eating through changes in community design, policies, and promotions.

In late 2003, twenty-five diverse partnerships from across the nation were selected from 966 applicants to receive $200,000 grants and technical assistance over five years to implement comprehensive initiatives to increase physical activity in their communities. More recently, 12 of these partnerships received an additional $50,000 over eighteen months to pilot test approaches to increase access to healthy foods for children in low-income neighborhoods.

ALbD provides technical assistance through a team of project officers and a comprehensive learning network. Like the partnerships they support, the ALbD project team includes representatives from a variety of disciplines, including public health, health policy, city and regional planning, parks and recreation, nutrition, and communications.

Community partnerships implement five strategies that address the social-ecological influences on physical activity and healthy eating: preparation, promotions, programs, policies, and physical projects. This "5P community action model" provides the intervention framework for each of the partnerships. Evidence of the effectiveness of these strategies can be found in various studies, many of which were summarized by the US Task Force on Community Preventive Services, which recommends interventions with informational, behavioral, environmental and policy approaches.

Now midway through their initiatives, the ALbD community partnerships are making excellent progress. While it is too early to measure long-term behavior change, it is clear that community changes already are occurring. Partnerships have amended development ordinances and approved new street design standards, created trails and greenways, implemented social marketing campaigns to increase awareness of opportunities for physical activity, changed school policies regarding recess and lunch menus, established new community gardens and bicycle recycle programs, and more. In addition, during their first two-and-one-half years the ALbD partnerships have secured or leveraged additional funding equal to over sixteen times that of RWJF's initial investment in their communities.

In an effort to continue to test and replicate the 5P approach, ALbD is working with a variety of other organizations across the country. For example, ALbD is providing technical assistance to local partnerships in Minnesota for community engagement and assessment addressing active living. Funded by Blue Cross and Blue Shield of Minnesota, ALbD anticipates that these partnerships will eventually build a vision and principles for active living into their communities' comprehensive plans.

Closer to home, ALbD also provides technical assistance to counties and municipalities funded through the North Carolina Health and Wellness Trust Fund's Fit Community initiative and to rural communities through Blue Cross and Blue Shield of North Carolina Foundation's Fit Together grant program.

Through these comprehensive efforts, ALbD and local partnerships are collaborating in neighborhoods, communities, counties and regions across the United States to combat the nation's epidemics of physical inactivity and poor nutrition.

For more information on ALbD, go to: www.activelivingbydesign.org.

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Coordinating School Efforts to Help Address the Obesity Epidemic in North Carolina

Paula Hudson Collins, MHDL, RHEd

While the world is getting flatter, Americans—especially our young people—are getting rounder. According to Thomas Friedman, New York Times columnist and author of *The World Is Flat*,[1] America is working in a globally competitive world in which the field is increasingly "flat" or equally competitive for all developed nations. With everyone seeking an advantage, the terms "lean and mean" take on even greater significance. Healthy workers are more productive, learn more effectively and cost less in the long run than unhealthy workers. Research indicates that there is a positive link between healthy students and greater academic gain. This ultimately leads to a healthier and more competitive workforce.

The causes of the "rounding of America" are well known. Some of the culprits include the sedentary use of technology for learning, shopping as recreation, greater access to fast food, cola consumption, a "quantity is quality" attitude about food, less time and safe space available for exercising, and over-scheduled families relying on multiple remote controls. Could schools unintentionally be culprits as well? With a wide array of vending machines, little time scheduled for physical activity and even less time for students to choose and eat a healthy lunch, they may also be culpable. Even students who want to be healthier during the school day, often encounter unintentioned obstacles.

> *"Healthy workers are more productive, learn more effectively and cost less in the long run than unhealthy workers."*

Today, educators are being asked to prepare students to successfully compete in a world that many adults could not have imagined. In response to this challenge, a wide range of educators, advocacy groups and businesses are enthusiastically emphasizing strategies focused largely on assessments of student academic performance and teacher effectiveness. With this framework in place, it is no surprise that our schools have become environments, for students and teachers alike, of the over-tested and over-stressed! It is time to utilize our educational resources to provide a winning strategy for healthy students in an even healthier school environment.

The best way for schools to address the obesity epidemic is to work in a coordinated effort to do what they do best… educate! Former United States Senator William Cohen from Maine said, "It is clear that children must be healthy to be educated and they must be educated to be healthy." While this might appear to be the old chicken or the egg quandary, we must address learning to be healthy and being healthy to learn, simultaneously. A school health program that effectively addresses students' health improves their ability to learn.

North Carolina is fortunate to be one of 23 states in the nation to receive competitive funding from the Centers for Disease Control and Prevention to promote Coordinated School Health Programs (CSHP) at the state and local levels. The model promotes eight components of a healthy school with school professionals working together to address health issues. The model combines their collective wisdom, experience, and efforts in order to provide the greatest benefit to the students.

According to Marx, Wooley, and Northrop, authors of *Health is Academic*,[2] the recognized template for establishing a Coordinated School Health Program, each of the eight components described below contribute to students' health in unique ways and at the same time, they enhance each other. A Coordinated School Health Program (CSHP) includes:

- Comprehensive School Health Education
- Physical Education
- School Nutrition Services
- Healthy School Environment
- School Health Services
- School Counseling, Psychological and Social Services

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- School-Site Health Promotion for Staff
- Family and Community Involvement in Schools

Comprehensive School Health Education focuses on the health information, strategies, and objectives taught to students. This classroom-based education addresses the physical, mental, emotional, and social dimension of health; develops health knowledge, attitudes, and skills; and is tailored to each age level. It is designed to motivate and assist students to maintain and improve their health, prevent disease, and reduce health-related risk behaviors. Typically, North Carolina elementary students receive health instruction taught by their classroom teacher in lessons often integrated into other subjects. Time for health instruction is in competition with other equally important and tested subjects during the elementary student's day. In middle school, grades six to eight, students receive health instruction from certified health and/or physical education teachers in a variety of ways. Health and physical education are referred to as Healthful Living and students usually receive health instruction in the classroom setting, alternated with physical education held in the gymnasium or other activity facility or athletic fields. In high school, students have one Healthful Living unit graduation requirement, which is typically half health and half physical education. Over 95% of high school students complete the Healthful Living graduation requirement in the ninth grade. The Healthful Living Standard Course of Study guides the grade-level objectives utilizing national standards and health methods and theory. While health has its own discipline, health objectives are frequently integrated into other subjects such as examining the nutritional composition of the foods in a foreign culture through a social studies class, plotting a graph of the number of steps recorded on a pedometer in math class, reading a book about an unhealthy rabbit in language arts or discovering the effects of a compromised immune system due to HIV infection in a biology class. The North Carolina Department of Public Instruction has written the Balanced Curriculum Document to assist educators in pacing and balancing time to allow them to teach the entire curriculum. The Healthful Living Standard Course of Study is available at www.ncpublicschool.org.

Physical Education is planned, sequential instruction that promotes lifelong physical activity. It is designed to develop basic motor skills, sports skills and physical fitness as well as to enhance the students' mental, physical, social and emotion abilities. Physical activity is a behavior that is cultivated and includes a variety of activities, with the focus on being active. The Centers for Disease Control and Prevention suggests a minimal requirement of 60 minutes of moderate to rigorous physical activity each day for optimal health. In North Carolina, students receive 30 minutes of daily physical activity during the school day as required by the Healthy Active Children Policy. This policy suggests that elementary schools should consider the benefits of having 150 minutes of physical education weekly and that middle schools should move toward having 225 minutes of Healthful Living education per week. The Healthy Active Children Policy is available at www.ncpublicschools.org/State_Board.

School Nutrition Services focus on the integration of nutritious, affordable and appealing meals, nutrition education, and the creation of an environment that promotes healthy eating behaviors for all children. Some people are quick to criticize the school lunch program as contributing to childhood obesity. However, reimbursable lunches meet USDA recommended guidelines for nutrients and while pizza is still served, it is made on whole-wheat crust with turkey sausage and low fat cheese. Continually problematic are the vending machines and à la carte food sales used to supplement necessary operating costs for the school lunch program. In North Carolina, great strides continue to be made to offer more fresh fruits, vegetables and healthier meals in a cost effective manner.

Healthy School Environment addresses the physical, emotional, and social climate of the school. It is designed to provide a safe physical plant, as well as a healthy and supportive environment that fosters learning. In North Carolina, the healthy schools environment deals with a range of issues from providing a tobacco-free, weapon-free, bully-free, vending-free, mold-free campus to one which addresses health disparities and equal learning opportunities for all students. A school environment where adults are role models of good health and active behaviors and where students feel safe, provides one strategy to help fight childhood obesity.

School Health Services include preventive services, education, emergency care, referral and management of acute and chronic health conditions. It is designed to identify and prevent health problems and injuries as well as to care for students. In North Carolina, health services are provided through school nurses, school-based or school-linked health centers, and local health departments, hospitals and many community health partners. Collaborative work between schools and public health agencies has proven to be tremendously successful in addressing the obesity epidemic. No one agency can or should try to address this issue, alone.

School Counseling, Psychological, and Social Services include activities that focus on the cognitive, emotional, behavioral and social needs of individuals, groups and families. It is designed to prevent and address problems, facilitate positive learning and healthy behavior and development. In North Carolina, there is a tremendous need for increased access to mental health services for students. Research indicates that many self-esteem issues and mental health concerns contribute to overeating and depression.

School-Site Health Promotion for Staff includes assessment, education and fitness activities for school faculty and staff. It is designed to maintain and improve the health and well-being of school staff, who serve as role models for students. In North Carolina, numerous staff wellness programs are conducted in school systems. When students see their teachers participating in a walking program, choosing healthy foods and teaching about the benefits of a healthier lifestyle, it helps to eliminate the "do is say, not as I do" hypocrisy. Further, a healthy, engaged faculty is more productive and misses fewer days of work.

Family and Community Involvement in Schools creates partnerships among schools, families, community groups, and individuals. It is designed to maximize resources and expertise in addressing the healthy development of children, youth, and their families. Efforts to involve families in their child's education has proven to contribute to the child's overall school success. Likewise, students who learn about healthy lifestyle choices at school but go home to a setting with differing choices are often conflicted. Teaching the child to be healthy can impact family health practices, particularly if the family understands and reinforces what the child is taught.

On any given school day, as part of a Coordinated School Health program, a student battling obesity will have access to a collaborative system of resources for assistance. He will receive decision-making information during a health education class, learn a life-time skill in physical education, and be able to select and eat a nutritious meal in the school cafeteria. He, along with his family, will have the opportunity to talk with the school counselor or social worker and meet with the school nurse to discuss health options as part of a Child and Family Support Team. He will interact with teachers who are good health role models and are actively taking care of their own mental and physical health as part of the staff wellness program. He will be challenged to learn in a safe and healthy school environment and will have the opportunity to participate in an after school fitness group co-sponsored by the school and a community agency. He will function in an opportunity rich environment, which links health and academics and is designed for overall student success.

The Coordinated School Health Program is supported through 115 district level School Health Advisory Councils, which are required by the Healthy Active Children Policy and championed by the Local Education Area School Health Coordinator.

A complete overview of the Coordinated School Health Program and supporting resources is available at www.nchealthyschools.org.

Reversing the obesity epidemic requires a long-term, well-coordinated approach to reach young people where they live, learn, and play. Schools have an important role in helping to address childhood obesity. Schools provide a safe place in which to apply what is learned, encourage the development of healthy behaviors, and foster understanding of how health impacts overall student success. After all, Health is Academic! **NCMedJ**

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Yes, Virginia, Bariatric Surgery Works, and It Is Safe

Walter J. Pories, MD, FACS

About two weeks ago it happened again. A friend stopped me in the hall of the hospital and asked me if there wasn't something we could do for his patient, a young but massive woman with diabetes, crippling arthritis and hypertension, now on 11 medications. When I asked if he had considered bariatric surgery, he recoiled at the suggestion and told me, in no uncertain terms, that the gastric bypass "doesn't work" and "it's far too risky."

It's time to set the record straight.

A Few Facts

Let me start this brief review of bariatric surgery with a few facts with which most physicians will readily agree:

- ***Obesity is epidemic.*** Two thirds of the American population are overweight or obese with even higher proportions in the African American and Hispanic populations. Twenty three million Americans have a Body Mass Index (BMI) greater than or equal to 35, exceeding their ideal body weight by about 100 pounds; 8 million, equal to the population of North Carolina, have BMIs greater than or equal to 40. Of even greater concern is the exploding prevalence of obesity among young people. More than one million children and adolescents are severely obese—many with type 2 diabetes.
- ***Severe obesity is a disease.*** It is not a moral failing or a punishment for some sin. While we do not know the cause of this recent epidemic, many factors have been implicated including genetics, viral infections, change in the national diet, portion sizes, high sugar drinks, availability of food, decreased activity, loss of physical education programs in schools, coin machines in public places, lack of sidewalks, lack of security in neighborhoods, etc. The fact is that we do not know why obesity has overtaken this nation in 20 years with the ferocity of an infectious plague. To blame it on afflicted individuals is unfair and cruel.
- ***"Morbid" is an appropriate descriptor for severe obesity.*** Virtually all patients with BMIs greater than or equal to 40 have at least one co-morbidity (i.e., a deadly disease associated with severe obesity). The list is long because obesity afflicts every system: diabetes, hypertension, cardiac failure, asthma, metabolic syndrome, pulmonary failure, hiatal hernia, deep venous thrombosis, pulmonary emboli, hernias, pseudotumor cerebri, stress incontinence as well as cancers of the breast, colon, prostate, and intestine. Early deaths are common among the mordibly obese.

More Facts that May Be a Bit Surprising

- ***Morbid obesity does not respond to diets, exercise, behavioral modification or even drugs*** in the long run. As long ago as 1991, the National Institutes of Health Consensus Conference on the Surgery of Obesity[1] concluded that surgery is the only effective treatment for patients who exceed their ideal body weight by more than 100 pounds. Non-operative approaches are ineffective, expensive, and not worth the effort.
- ***The BMI is not a good measure of adiposity.*** There are major differences in adiposity, i.e. the percentage of fat in the human body, depending on gender, muscle mass, mass, and ethnicity.[2] The problem is that most consider a high BMI a measure of adiposity, but it is not; it is merely an indicator of mass, thus able to represent muscle or fat. Selecting the

> *"Type 2 diabetes is no longer a hopeless disease. Diabetes can, for the first time, be fully reversed with bariatric surgery with a prolongation of life."*

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BMI of 35 as the critical index for surgical care is not based on fact. An Asian woman with a BMI of 32 has as much risk for co-morbidities as her Caucasian counterpart with a BMI of 35. We use the BMI because it is clinically efficient and correct most of the time, but we need to be aware of its serious limitations. With Tanita scales[a] and dual energy X-ray absorptiometry (DEXA)[b] becoming more widely available, we may be able to focus on adiposity and the co-morbidities as better indicators.

Some Facts that May Seem Unbelievable

- *Bariatric surgery can produce durable weight loss.* A series of 602 morbidly obese patients were studied at East Carolina University (ECU) for up to 16 years after they underwent gastric bypass operations, with a 95% follow-up These patients maintained a mean weight loss of 106 lbs. This long-term weight loss has now been confirmed by other centers.[3]
- *Type 2 diabetes is no longer a hopeless disease.* Diabetes can, for the first time, be fully reversed with bariatric surgery with a prolongation of life. At ECU, we documented that 83% of our diabetic patients enjoyed a full remission of the disease with a sharp reduction in mortality.[4] This work has also been confirmed around the world.[5] One of our patients has now remained euglycemic (normal glucose levels) for over 23 years following a gastric bypass even though she required 90 units of insulin at the time of surgery. The explanations for the rapid remission prior to significant weight loss are not clear, but it appears to be indirectly related to the contact of the small bowel with food [i.e., the less food and the greater the exclusion of gut, the more complete the remission (see Table 1)].[6]
- *Bariatric surgery reduces the mortality from diabetes.* Two reports document that severely obese patients who undergo bariatric surgery live longer than those who don't. MacDonald,[7] based on the experience at ECU, reported a mortality of 1% per year in those who underwent bariatric surgery versus 4.5% per year in a group of people who were scheduled for surgery, but cancelled at the last minute. Christou,[8] following analysis of the results in the Canadian health system document,[9] concluded that bariatric surgery reduced mortality risk by 89%.
- *Most of the other co-morbidities of morbid obesity also resolve following bariatric surgery.* The exact figures are not available, but reports suggest that asthma, pseudotumor cerebri, stress incontinence, and cardiac failure due to fatty infiltration cardiomyopathy clear in almost all patients. Hypertension is alleviated in about half of bariatric surgical patients. Arthritis is not reversed, but the loss of weight can produce marked improvement in function. Seeing a wheel chair-bound patient progress to a walker and then a cane and finally a free gait is not unusual. Although patients enjoy a period of euphoria during the first year or two after the surgery, whether emotional disorders improve long-term is not clear.

Finally, Some Really Startling Facts

- *Diabetes clears before there is significant weight loss.* Obesity may be a contributing factor, but the cause of the type 2 diabetes appears to lie within the molecular mechanisms within the gut. The islets, long blamed for the problem, are most likely innocent, overworked bystanders. Bariatric surgery has opened exciting areas for research into our most serious chronic diseases.
- *Bariatric surgery may become the treatment of choice of type 2 diabetics who are not obese.* Bypassing the duodenum and proximal jejunum in lean, genetically diabetic rats prevents the development of the disease without loss of weight.[10] Similarly, Arguelles and his colleagues in Mexico,[11] recently reversed diabetes in a small series of non-obese patients with a stomach sparing bypass of the proximal foregut.
- *Bariatric surgery is as safe as cholecystectomy* and far safer than most major operations when the procedures are performed in "Centers of Excellence." Based on the experience of 55,000 patients reported by 106 Centers of Excellence in their applications to the American Society for Bariatric Surgery (ASBS) and the Surgical Review Corporation (SRC), the operations were performed with a 90-day mortality rate of 0.35%, about the same as cholecystectomies.[12] In

Table 1.
Weight Loss, Resolution of Diabetes, and Operative Mortality after Four Bariatric Surgical Operations (n = 22,094 patients; 2738 citations 1990-2002; Buchwald et al)

	Restrictive Operations		Restrictive and Malabsorptive Operations	
	Gastric Banding	Gastroplasty	Gastric Bypass	Duodenal Switch
Excess weight loss	47.5%	68.2%	61.6%	70.1%
Resolution of diabetes	47.8%	62.2%	83.6%	97.9%
Operative mortality	0.1%	0.1%	0.5%	1.1%

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[a] Tanita scales use impedance technology to determine body weight and composition including assessments of Fat Mass, Fat Free Mass, Fat %, Total Body Water and BMI in one step

[b] Dual-energy x-ray absorptiometry (DXA or DEXA) densitometry is today's established standard for measuring bone mineral density and bone loss. Measurement of the lower spine and hips are most often done. More portable devices that measure the wrist, fingers or heel are sometimes used for screening, including some that use ultrasound waves rather than x-rays.

Table 2.
Mortality Rates Following Common Operations in United States Hospitals

	Aortic Resection	Coronary Artery Bypass Graft	Craniotomy	Esophagectomy	Pancreatic Resection	Pediatric Heart Surgery	Hip Replacement
# of Hospitals	2485	1036	1600	1717	1302	458	3445
National Average Mortality Rate (%)	3.9	3.5	10.7	9.1	8.3	5.4	0.3
Average Hospital Case Loads	30	491	12	5	8	4	24

Source: Dimick JB, Welch HG, Birkmeyer JD. Surgical mortality as an indicator of hospital quality. *JAMA* 2004;292:847-851

contrast, Table 2 shows Dimick's review of the outcomes for other common operations in the United States[13] after only 30 days: aortic resection 3.9%, craniotomy 10.7%, esophagectomy 9.1%, pancreatic resection 8.3%, and pediatric heart surgery 5.4%. Only hip replacement, with its mortality rate of 0.3%, is as safe as bariatric surgery when performed in Centers of Excellence.

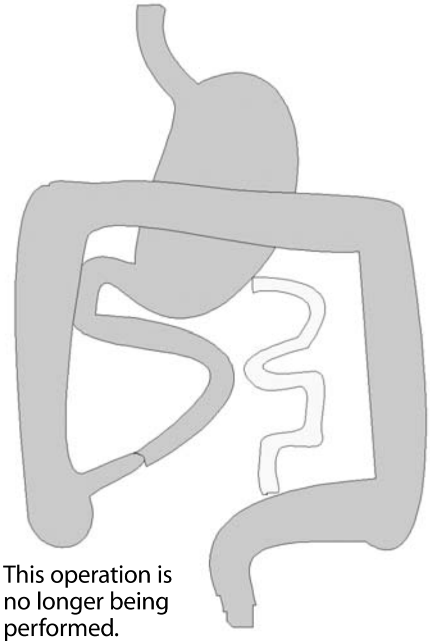
The Bariatric Surgical Procedures

Bariatric surgery is designed to produce weight loss by (1) reducing intake and/or (2) interfering with digestion and absorption.

The Intestinal Bypass, a Purely Malabsorptive Operation

The *intestinal bypass*, shown in Figure 1, although no longer performed, was important in its recognition that obesity could be a serious enough problem to warrant surgical intervention. The operation excluded the majority of the jejunum and ileum from contact with food, leaving only 14 inches of jejunum and four inches of ileum in the intestinal conduit. The excluded gut was turned into a diverticulum to empty into the colon. The operation induced significant weight loss through its interference with small bowel function, but the procedure was abandoned due to its serious long-term effects, including liver failure, kidney stones, mineral imbalances, and severe protein deficits, perhaps due in part to overgrowth of bacteria in the excluded segment. Unfortunately, more than 30,000 of these operations were performed before the operation was abandoned.

Figure 1.
Intestinal Bypass



This operation is no longer being performed.

Purely restrictive operations

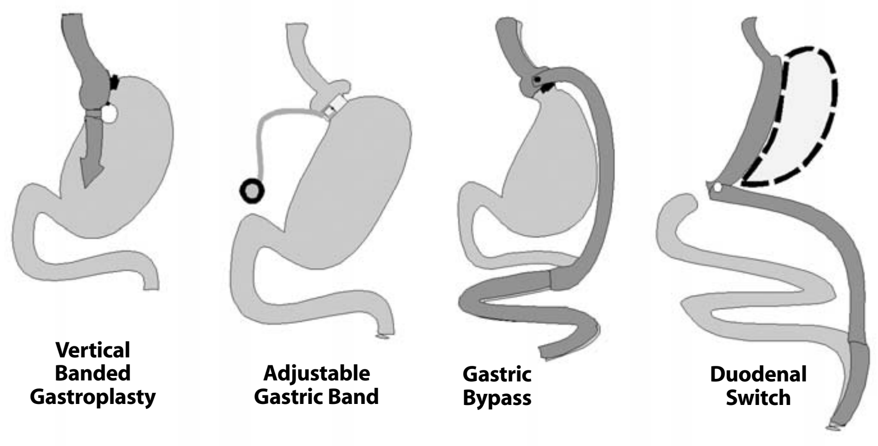
The *vertical banded gastroplasty* and *adjustable gastric banding* are two similar operations that induce weight loss solely by restricting intake. The vertical banded gastroplasty has been replaced almost totally by the adjustable gastric band, a far less traumatic and equally effective operation that consists of placing a bracelet-like band to create a golf ball-sized pouch. The advantage of the procedure is that the size of the stomach can be adjusted by changing the fluid volume of the balloon lining of the band through the subcutaneous port.

Combined restrictive and malabsorptive operations

The *gastric bypass* and the *bilio-pancreatic bypass with duodenal switch* are two operations with both restrictive and malabsorptive components. The gastric bypass supplements the actions of a small proximal gastric pouch with exclusion of the distal stomach, duodenum, and proximal jejunum from contact with food. The "duodenal switch" allows the patient to eat more because the entire lesser curvature of the stomach is maintained as a tube, providing a larger gastric pouch. This requires bypassing a significantly longer segment of the small bowel in addition to the resection of most of the stomach.

Of all of these operations, only the duodenal switch is not reversible.

Figure 2.
The Currently Accepted Bariatric Operations in the United States



The two operations on the left are restictive; the two on the right include a malabsorptive component.

Outcomes after Bariatric Surgery

A *comparison of the outcomes* of adjustable gastric banding, vertical banded gastroplasty, gastric bypass, and duodenal switch based on a meta-analysis of the bariatric surgical literature from 1990-2002 is shown in Table 1. The data are not quite fair since the experience with the adjustable gastric band was limited. More recent experience has shown that this newer procedure will also achieve excess weight loss in the 60-65% range after three years. In general, however, operations that combine restrictive and malabsorptive components, such as the gastric bypass and the duodenal switch, produce more weight loss and higher remission rates of diabetes, but with somewhat higher mortality rates.

Short-term complications after bariatric surgery are similar to other abdominal procedures (i.e., anastomotic leaks, bleeding, stenosis, and intestinal obstruction) and probably less frequent. They are, however, more dangerous in the morbidly obese with their co-morbidities and limited immune response. Anastomotic leaks, for example, require immediate attention because even short delays in repair and drainage may lead to fatal sepsis. A remarkable indicator of the safety of the surgery is that pulmonary emboli, though uncommon, now represent the most common cause of death.

The most serious *long-term complications*, however, are nutritional. Bariatric surgical patients require vitamin and mineral supplementation for life, including a broad multivitamin and mineral preparation, such as two Flintstone chewable vitamins tablets per day plus calcium. Menstruating women may require additional iron. Some patients also require vitamin B12 supplementation. Women in the child-bearing years are strongly urged not to become pregnant until their weight stabilizes, usually a period of 18-24 months after the bariatric surgery. If pregnancy ensues during this period, the mothers should be treated as high risk with special attention to meeting nutritional needs. Unfortunately, some patients refuse to comply even with these simple requirements with disastrous results, including full-blown cases of kwashiorkor, beri beri, pellagra, pernicious anemia, and Wernicke-Korsakoff neuropathies. Other long-term complications include bowel obstruction due to internal hernias or adhesions, functional problems with the band or reservoir, arrhythmias, and pulmonary emboli.

Patient Selection

According to the National Institutes of Health, the American Society of Bariatric Surgery, and the Centers for Medicare and Medicaid Services, patients should be offered bariatric surgery if they meet the following indications:

1. Have a BMI greater than or equal to 35 with significant co-morbidities, such as diabetes, hypertension, severe arthritis, cardiac failure.
2. Have a BMI greater than or equal to 40.
3. Are 18-65 years of age.
4. Have no unresolved issues regarding alcohol or substance abuse, depression, and/or other emotional problems.
5. Have acceptable surgical risk.
6. Have a full understanding of the procedure with realistic expectations.
7. Agree to life-long follow-up.

Most bariatric surgeons also require a strong family support system. Strong disagreement from a spouse or relative should be resolved prior to undertaking this elective surgery.

Insurance Coverage

Even though bariatric surgery is the only effective therapy for morbid obesity, many carriers still refuse to cover the procedures. We are fortunate in North Carolina that Blue Cross Blue Shield, Medicare, and Medicaid provide reimbursement if the operations are performed at Centers of Excellence certified by the ASBS or the American College of Surgeons. Other carriers are also becoming more responsive through pressure from employers and the realization that they can incur significant savings in reduced healthcare costs following bariatric surgery.

A Final Word

Bariatric surgery is a major medical advance. Finally, severe obesity, diabetes, hypertension, crippling arthritis, stress incontinence, sleep apnea, and pseudotumor cerebri are no longer hopeless conditions. With operations that last less than two hours and with hospital stays of two-to-four days, patients can regain a level of health and function previously thought impossible.

Even so, patients who have undergone bariatric surgery, although significantly healthier, cannot be considered "normal" without potential problems. Long-term follow-up for malnutrition, especially the thiamine, niacin, B12, calcium, and iron is essential. Rarely, patients may also develop internal hernias, bouts of hypoglycemia, and other metabolic problems. In such cases, patients are encouraged to call a bariatric surgeon or someone familiar with these complex patients. **NCMedJ**

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Addressing Disparities in the Obesity Epidemic

Alice Ammerman, DrPH, RD; May May Leung, MS, RD and David Cavallo, BA

Disparities In Overweight and Obesity Rates

As with so many health problems in the United States today, individuals who have been the most marginalized by society and can least afford the consequences of poor health are often the most likely to be overweight or obese. Currently in the United States, with over 65% of the population affected, it is the norm to be overweight or obese.[1] Among some ethnic groups, this proportion rises to three quarters, with approximately 76% of Black and Mexican-American adults overweight or obese.[2] Disparities exist among youth as well, with 37% of Mexican-American and 35% of Black youth already overweight or at risk, compared to 33.5% of Caucasians.[2] Obesity rates are also rising in the young American Indian population, with an estimated obesity prevalence of 22% for boys and 18% for girls.[3]

Disparities In Lifestyle Behavior and the Environment

Racial, ethnic, and income disparities are not limited to body weight. Low income and minority groups are more likely to be physically inactive, consume a less healthy diet, live in neighborhoods with limited healthier food options or exercise opportunities, and work in jobs that provide limited support for healthier lifestyle behaviors.[4,5] Minority adolescents engage in consistently higher levels of sedentary activities, such as television viewing and playing of video/computer games.[6]

Food Access and Availability

In contrast to more affluent communities, those with a greater proportion of ethnic minority residents often have about 30% fewer supermarkets and grocery stores that carry high quality, fresh fruits and vegetables and affordable healthy foods such as whole grains, low-fat dairy, and meats.[7,8] Given limited access to supermarkets, families living in these communities are more likely to purchase food from local corner stores or bodegas where the price of fruits and vegetables is generally higher and the quality lower than in standard supermarkets.[9] At the same time, fast food restaurants tend to be highly accessible in low-income and minority neighborhoods.[5] Among African Americans in North Carolina, higher fast food consumption has been associated with obesity, higher saturated fat intake, lower consumption of fruits and vegetables, and low self confidence in healthy meal preparation.[10]

The Built Environment

Access to parks, gyms, and other opportunities for exercise has been shown to correlate with higher levels of physical activity.[11,12] Affordability as well as distance and transportation availability are factors that effect access and may put lower income individuals at a disadvantage in terms of opportunities to be active.[13,14] Heavy traffic, inadequate street lighting, unleashed dogs, and high crime rates are other factors in the built environment that may decrease physical activity for both adults and children.[15-18] Again, many of these factors are more likely to be a problem in lower income neighborhoods.

Societal vs. Personal Responsibility and Adverse Psychosocial Impact of Obesity

Despite the many environmental obstacles to good nutrition and adequate physical activity, low income and minority individuals living in these environments are often blamed for making poor personal dietary choices and favoring sedentary behaviors. In fact, the debate rages about whether the obesity epidemic will be most effectively addressed through personal responsibility for nutrition and physical activity behaviors or through community-level change. While most would argue the answer lies in a combination of the two, there is increasing interest in environmental and policy level change as an approach that has potential to combat ethnic and income disparities related to access to healthy food and opportunities for physical activity. While not

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sufficient to reverse the rates of obesity, the easy availability of healthy, affordable food, and safe opportunities for exercise would make it easier for individuals who face many life challenges to make better choices regarding lifestyle behaviors.

Once overweight, children may be less likely to participate in sports or recreational activities and frequently experience problems with peer acceptance in school.[19-21] With obesity, the risk of experiencing psychosocial problems such as depression, poor self-esteem, and poor quality of life are also present, especially in a society that stigmatizes obesity.[22,23] These factors can serve to further marginalize the poor and persons of color, thereby helping to perpetuate the obesity cycle. Interventions to address obesity in minority and low-income communities must carefully avoid adding or exacerbating the stigma of obesity given an already long list of negative characterizations of these individuals and their communities. Kumanyika has stated this well, “Raising awareness and concern about obesity may render people in communities of color less satisfied with themselves and less able to cope with one more thing for which we cannot yet offer a good solution. This is a reason for serious reflection as we go forward.”[24]

> *“...the debate rages about whether the obesity epidemic will be most effectively addressed through personal responsibility for nutrition and physical activity behaviors or through community-level change.”*

Cultural norms may serve to both buffer the adverse psychological impacts of obesity and perpetuate the health-related problems. There appears to be greater aesthetic tolerance among some minority groups for body types that are heavier than what is portrayed by the popular media as most fashionable.[25] The positive side of this is that women, in particular, are not held to an unrealistic and nearly unachievable standard that can create lifelong internal conflict between the pleasures and comfort of food and the desire to achieve a body image deemed flattering. On the other hand, the relative absence of such pressures may “give permission” to maintain a weight that contributes to long-term chronic disease and poor health outcomes.

There is substantial evidence of an association between poverty and obesity.[26-28] It is a source of confusion to many, however, that someone of limited means could be overweight and simultaneously food insecure, or hungry.[29] This apparent paradox may stem from historical evidence that those who could afford adequate food were generally the wealthy and the more “portly.” Harder to grasp is the current situation with the relatively low cost of high calorie, low nutrient dense food, such as foods containing high fructose corn syrup sweeteners and many forms of hydrogenated fats used in processed foods, compared to the high cost of whole grains, fruits and vegetables, and lean meats.[28] This leads to a form of malnutrition where overall the diet is “calorie dense,” as opposed to what is recommended by nutritionists as “nutrient dense,” referring to a higher ratio of vitamins and minerals to calories. A southern staple, collard greens, for example, are “nutrient dense”, particularly when seasoned *without* fatback, as they are packed with nutrients, but have few calories.

The Southern Diet and Agricultural Tradition

The often-maligned southern diet may be more associated with region and income than ethnicity. Though often referred to as “soul food,” the traditions of fried chicken, corn bread, pinto beans, and greens are often shared across lower income whites, blacks, and even acculturated American Indians in North Carolina and the southeastern United States. Latino immigrants bring new healthier food options such as salsa, while sharing or adopting some of the less favorable southern dietary practices such as seasoning with meat fat and consumption of fast food. While often high in animal fat, the traditional southern diet has many health-promoting elements, including garden vegetables, pinto and other dried peas and beans (an excellent high fiber, lower fat protein source), and buttermilk (a low-fat cultured milk product that remains after the butter has been removed). Despite the tradition of large family meals and tables overflowing with a wide variety of food, southerners, like many others, are substituting convenience, take out, and fast food for home cooked meals. As a result, families prepare and eat fewer meals together. Some studies have shown that the children of families who eat home-prepared meals together are less likely to face problems with obesity and may experience other benefits such as enhanced school performance.[30,31] Rather than always finding fault with the traditional diet, southerners would be better served by slight refinements (e.g., seasoning collards and pinto beans with onions and garlic, instead of fat back) rather than abandoning it for processed and packaged foods consumed away from home and on the run.

Considering the calorie expenditure side of the obesity equation, North Carolina has traditionally been an agricultural state. In addition to the potential benefit of providing homegrown produce, an agricultural lifestyle involves hard physical labor. With the advent of more mechanized farming and agribusiness, and with fewer individuals tending their own crops or livestock, agricultural jobs can no longer be seen as a significant source of physical activity for North Carolinians. In fact, many rural North Carolinians spend significant time commuting to more urban areas for work but continue to live in communities with very limited access to opportunities for physical activity. Even walking for exercise is difficult with few parks and no sidewalks along high speed rural roads.

Overcoming Disparities with Community-based Approaches

Not only are low-income and minority individuals more likely to suffer from the causes and consequences of obesity, interventions and policies designed to curb the obesity epidemic may differentially benefit those who suffer least from the problem. Individual-level interventions often require payment for health counseling, purchase of specialty foods, and access to exercise equipment or facilities. Blue collar worksites are less likely to have flexible scheduling or exercise equipment to facilitate increased physical activity while on the job. Similarly, vending machines and snack bars are probably more common than cafeterias with healthy food options.

Thus far, local policies and environmental change have primarily benefited those living in newer or wealthier communities. For example, ordinances requiring sidewalks are applied to new developments, and new parks, walking trails, and bike lanes are often added in more suburban communities. Likewise, environmental changes such as walking and biking trails are more likely to be effective when located in communities where personal safety concerns are limited.

Population or community-level policy and environmental interventions take a more "upstream" approach and consider multiple factors, such as politics, economics, socio-cultural factors, and the built environment. Ethnically-inclusive interventions that have been shown effective often prioritize coalition building and extensive community input in the early phases of development and implementation. This approach increases buy-in and focuses on the mobilization of social networks, use of local resources such as lay health advisors and community health workers, and tailoring of culturally-specific messages.[32-34] Some research suggests that minority populations and communities with strong histories of interdependence for survival purposes may respond better to interventions that build on social support and community norms rather than a focus on individual education and behavior change.[32]

Future Research Directions and Public Health Priorities

Careful thought is needed regarding research priorities to address health disparities and the obesity epidemic. While not addressing all ethnic groups, AACORN (the African American Collaborative Obesity Research Network) was formed to "stimulate and support greater participation in framing and implementing the obesity research agenda by investigators who have both social and cultural grounding in African-American life experiences and obesity-related scientific expertise."[35] This group has proposed a number of research priorities that have broad potential to address health disparities and obesity. Their suggestions range from determining the extent to which lifestyle behaviors associated with obesity are influenced by ethnically-targeted marketing, to understanding more about differential health effects of obesity across ethnic and racial groups.[35] Also important to consider in framing a research agenda is the history of exploitation and resulting distrust of the research and medical communities.[32] In order to successfully address the obesity epidemic, researchers and practitioners must continue to challenge themselves to think broadly and deeply about the causes and consequences of access, behavioral, environmental, policy, and health outcome disparities among low-income and minority populations. **NCMedJ**

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Empowering Consumers and Employees to Lead Active, Healthy Lifestyles

Steven S Reinemund

Few health issues facing America today generate the same galvanizing concern as obesity. In the course of the last few years, those who work in, and around, the business of healthcare have begun to share an understanding of both the scope of the problem, and the sense of urgency needed to address it.

But the consequences of obesity have moved well beyond the healthcare industry. Whether as a consumer, an employer, a healthcare provider, insurer or policy maker, this critical health issue is shaping everything from how we eat to how we move. And food and beverage companies, in particular, understand their responsibilities for finding solutions. In short, obesity has become everyone's business.

Understandably, everyone wants quick solutions that work. Where America struggles today is in finding effective answers for a complex problem that has been in the making for decades. Not surprisingly, even a daily scan of news media shows there are as many opinions on how to address obesity as there are people and industries to sponsor them.

For PepsiCo, the solution starts with a fundamental belief in energy balance—the balance between calories consumed and calories expended through activity. It's a simple idea in concept, but how it works is as unique to an individual as a set of fingerprints. From the kinds of foods consumers eat to the kind of incentives that can motivate physical activity, the solution ultimately is specific to each of us.

That's why—while there are many different public policy solutions being proposed and implemented—we believe the solutions that will work best are those that meet consumers where they are, providing them with the information, the tools, and the motivation to change.

There are things companies like PepsiCo can do to make sure our marketing practices help consumers clearly understand the choices they're making. For example, PepsiCo launched its Smart Spot symbol in 2004, the first-of-its-kind designation that makes it easier for consumers to identify PepsiCo products that can contribute to healthier lifestyles.

But in addition to making it easier to find these choices, what consumers really need is a wider range of healthier foods and beverages they really want to eat and drink. And they need those foods and beverages to be marketed in a way that encourages and motivates them to adopt a healthier lifestyle. That's something we definitely know how to do as a company.

With brands like Tropicana, Quaker, Gatorade, Aquafina and Frito-Lay's Baked! products, we're continually expanding our portfolio to offer more foods and beverages that can play a role in healthier lifestyles. And to be transparent, it's not only the right thing to do for consumers; it's the right thing to do for our business.

> *"...we believe the solutions that will work best are those that meet consumers where they are, providing them with the information, the tools, and the motivation to change."*

In fact, in 2005, our Smart Spot-eligible product revenues grew more than two-and-one-half times faster than the rest of our portfolio, and we're seeing the same growth trends this year. So in essence, PepsiCo's efforts to find solutions are about putting our resources squarely at the intersection of business and public interests.

That includes taking some big steps to improve the healthfulness of our existing products. In 2004, PepsiCo's Frito-Lay

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business was the first food company and the largest-to-date to eliminate trans fats from its products. This action equates to removing 55 million pounds of trans fats from the American diet. In 2006, Frito-Lay made the move to reduce saturated fats in Lay's and Ruffles potato chips by more than 50 percent by switching to NuSun sunflower oil, a heart healthy oil. By converting to NuSun sunflower oil, nearly 60 million pounds of saturated fats are removed annually from the American diet.

We've also partnered with the U.S. beverage industry and government and health officials to find solutions. In partnership with a respected health advocacy organization formed by the American Heart Association, the William J. Clinton Foundation, and Arkansas Goveror Mike Huckabee, PepsiCo and other industry members developed a school vending policy in May 2006 aimed at providing lower-calorie and/or nutritious beverages and limiting the availability of soft drinks in schools. Moving forward, we are equally committed to continue working with industry, government, and health officials on snack and food choices in the nation's schools—important work that is taking place in the coming months.

But there's more work to be done in, and for, our schools. To help educate kids about energy balance, PepsiCo and America On The Move—a national on-line program dedicated to helping individuals, families and communities make positive changes to health and quality of life—developed a lesson plan called Balance First. This program already reached three million elementary students in 2004. In 2005, we continued to distribute the lesson plans to elementary schools. And in partnership with Discovery Education, we've distributed the Balance First program to 15,000 middle schools in the United States—virtually every middle school in the nation.

We're also passionate about motivating our own employees to adopt healthier lifestyles. We have to be. Healthy employees are a priority for us—our company's success depends on the day-to-day well-being of our people.

PepsiCo is a very "people-intensive" and people-dependent business. In North America, for example, the majority of our products are manufactured, sold, delivered, and merchandised on store shelves for our retail partners entirely by our own employees. Together, our team produces and delivers more than 500 different products to over 435,000 outlets of every description—supermarkets, mass merchandisers and club stores, gas stations, convenience and drug stores, restaurants and hotels and other food service accounts, and so on. In the United States alone that requires dawn-to-dusk efforts from 27,000 manufacturing and distribution employees and 22,000 salespeople. They all work together effectively as one incredible business machine.

Keeping those people on the job and in good health isn't a nice-to-do—it's a must-do, and we've been at it for many years. In fact, PepsiCo had one of the nation's first on-site health facilities in the 1960s, and continues to pioneer health benefits decades later that promote healthcare choice for our employees.

Those programs certainly help us manage healthcare costs and provide great tools for employees. But to address today's health needs for our people, we knew we needed to take a quantum leap. Like many employers, we recognized an increasing opportunity to invest in keeping our associates well. So, in 2004, we launched HealthRoads, an innovative health program for PepsiCo employees that's focused on taking action and changing behavior.

Essentially, HealthRoads is a highly accessible, simple, confidential, and personalized health program using an interactive web tool. It's based on the idea of customizing information and programs to each PepsiCo associate, starting with the voluntary and confidential completion of a Health Risk Assessment to identify individual needs.

Every quarter we launch new fitness or nutrition programs to generate added excitement. We have experts who reach out to employees with specific health risks and engage them in developing healthier habits. We provide tools that are integrated with our benefits to help employees make good purchasing decisions. And all of the HealthRoads programs include incentives to provide that little extra boost that many participants need.

Clearly, there isn't a one-size-fits-all solution, nor is there a single initiative that will solve the issue of obesity. If anything, there is more evidence than ever that the only way to make a real difference is by pulling many different levers, tapping the expertise of many partners, and working both sides of the energy balance equation.

There has never been a bigger need, more attention and more consumer knowledge coming together around obesity than there is today. The real opportunity is harnessing our collective resources, and showing consumers the way to healthier habits. We can do that with simple and consistent messages, with products and programs that make improving lifestyles easier, and with marketing that motivates consumers to take charge of their health by capturing their imaginations. **NCMedJ**

Obesity in (Corporate) America:
Large Employer Concerns and Strategies of Response

LuAnn Heinen, MPP

The epidemic of obesity in America has been likened to "a massive tsunami heading towards the shoreline".[1] Employers understand very well that they and their employees finance healthcare in the United States, either directly through the purchase of employer-sponsored healthcare or indirectly as corporate and individual taxpayers for publicly provided care. If the obesity tsunami strikes with the gale force predicted, employers will see financial and human capital effects even greater than those they now face. An expected proliferation of new treatment options will further challenge cost and quality management efforts.

A Familiar Problem

Compared to five years ago, employees are paying 64% more in healthcare costs today and employers are paying 78% more.[2] As health costs dramatically outpace economic growth, both private and public resources are reallocated to cover this burgeoning expense. The high cost of healthcare limits job growth and wage increases, leads to higher numbers of uninsured Americans, and diverts resources from other social needs, such as education, which, along with healthcare, is critical to ensuring a competitive workforce in years to come.

Employers, as purchasers of healthcare, try to (1) stem the growth in spending on healthcare and (2) ensure they are paying for quality. It is a terrible truth that while United States healthcare expenditures are out of control, we are still not receiving care commensurate with established quality standards more than about half the time.[3] Of the multitude of strategies deployed by employers over the years for dealing with these quality of care issues, some of the more enduring include: disease management and health improvement programs, employee cost-sharing and plan design changes to limit or restrict coverage, information and incentives for employees to manage their own health, and strong support for the National Committee for Quality Assurance's HEDIS (Health Plan Employer Data and Information Set) performance measures and other quality purchasing initiatives. Newer pay-for-performance incentives also appear promising.[4]

Current Game Plan: Health Improvement

Increasingly large self-insured employers, especially those with high employee retention, see their challenge as *population health management*. The argument that trends in health spending can be managed by improving employee (and dependent) health status appears to hold. Employers therefore are focused on reducing the number of health risks (e.g., high blood pressure, unhealthy weight gain, high cholesterol, sedentary lifestyle, poor diet, high stress, etc.) across their population in an effort to flatten the cost trend. Such health improvement/risk reduction efforts often co-exist with "disease management" programs targeting individuals with diabetes, back pain, heart disease, etc.

> *"The bigger the bite healthcare takes out of corporate profits, the higher healthcare falls on the CEO and CFO priority list."*

Employers work with health plans, consultants, and vendors to develop and execute their own population health strategy. Typically an analysis of medical claims data and health risk appraisal (HRA) biometric information sets the stage. Sometimes employees are surveyed to determine their priorities. Specific programs are purchased from health plans or other companies to address priority areas; program cost and intensity are tied to an expected financial return. Financial incentives for employees/dependents are commonly used to encourage participation.

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Evidence that this may be working comes from published literature on return-on-investment from well designed health promotion programs.[5] In addition, employee benefits consultants have shown that companies identified as "best performers" (i.e., experiencing the lowest medical cost trend) are disproportionately found to be early adopters of aggressive health improvement programs.[6]

Ultimately, however, these efforts to improve population health may be swamped by the increasing numbers of obese individuals and the corresponding, exponentially increasing, healthcare costs. Unless employers can "turn the tide," costs are more likely to escalate than flatten.

Senior Leadership Response

The bigger the bite healthcare takes out of corporate profits, the higher healthcare falls on the CEO and CFO priority list. The magnitude of expense affects global competitiveness (for example, think of the $1,500 added to the price of every GM car to cover healthcare). It also can directly impact earnings per share (EPS), as in the Fortune 500 company whose CEO reported a drop of $0.19 in EPS due to an overage in healthcare expenses (i.e., the amount actual expenses exceeded the healthcare budget in a year).

More and more companies, with top leadership support, are intensifying their efforts to:

- Define a strategy based on company data and consistent with corporate culture to improve employee health, establishing appropriate goals and measures.
- Communicate with employees and dependents about why healthy weight and healthy lifestyle improvements are a win-win opportunity, using corporate branding and messages tied to business goals.
- Provide tools and incentives to help employees and dependents understand their own health risk profile and start to improve their personal health risks.
- Create a supportive work environment, including healthy on-site dining, vending and catering for employees as well as opportunities for physical activity at work and on the employee's own time.
- Develop a benefit plan that, consistent with company resources, reflects the importance of a non-sedentary, non-smoking, healthy-weight workforce.

Companies who are engaged in these activities may apply for the National Business Group on Health's *Best Employers for Healthy Lifestyles* awards. Platinum, Gold and Silver award levels recognize large employers who have implemented robust health and wellness programs at the worksite; 57 awards have been made in the first two years of the program. Examples of Platinum winners include: Aetna, Florida Power & Light, IBM, Johnson and Johnson, Pitney Bowes, and Union Pacific Railroad.

Overweight and Obesity Compound the Problem

It is well documented that overweight and obesity are important drivers of healthcare costs both today *and* tomorrow. Physicians provide (and employers finance) care for more cases of diabetes, hip, knee and back problems, cancer, heart disease, high-risk pregnancy and many other conditions due to the prevalence of obesity, especially severe obesity, and its complications. One study attributed 27% of private insurance spending increases between 1987 and 2001 to obesity.[7]

In addition, obesity itself is beginning to be treated as a disease with drugs, surgery, and behavior therapy in various combinations. We have seen only the tip of the proverbial iceberg to date. *Treated prevalence* is growing rapidly, and along with this growth in treated prevalence, significant cost increases are expected (similar to the increase in costs for treated hyperlipidemia when widespread use of cholesterol-lowering medications became the standard of care). Although per case costs are high, it is the treated prevalence that drives the total cost, according to Thorpe's work in the privately insured market.[8]

For example, a large employer (35,000 employees) in the northeast discovered that 85% of its employees are overweight or obese, with only 15% currently at a healthy weight. It is not a stretch to assume that half of the 85% (14,875 employees) might qualify for a new weight loss drug expected to receive FDA approval in late 2006. Imagine the economic impact of putting even 14,875 employees on a new prescription drug at an estimated $1,800 per person—nearly *$27,000,000 per year*, for a drug that is prescribed indefinitely.

The provider community views the epidemic of obesity as a tremendous opportunity; from this perspective, the "unmet need" is pressing. Because fewer than five percent of obese Americans are now receiving surgery, drugs and/or behavioral therapy for obesity, the remaining 95% of the obese patient population—some 58 million people—can be seen to represent "unmet need." If even a fraction of those millions begin receiving obesity care, the costs can be staggering, given the high cost of treatment per patient (for new drugs in the pipeline, surgeries such as the lap band and gastric bypass, and others still in development) and, especially, the vast number of potentially eligible patients.

Arguments will be made that obesity surgery cures diabetes, and that the return on investment is such that the treatments achieve breakeven in a few years' time. It's likely that some treatments will prove cost-effective for *some* patients, but in many cases coverage is requested without standardized treatments or patient selection protocols.

The Challenge

Increasingly, employers recognize that *everyone* needs weight management. Those (often younger) employees with healthy BMI levels (<25) need to be encouraged and supported to maintain their health. Those in the overweight-to-obese category (BMI 25-35) are candidates for various types of weight loss programs (group support, individual coaching, medically supervised, etc.). And those in the over-35 BMI category need individualized plans and are, potentially, candidates for surgical treatment.

Historically very little insurance coverage has been provided until patients reach a BMI of 35 or greater and present with co-morbidities. Today, however, employers are asked to cover everything from Weight Watchers at Work to gastric bypass surgery with subsequent excess skin removal. Given the importance of weight management at lower and moderate BMI levels, as well as in the pediatric population, employers are reevaluating their benefit plans and coverage policies.

Evidence-based benefit design is the goal, and offers the best answer to the question: Which obesity treatments should be covered? Even partial coverage would help assure quality standards and allow employees to benefit from network pricing in every category (outpatient pharmaceuticals, behavioral therapy/lifestyle management, bariatric surgery). But how can the already-burdened employer-sponsored health plan take on a new category of expense that, given the prevalence of the problem, is likely to increase medical spending so significantly? In any case, employees will need to brace for even more cost-sharing and the likelihood of much higher cost-sharing, or no coverage, for high-cost services related to health problems associated with individual lifestyle choices. **NCMedJ**

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Why Does the Private Sector Underinvest in Obesity Prevention and Treatment?

Eric A. Finkelstein, PhD and Derek S. Brown, PhD

Introduction

Over the past several decades there has been a rapid rise in the prevalence of obesity. Currently, 65% of adults are either overweight or obese, an increase from 46% in 1976-1980 and 56% in 1988-1994.[1] These increases in obesity rates have spurred corresponding growth in the prevalence of several diseases, including type 2 diabetes, cardiovascular disease, hypertension, osteoarthritis, several types of cancer, gallbladder disease, and sleep apnea.[2]

As a result of the increase in obesity and related diseases, medical expenditures attributable to obesity have also ballooned. We have estimated that complications from obesity now cost the United States medical system over $93 billion per year.[3] Costs in North Carolina alone exceed $2 billion annually.[4] In addition to medical expenditures, obesity results in greater absenteeism and reduced worker productivity. For example, female employees with a BMI over 40 miss roughly one week more per year on average than female employees of normal weight.[5] Including both medical expenditures and increased absenteeism, the costs of obesity at a firm with 1,000 employees are estimated to be $277,000 per year.

The dramatic increase in prevalence and costs of obesity has captured unprecedented attention by the media. According to the North American Association for the Study of Obesity (NAASO), the number of obesity-related articles appearing in United States newspapers and newswires has more than tripled in the last five years, from approximately 8,000 articles in 1999 to almost 30,000 articles in 2004. National, state, and local governments have also increased efforts to inform the public about the consequences of obesity and strategies for obtaining a healthy weight (e.g., the *Healthy Lifestyles and Disease Prevention Initiative*, a part of the U.S. Department of Health and Human Services' *Small Steps* program). Despite the attention of policymakers and the media, most employers and insurers have taken little action to fight obesity.

Why have insurers and employers been reluctant to aggressively pursue obesity treatment and prevention strategies? One answer—which is not without merit—is that few proven long-term weight loss and weight maintenance interventions exist. However, even as these strategies are developed and refined, our research suggests that employers may be reluctant to adopt them. In this commentary, we provide an economic perspective on the behavior of employers and insurers in fighting obesity and highlight three key points that reveal why obesity prevention and treatment efforts are likely to be underprovided by the private sector.

> *"Employment-based health insurance, combined with the transient nature of the United States workforce, further reduces the incentives to invest in obesity treatment, even among firms who may have a high prevalence of obesity in their employed/enrolled populations."*

The three primary factors behind the private sector's under-provision of obesity treatment and prevention are the chronic

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nature of obesity-related diseases that tend to accrue later in life, the fragmented nature of healthcare financing in the United States, and the high rate of job mobility of employees. The implications of these factors can be discerned from the following figure, which shows the increase in costs attributable to obesity for each age between 18 and 75, based on data from the nationally representative 2001-2003 Medical Expenditure Panel Survey (MEPS):

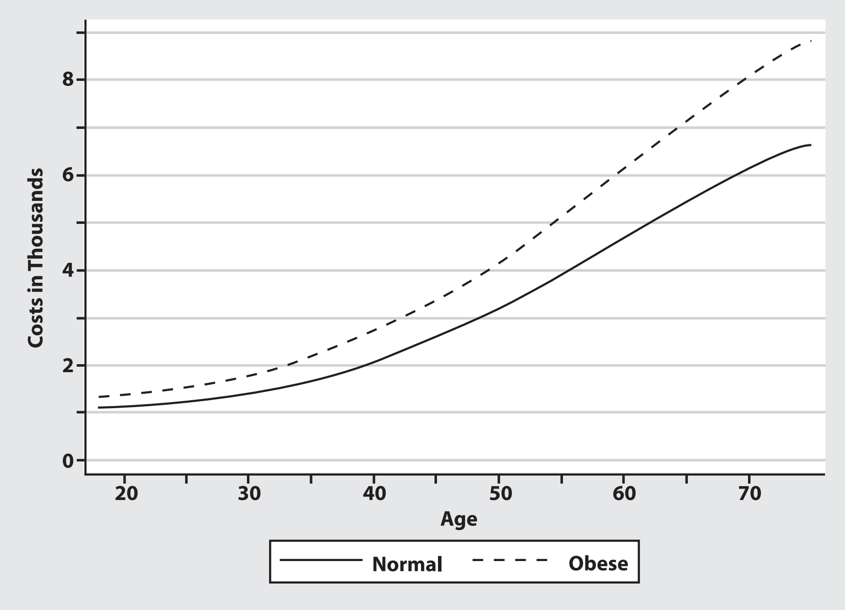
1 **Firms have little financial incentive to invest in obesity treatment for younger obese individuals who have not yet developed costly complications.** Although the prevalence of obesity is growing rapidly among youth and young adults, the date in Figure 1 show that the medical costs of a young obese individual are similar to those of a normal weight individual of the same age. The risk of type 2 diabetes and other obesity-related diseases is greater among overweight youth and young adults, but the MEPS data reveal that these conditions are relatively rare among this group. In fact, the annual medical costs for an obese individual do not become statistically greater than the costs for someone of normal weight until they reach their early to mid 30s. Because overweight and obesity is not especially costly among younger populations, firms have little financial incentives to invest in obesity prevention and treatment for them.

2 **Employment-based health insurance, combined with the transient nature of the United States workforce, further reduces the incentives to invest in obesity treatment, even among firms who may have a high prevalence of obesity in their employed/enrolled populations.** One may argue that focusing solely on current costs of obesity is short-sighted. In practice, however, firms rarely look to benefits beyond five years when considering investments in employee wellness. Individuals in today's economy tend to switch jobs roughly every four to five years.[6,7] Employers also switch insurance carriers intermittently; most employees will not remain with the same employer or insurer for more than a few years. As a result, a firm that pays most of the initial costs of obesity treatment will not garner the long-term benefits of improved health, including reduced medical expenditures and increased productivity—a future firm will instead. As a result, the incentive for firms to invest in obesity prevention and treatment is diminished, leading to reduced offering of such benefits.

3 **The existence of the Medicare program further reduces private sector incentives to invest in obesity treatment.** Even organizations that are able to keep their populations enrolled for long periods of time, such as public sector employees, are unlikely to adequately invest in obesity prevention and treatment because of the existence of the Medicare program, which assumes responsibility for primary health insurance coverage for most Americans once they reach age 65. The chronic nature of obesity-attributable diseases implies that a significant percentage of the costs of obesity occur after age 65. In fact, the figure reveals that of the roughly $58,000 cost of obesity incurred between the ages of 18 and 75, 38% accrued after age 65.

As retiree health insurance benefits become increasingly rare, firms are less likely to take the costs of obesity after age 65 into account when determining the optimal amount to invest in obesity treatment. For example, suppose a medical treatment was available for a one-time cost of $40,000 that guaranteed that an obese individual would have the same medical cost profile as someone of normal weight for their entire life (assumed to be to age 75). Assuming a 0% discount rate (money today has the same value as money in the future), a firm that considers an individual's entire cost profile would invest in this technology for its captive obese population. However, if firms only consider the time period up to age 65, the cost of the treatment technology is greater than the $36,000 in savings (62% of $58,000) that would accrue to the firm, and therefore firms are unlikely to make this investment.

Figure 1.
Annual Medical Expenditures for Normal Weight and Obese Employees in the 2001-2003 Medical Expenditure Panel Survey



Discussion

In summary, the chronic nature of obesity-related diseases, employment-based health insurance, the high rate of job mobility of today's workforce, and the existence of the Medicare trust fund reduce the incentives of the private sector to invest in obesity prevention and treatment. For these same reasons, there is also likely to be an underinvestment of research into effective employer-based obesity intervention strategies because of concerns that the private sector might be unlikely to finance them even if proven effective.

It should be noted that while these factors reveal that firms are likely to underinvest in obesity prevention and treatment, the increasingly high prevalence and costs of obesity suggest that the profit maximizing level of obesity prevention and treatment is positive and growing. As noted earlier in this edition, Blue Cross Blue Shield of North Carolina (BCBSNC) has committed a substantial amount of resources toward obesity treatment and is optimistic that their investment will pay off in terms of improved health and reduced costs. Given the high prevalence of obesity in their enrolled population and the fact that tenure in their plan is relatively long compared to the rest of the industry, it makes economic sense that they are one of the few private sector insurance plans to offer expanded benefits for obesity prevention and treatment. In fact, they remain one of a shrinking number of health plans that provide coverage for gastric bypass surgery, a high cost procedure that many employers/insurers have opted not to cover. Other firms will look to BCBSNC for feedback concerning the costs, cost-effectiveness, and budgetary implications of their coverage decisions. If they are able to show that their investments result in improved health and reductions in future—but not too distant—expenditures, other insurers are likely to follow their path.

Given the issues presented above and the increasing national prevalence of obesity, BCBSNC and other insurers should also pursue development and marketing of innovative health plans that are structured to keep individuals enrolled in the plan for long periods of time so the investment in prevention and treatment can be recouped by the plan. Although not directly addressed above, firms might also consider incorporating financial incentives for individuals to make personal investments aimed at maintaining their health. For example, a few firms offer premium discounts or rewards to employees who maintain or move towards a healthy BMI or who meet other health criteria.[8] These reductions in premiums may be worth the investment to an employer/insurer that can keep their captive population healthy and enrolled in the plan long enough to recoup the investment.

Given the abundance of affordable high calorie foods, the sedentary nature of modern lifestyles and most occupations, and the reliance on technology to accomplish everyday tasks, a majority of Americans find it increasingly difficult to maintain a healthy weight. Employers and insurers have an opportunity to implement strategies to help them maintain and improve health, but in a competitive marketplace, they will do so only to the extent that it serves the best interest of the firm. As a result, halting the obesity epidemic may require a substantial deviation from the current approach of healthcare financing in the United States. **NCMedJ**

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The Payer Perspective:
Blue Cross and Blue Shield of North Carolina's Approach to the Obesity Epidemic

Robert T. Harris, MD

The health and cost impacts of overweight and obesity have been well documented over the past several years. Rates of obesity and overweight have increased within the United States at an alarming pace, as have rates of bariatric surgery, type 2 diabetes, and healthcare costs associated with weight-related illnesses. In North Carolina, 23 percent of adults are classified as obese and an additional 36 percent are overweight. The rate of adults who are overweight has doubled over the past 20 years, and the number of overweight teens has tripled during the same time period.[1] Studies have shown that as body mass index (BMI) increases, healthcare expenditures increase with costs being 25 percent higher in people with a BMI of 30 to 35, and 44 percent higher for people with a BMI greater than 35.[2]

> *"In North Carolina, 23 percent of adults are classified as obese and an additional 36 percent are overweight. The rate of adults who are overweight has doubled over the past 20 years, and the number of overweight teens has tripled..."*

Preventive health has long been a focus of Blue Cross and Blue Shield of North Carolina (BCBSNC), and the company is committed to working with members and healthcare providers to combat obesity and excessive weight. In designing our comprehensive approach to this issue, we faced a number of challenges including member lifestyles and perceptions, traditional health plan design, and provider time stresses and reimbursement practices. However, the early results of our comprehensive, evidence-based approach are promising and provide hope that collaborative approaches may make a long-term difference.

Background

Traditionally, health plans have excluded coverage for weight reduction services, except for bariatric surgery when it is deemed medically necessary. Coverage exclusions have included physician assessment, counseling or medical management of weight issues, weight loss medications and weight loss programs. The reluctance to cover services has been attributable to several factors: no clear benefit models; few programs tracking long-term outcomes; frequency of weight gain; and no strong evidence of success with more traditional medical approaches such as case management, physician supervision (without the support of a structured nutrition, physical activity and behavior change program) or drug therapy (without concurrent behavior change).

In a 2003 survey of HMO and PPO members, Blue Cross and Blue Shield of North Carolina found 55 percent of its adult members were overweight or obese. The survey also pointed to startling perception gaps among members—Nearly one-third of overweight members believed their weight was "just right," and many were unaware of the extensively documented health impact of obesity. An analysis of claims data associated with these members found that obese member costs were 32 percent higher than those of normal weight members, and overweight members' costs were 18 percent more. Overweight and obesity accounted for $83.1 million in medical costs in 2003 for BCBSNC.

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The survey also found that only 57 percent of obese members and 32 percent of overweight members reported being advised by their doctors to lose weight within the past 12 months. At the same time, a report from the United States Preventive Services Task Force[3] found that patients who were advised to lose weight were more than three times as likely to drop pounds as those who didn't discuss weight with their doctors.

BCBSNC had recognized for some time that North Carolinians were struggling with growing waistlines, and over several years had initiated a number of community and member-specific strategies. But with fresh claims and member survey data in hand, BCBSNC clearly identified the need for a more comprehensive and innovative approach to a complex problem. This approach would have the goal of decreasing the prevalence of obesity among the commercial BCBSNC membership through physical activity, healthy eating, weight control and safe and effective treatment.

Effective Solutions

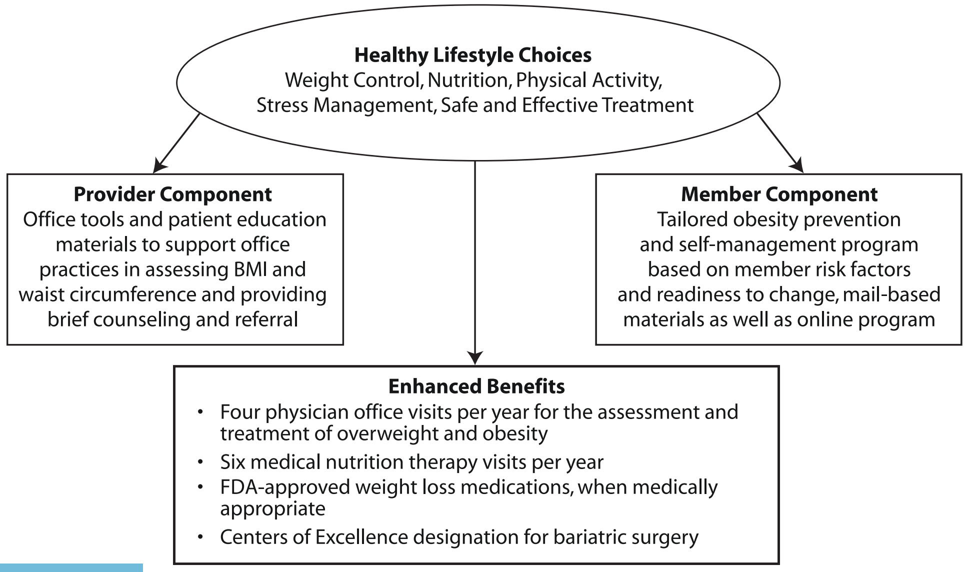
The National Institute of Health's National Heart, Lung and Blood Institute issued an evidence-based report in June 1998, which provided clinical guidelines for identifying, evaluating, and treating overweight and obesity in adults.[4] This report provides a comprehensive literature review of randomized controlled trials, evidence statements, and recommendations for what determines a successful weight loss regimen. The panel concluded that weight loss and weight maintenance therapy should employ a combination of low-calorie diets, increased physical activity, and behavior therapy. Behavior therapies include self-monitoring of eating and physical activity, stress management, stimulus control, problem solving, contingency management, cognitive restructuring, and social support. Additional relevant recommendations include:

- Treatment of an overweight or obese person must incorporate a two-step process—medical assessment followed by treatment. Medical assessment includes determination of the degree of obesity and overall health status. In addition, providers should assess patient motivation to enter weight loss therapy and readiness of the patient to implement the plan.
- The initial goal of weight loss therapy should be to reduce body weight by approximately 10 percent from baseline. Significant health improvements can be achieved with this modest level of weight loss. With success, further weight loss can be attempted, if indicated.
- Weight loss drugs approved by the United States Food and Drug Administration (FDA) may be used as part of a comprehensive weight loss program including diet and physical activity for high-risk patients. Drugs should never be used without concomitant lifestyle modification. Continual assessment of efficacy and safety is necessary and should only be continued if the drug is efficacious.
- Weight loss surgery is an option for carefully selected patients with clinically severe obesity when less invasive methods have failed. Surgical patients should be monitored for complications by multidisciplinary teams.

Blue Cross and Blue Shield of North Carolina's Strategy

In 2004, BCBSNC launched Healthy Lifestyle Choices,^{SM} a comprehensive set of health improvement services developed to prevent and reduce obesity. BCBSNC conducted extensive literature reviews on what is most effective in the prevention and management of obesity and solicited input from national experts, physician advisors and BCBSNC members in the development of the program. In addition, a baseline member survey and formative evaluations provided key guidance in project development. Healthy Lifestyle Choices includes a member self-management program, a physician toolkit to support clinician evaluation of weight and treatment of obesity, and enhanced benefits covering physician assessment, medical nutrition therapy, and FDA-approved weight loss medications for long-term treatment of obesity (when medically appropriate). These new services are standard benefits available to members enrolled in BCBSNC's HMO, PPO and individual products.

Figure 1.
Components of BCBSNC's Healthy Lifestyles Choices^{SM} Program



Physician Component

As part of the Healthy Lifestyle Choices program, BCBSNC developed toolkits to aid physicians in the assessment of weight and the treatment of obesity. Two different toolkits were developed, one specifically addressing assessment and treatment of adult overweight and obesity and the other for pediatric patients and their parents. BCBSNC piloted these toolkits with 200 of the highest volume primary care practices. The toolkits include: BMI wheels for the assessment of body mass index, retractable tape measures for the assessment of waist circumference, patient and parent education tear sheets, NHLBI practical guidelines for assessment and treatment of obesity, pocket cards outlining practical guidelines in a brief stepwise manner, removable patient stickers with reminders for BMI and waist circumference assessment, and "get up and move" posters for pediatric offices.

Enhanced Benefits

As part of Healthy Lifestyle Choices, and to support physicians' appropriate assessment and treatment of obesity, BCBSNC examined and adopted benefit changes. Physicians reported that they needed both the tools and the time for the assessment and treatment of obesity. Reimbursement would allow for dedicated time and appropriate follow-up care. In addition, physicians acknowledged the value of nutrition counseling for members if they needed extra support. BCBSNC worked closely with a Physician Advisory Group to establish a reasonable benefit structure that would encourage assessment and monitoring, while discouraging inappropriate utilization such as "physician weight loss clinics" springing up in offices across the state. New benefits include:

- Coverage for four physician office visits and related testing for the evaluation and treatment of obesity per benefit period.
- Six medical nutrition therapy visits for members enrolled in BCBSNC's Healthy Lifestyle Choices program. Copayments and coinsurance are waived to encourage utilization.
- Coverage of FDA-approved weight loss drugs for the long-term treatment of obesity—coverage requires prior authorization from BCBSNC, and the member must be enrolled in the Healthy Lifestyle Choices program.

The above benefit changes were approved by the North Carolina Department of Insurance and are part of the standard benefit package offered by BCBSNC.

BCBSNC is credentialing licensed, registered dietitians to be included in the BCBSNC provider network. Credentialed dietitians are listed in the online BCBSNC provider directory, which allows both physicians and members to easily locate an in-network dietitian in a particular area of the state.

In addition, BCBSNC announced the establishment of a network of Centers of Excellence (COE) for bariatric surgery in July 2004. Seven facilities, including 12 bariatric surgeons across North Carolina, are included in the network. The COEs are listed in the BCBSNC provider directory, which can be found online at bcbsnc.com.

Self-management program

The Member Health Partnerships^{SM} Healthy Lifestyle Choices program is free to eligible members and provides educational materials and self-help tools. BCBSNC proactively identifies and invites members with specific diagnoses such as hypertension, dyslipidemia and metabolic syndrome (conditions that can significantly benefit from dietary changes, increased physical activity and weight management) into the program. Members can also self-refer. Members do not need to be overweight or obese to join; however, more than 85 percent of program participants both need and want to lose weight. Materials are customized to the member's individual health status and readiness to make lifestyle changes. Members complete a short health assessment survey as part of the enrollment process to determine health risks and needs. As part of the Healthy Lifestyle Choices program, a member receives customized mailings over a six-month period. Materials include a personalized health feedback report (based on survey results), a lifestyle diary, step counter, interactive online tools, condition-specific materials, and a quarterly newsletter.

The Results

BCBSNC was the first major health insurer in the country to make coverage available for doctors to talk specifically to their patients about how weight affects their health. The Healthy Lifestyle Choices program is helping participants achieve a healthier weight and engage in lifestyle changes that can prevent serious health problems. Since its inception, 9,296 BCBSNC members have actively engaged in the Healthy Lifestyle Choices program. Early program results are promising. The following results reflect self-reported, pre-post survey data following the first six months of the program:

- 47% of participants who reported wanting to lose weight lost an average of 9.5 pounds.
- 14% lost 10 pounds or more.
- 46% of participants lost an average of 0.86 inches around their waist.
- 70% of participants in the Hypertension Stage I/Stage II categories moved to a lower hypertension severity category (e.g. Prehypertension or Normal categories).
- 13% of participants in the Prehypertension category lowered their hypertension severity to Normal.
- 46% of participants reported an increase in days of exercise. On average, members increased their days of exercise by 0.64 days.
- 90% of program participants were satisfied or very satisfied with the program.

Future process and outcome measures of the program will include:

- Utilization and costs (pre-post against a similar cohort of non-participants)
- Incidence of type 2 diabetes onset

- Provider assessment of BMI and counseling
- Utilization of various program components
- Program return-on-investment

BCBSNC is currently collaborating with the American Dietetics Association and the Blue Cross and Blue Shield Association to conduct an in-depth analysis of the effectiveness of the medical nutrition therapy component of the program.

BCBSNC gained solid recognition as an industry leader, willing to work collaboratively with doctors and other healthcare professionals for the good of its members to offer an obesity solution. Others have publicly recognized this effort:

> *"The move will probably become a model for other insurers and private companies," said Morgan Downey, executive director of the American Obesity Association, a Washington Advocacy group. "It is very comprehensive and unprecedented…"*
>
> —The Washington Post

> *"Other insurance companies and health plans and employers will be watching this very closely."*
>
> —Helen Darling,
> President, National Business Group on Health

> *"This program represents a direction that a lot more health insurers could pursue. Clearly, BCBSNC is making a serious commitment of resources to support its members in their efforts to manage their weight."*
>
> —William Dietz, M.D.,
> Director of the Centers for Disease Control and Prevention's Division of Nutrition and Physical Activity.

BCBSNC remains committed to working with members and providers over the long term and to refining our approach based upon our results, emerging medical literature, and best practices. Successfully combating obesity and overweight are one of the leading challenges of our entire healthcare system, akin to the anti-tobacco campaigns that began in the last half of the 20th century. Winning this battle is crucial to moderating healthcare costs, sustaining the viability of our healthcare system, and maintaining the economic vitality and quality of life of our state and nation. **NCMedJ**

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SPECIAL ARTICLE

The Kate B. Reynolds Smoking Education Lifestyle Fitness Improvement Program:

Preventing and Reducing Chronic Disease in Low-Income North Carolina Communities

Margaret L. Sauer, MS, MHA; John H. Frank, MBA; J. Lloyd Michener, MD; Susan D. Yaggy, MPA and Truls Østbye, MD, PhD

Seven of every ten Americans die from chronic disease. Uncontrolled chronic diseases result in premature disability, diminished functional status, and diminished quality of life. They account for more than 75% of medical care expenditures.[1] The effects of chronic disease can be prevented or controlled by changing three health behaviors: smoking, poor nutrition and physical inactivity.[2]

North Carolina consistently ranks poorly on these behaviors. More 60% of adults in NC are overweight or obese, and the prevalence of obesity and overweight is greater in minority populations. Only 37.6% of NC residents receive the recommended amount of physical activity,[3] and 22.6% of adults smoke.[4]

The Kate B. Reynolds Charitable Trust launched the SELF Improvement Program in 2001, offering to fund community-based organizations and their local partners to reduce and prevent chronic disease in low-income North Carolina residents. The Trust's goals were to change the perception of chronic disease and its complications from inevitable to preventable, develop sustainable collaborative community-based services to increase physical activity, improve nutrition, and curb or eliminate tobacco use. SELF Improvement built on the understanding that health promotion strategies that incorporate multiple interventions based in the community have been more successful than those targeting individuals.[5,6]

The Trust committed $10 million to SELF Improvement and contracted with the Department of Community and Family Medicine, Duke University Medical Center, to administer the program. The Trust and the Duke team established an advisory board to review the requests for proposals and select grantees to be funded. SELF Improvement represented the largest and longest single commitment by the Kate B. Reynolds Charitable Trust in its history.

> *"More than one million North Carolina residents have received information on improving nutrition and physical activity, and on smoking cessation."*

Project Selection

The Request For Proposals (RFP) targeted traditional health organizations as well as non-traditional organizations, such as

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United Way and Parks and Recreation Departments. Per the Trust's indenture, projects had to serve low-income North Carolina residents. The RFP requested collaboratively developed, multi-level, community-based interventions to improve nutrition, physical activity, and prevent tobacco use. Applicants were asked to document active involvement of the target population in program planning, willingness to submit data and participate in ongoing program evaluation, commit to attend statewide meetings to review progress, share lessons learned, and engage in mutual problem solving.

Selected Projects

All projects applied community-based models to help low-income, underserved North Carolinians change their lifestyles to prevent and reduce chronic disease. Each project built on the resources and characteristics of its region and culture, and each was unique in its approach to prevention of chronic disease. Each project targeted the community at multiple levels, using a variety of strategies. While not strictly categorized, projects have been organized by primary target audience as described below.

Schools

Illustrative school-based projects have targeted and attempted to change health behaviors in students, teachers, parents, and staff, modified how meals are prepared for children, and altered the tools teachers use to deliver a "standard" curriculum.

- In Dare County, PEER Power, a partnership between the Health Department and the schools, high school students were trained as peer health educators to help other elementary and middle school students learn the importance of physical activity, smoking cessation, and good nutrition.
- In Swain County, the Health Department partnered with schools and the town of Bryson City to improve the nutrition of children as well as other residents. The program replaced fryers with ovens in the school cafeterias and built a community walking trail. Physicians distributed medication without charge to help participants stop smoking.

Community

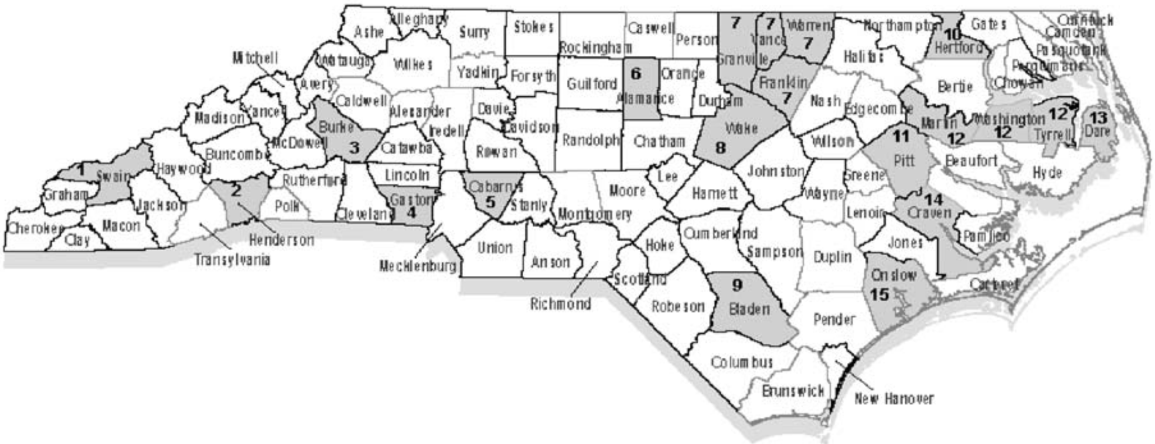
Community-based projects offered participants a mix of services designed to complement local culture and resources. Key strategies included: shopping and meal preparation on a budget, walking trails, individual nutrition and physical activity advice, and group classes.

- In Wake County, Strengthening the Black Family, Inc., organized activities through community leaders in three Wake communities. Families learned to prepare nutritious food that is culturally appropriate for African-American participants with a limited budget. The program also provided group physical activity and health screenings.
- Triangle E, located in Duffyfield, is a low-income, historically African-American neighborhood in New Bern. Churches convened Action Teams to assist the project, the Craven County Health Department provided health screenings, and the City's Parks and Recreation Department provided nutritional counseling and physical activity. The program was integrated in the long-range strategic plan for the city and officials expanded the program to all city employees.

Healthcare

Healthcare projects shifted the focus from providing care in hospital/clinic-based settings, to neighborhood settings more accessible and better able to meet community members' needs.

Figure 1.
Selected SELF Improvement Projects



1. Swain County Health Dept.
2. Partnership for Health
3. Burke County United Way
4. Gaston County Health Dept.
5. Cabarrus Health Alliance
6. Elon University
7. General Baptist State Convention of NC **
8. Strengthening the Black Family
9. Bladen County Hospital
10. Hertford County Public Health Authority
11. N.C. Agromedicine
12. Martin-Tyrrell-Washington Health Dept.
13. Dare County Health Dept.
14. New Bern, City of - Parks & Recreation
15. Onslow County Health Dept.

** Statewide, focusing on the four highlighted counties

Projects addressed barriers including; transportation, insurance coverage, language, culture, and access to primary care providers.

- In Alamance County, Elon University, Alamance Regional Medical Center, Alamance Community College, Centro La Communidad, International Family Clinic, and Piedmont Health Services collaborated on "SALSA" (**S**alud **L**atina, **S**alud de **A**lamance). Alamance Community College taught English to Latinos using a curriculum to reduce and prevent chronic disease. Exercise training centers were established in churches under the supervision of Elon University's Exercise Physiology Department.

Faith-Based Organizations

Faith-based projects ministered to the whole person (body, mind, and spirit). These projects tailored their strategies to recognize the effect of behavior and lifestyle, social and political conditions, spiritual and emotional states, economics, and environmental conditions on health.

- The Faith and Health Initiative of the General Baptist Convention of North Carolina, headquartered in Durham, is based in four of North Carolina's poorest counties: Granville, Franklin, Vance and Warren. The initiative included 88 churches with more than 19,000 members. This project trained 136 lay leaders to serve as Faith and Health Advocates to motivate and mobilize church members to improve their diet and increase their physical activity. The program provided congregational education and nutritionally appropriate food choices at church events. Many participating churches established walking trails on their grounds.

Implementation and Ongoing Technical Assistance

A critical part of SELF Improvement was the development of partnerships with state agencies to provide additional technical assistance. The North Carolina Department of Public Health offered grantees ongoing support to develop sound nutrition programs, increase participants' physical activity, and decrease smoking. This partnership assured that SELF Improvement would complement not duplicate state-funded efforts.

Grantees developed detailed action plans with community partners to guide their work, delineating project activities, partner roles, costs, and timelines. Grantee partners were involved in the creation and implementation of the plan. These documents became the navigational road maps for the project and required endorsement by the "community," the Duke Management Team, and the Trust.

Data Collection

The Duke Management Team developed a comprehensive database to evaluate and record project activities/outcomes centrally, and to help grantees manage their projects. Questionnaires were developed using questions adapted from the Behavioral Risk Factor Surveillance System (BRFSS) and the Youth Risk Behavior Surveillance System (YRBSS). Program participants completed surveys describing changes in nutrition, physical activity and smoking behavior. Project teams recorded the amount and types of services provided in each community. Grantees submitted information quarterly to the Management Team for review and follow-up as needed.

Technical Assistance

To help grantees monitor progress and identify areas of weakness, the Duke Management Team created a quarterly score card system for each project. Score card reports provide a graphic display of progress toward each project's target goals and objectives outlined in the original proposal, including accomplishments, participation, and health behavior outcomes. Conference calls were conducted quarterly with each grantee to review progress and propose improvements.

Some projects struggled with gaps in leadership and staff turnover. The Management Team asked the Duke Center for Non-Profit Management, which provides classes in communities throughout North Carolina, to create a Certificate Program in Healthcare Leadership for the grantees. The new Certificate Program in Nonprofit Management provided opportunities for grantees to improve their management and leadership skills through local classes. As of June 2006, 23 staff members from 14 projects are enrolled in the Certificate program; one staff member completed the program; and two are enrolled in master's degree programs.

Results

SELF Improvement aimed for and achieved a broad reach across the state. More than one million North Carolina residents have received information on improving nutrition and physical activity, and on smoking cessation. More than 25,500 residents have engaged in individualized health promotion activities, including health assessments, counseling, classes, and case management. Combined outreach efforts from these programs have been extensive. Some of the outcomes in the most successful programs, which are far in excess of the overall program numbers below, will be the subject of future publications.

Tables 1 and 2 give an overview of participants' characteristics and the overall results from the 15 projects' interventions for nutrition, physical activity, and tobacco cessation. Data are not available for all participants, but overall, adults reduced BMI, increased physical activity, improved nutrition, and a small number stopped using tobacco. Increases in youth physical activity and nutrition were reported for the first two follow-up visits after administration of the baseline questionnaire. More detailed analysis of youth BMI will continue, although valid BMI data were not available for all projects.

Lessons Learned

The SELF Improvement Program just completed its fifth and final year of funding. Important lessons have been learned:

1. Lifestyle changes take time. The Kate B. Reynolds Charitable Trust found it useful to have offered grantees a five-year period in which to mobilize and integrate local resources and craft appropriate services.

Table 1.
Adult Participant Characteristics and Aggregate Results for 15 Projects 2001-2006

Participant Information		(n=7,480)
Age		Mean: 47 years 68% aged 26 - 65
Sex		
- Female		76%
-Male		24%
Race		
- African American		58%
- White		39%
BMI (At baseline)		
- Normal Weight		21%
- Overweight		30%
- Obese		49%
Changes in weight	(from baseline)	
1st Follow-up visit	(n=2,219)	-2 lbs.
2nd Follow-up visit	(n=1,019)	-2.3 lbs.
3rd Follow-up visit	(n=535)	-2.2 lbs.
Changes in BMI	(from baseline)	
1st Follow-up visit	(n=2,184)	-0.4 kg/m2
2nd Follow-up visit	(n=1,015)	-0.5 kg/m2
3rd Follow-up visit	(n=535)	-0.5 kg/m2
Moderate physical activity		
(all assessments: 11,028)		Mean: 3.1 days/week
Changes in days per week performing moderate physical activity (from baseline)		
1st Follow-up visit	(n=2,106)	+0.6 days
2nd Follow-up visit	(n=936)	+0.5 days
3rd Follow-up visit	(n=484)	+0.7 days
Current Smoking		
(all assessments: 9,179)		22.2%
Stopped smoking (from baseline)		
1st Follow-up visit	(n=1,908)	3.7%
2nd Follow-up visit	(n=912)	5.0%
3rd Follow-up visit	(n=497)	5.4%
Fruit intake		
(all assessments: 11,393)		Mean: 34.9 times/month
Increase in fruit intake (from baseline)		
1st Follow-up visit	(n=2,133)	+5.2/mo.
2nd Follow-up visit	(n=942)	+2.9/mo.
3rd Follow-up visit	(n=488)	+2.2/mo.
Vegetable intake		
(all assessments: 11,364)		Mean: 37.6 times/month
Increase in vegetable intake (from baseline)		
1st Follow-up visit	(n=2,132)	+3.2/mo.
2nd Follow-up visit	(n=935)	+2.4/mo.
3rd Follow-up visit	(n=486)	+3.1/mo.

2 Non-traditional providers in the community can be effective and successful in the delivery of community-based healthcare interventions.

3 Many grantees were unaccustomed to providing multi-level interventions, assuming “campaigns”, health fairs, and media messages by themselves could change health behavior. Extensive technical assistance helped grantees broaden their scope of services and apply multiple intervention strategies.

4 Some grantees labored to recruit and retain talented program directors and project coordinators. Classes to build skills for

Table 2.
Youth Participant Characteristics and Aggregate Results for 15 Projects 2001-2006

Participant Information		(n=16,901)
Age		Mean: 8.9 years 93% K-5th grade
Sex		
- Female		49%
- Male		51%
Race		
- African American		55%
- White		38%
BMI (At baseline-based on z-scores)		
- Normal Weight		54%
- Overweight		18%
- Obese		26%
Moderate physical activity		
(all assessments: 43,645)		
Changes in days per week performing moderate physical activity (from baseline)		Mean: 2.7 days/week
1st Follow-up visit	(n=5,972)	+0.2 days
2nd Follow-up visit	(n=4,281)	+0.6 days
3rd Follow-up visit	(n=3,287)	+0.9days
Tried Smoking		
(all assessments: 10,713)		14.0%
Change in smoking status (from baseline)		
1st Follow-up visit	(n=5,939)	
2nd Follow-up visit	(n=4,277)	No change in youth smoking status
3rd Follow-up visit	(n=3,288)	
Fruit intake		
(all assessments: 15,691)		Mean: 45.9 times/month
Increase in fruit intake (from baseline)		
1st Follow-up visit	(n=5,964)	+0.3/mo.
2nd Follow-up visit	(n=4,281)	+0.2/mo.
3rd Follow-up visit	(n=3,288)	0.2/mo.
Vegetable intake		
(all assessments: 15,037)		Mean: 41.1 times/month
Increase in vegetable intake (from baseline)		
1st Follow-up visit	(n=5,966)	+0.5/mo.
2nd Follow-up visit	(n=4,279)	+0.5/mo.
3rd Follow-up visit	(n=3,288)	- 0.5/mo.

program leadership in local communities were motivational and improved core management capacity.

5 Overall, projects struggled to find connections to local medical practices. Although two projects built strong connections with practices, a sizable gulf exists between medical practice and community-based chronic disease prevention programs. Community agencies and medical practices need to partner with one another to effectively treat/prevent chronic disease. As practicing physicians struggle to help their patients make difficult changes in their lifestyle, it is worth remembering that doctors and patients are not alone, and that in many communities, help is already available.

6 Extensive training to help projects develop sustainability strategies helped grantees learn to think beyond the "next grant." Several grantees have found ways to generate income to sustain their services to under-resourced people outside of additional grant funding.

7 Creating and managing data was difficult for many grantees, although extensive and ongoing technical assistance helped. Electronic databases for all program activities enabled the Management Team to generate score cards to coach and supervise grantees so improvements could be made.

The SELF Improvement program has created a foundation upon which North Carolina communities can model effective interventions to reduce and prevent chronic disease. **NCMedJ**

APPENDIX A.
SELF Improvement Grantees

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Duttonde@dare.k12.nc.us

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Partnership for Health
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Pediatric Healthy Weight Case Management

A Project Supported by the Duke Endowment

James Cox, MSW, ACSW and Peggy Sessoms, RD, LDN

The Pitt County Memorial Hospital (PCMH) Pediatric Healthy Weight Case Management Program (PHWCMP) is a multifaceted initiative supported through a grant from The Duke Endowment to address the epidemic of childhood obesity in Pitt County. The goal of the PHWCMP is to develop effective strategies that will reduce premature morbidity and the risk of premature mortality associated with "at-risk for overweight" and "overweight" children ages two to 18 years. The primary focus of the program is to inform children, families, and the community that the epidemic of childhood obesity is not an *appearance* issue, rather it is a *health* issue with life-long medical implications. The three interrelated components of the program include: interdisciplinary case management, care standardization, and social marketing.

Multidisciplinary case management is not a new concept for the management of chronic illness; however, the utilization of an interdisciplinary case management team is an innovative approach to the management of the complex issues related to childhood obesity. The PHWCMP interdisciplinary team consists of nursing, nutrition, and social work and depends upon input from the child's physician and other community partners.

Both at the beginning and throughout the duration of the PHWCMP intervention, *Readiness to Change* and *Quality of Life* surveys are administered to patients and their families. These results, along with a assessment of psychosocial, medical, nutritional, and physical activity needs are used to develop individualized treatment plans. The case manager develops and implements the treatment plan in partnership with the child, parent or guardian, and physician. Clinical case management services are provided in a variety of innovative settings including; homes, schools, medical clinics, the workplace, the community health office, and other community-based settings.

The PHWCMP is relationship-based and family-focused. To have success in dealing with the complex issues associated with childhood obesity (e.g. psychosocial, behavioral health, medical co-morbidities), the establishment of a long-term trusting relationship between patient, family, and case manager is essential. Each child and family member is encouraged to participate in "STARTING POINT," a ten-week program that provides the foundation for case management and healthy lifestyles changes. The curriculum focuses on helping families understand about childhood obesity by including information on behavioral health, nutrition-related, medical conditions, and physical activity. The goal is to move families through different levels of interventions, addressing barriers that may prevent them from making changes. The case manager implements a treatment plan recognizing that the child's and parent/guardian's participation is key to the success of the intervention. Each of the clinical case managers is responsible for their individual case load, but also relies upon the professional expertise of their interdisciplinary team members in order to provide comprehensive services to each referral.

Convincing families that childhood obesity is a chronic health issue is the focus of the social marketing campaign. In order to more effectively address this barrier, 500 families were surveyed. Focus groups were conducted in local day care centers. The information collected was incorporated into a social marketing campaign. This campaign utilizes television, print materials, and the internet to share information about childhood obesity with the public. The website will also be used for some case management with enrollees. A major component of the campaign focuses on the use of Body Mass Index (BMI) grids as screening and tracking tools. BMI "wheels," specific to the pediatric population, have been developed and shared with healthcare providers. The wheels are an important tool in the effort to standardize care and to help track the health status of children. A media campaign to educate the public about BMI is under development.

Childhood obesity has reached epidemic proportions locally and nationally. Given the complexity of the issue, the development of creative and innovative approaches is vital. Strategies developed have the potential to be replicated on a larger scale. The utilization of an interdisciplinary case management model, enhanced through implementation of social marketing and care standardization efforts, is a unique approach in addressing issues related to childhood obesity. **NCMedJ**

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Fit Families NC:
A Study Committee on Childhood Obesity

A Project Supported by the NC Health & Wellness Trust Commission

Lt. Governor Beverly E. Perdue

Childhood obesity is a growing problem with a startlingly simple solution: get kids to eat healthier and engage in more physical activity. While all segments of society have roles to play in fighting obesity, state government has a unique responsibility. Thanks in large part to contributions made by a project of the NC Health and Wellness Trust Fund Commission (HWTF), North Carolina has stepped forward to make change happen.

HWTF was created in 2000 by the General Assembly to receive one-quarter of North Carolina's share of the Master Settlement Agreement payments. Its Commissioners were charged with addressing the health needs of vulnerable and underserved populations and with developing a comprehensive, community-based plan to improve the health and wellness of the people of North Carolina.

The HWTF's core plan focuses on grants for state and local programs and multi-media campaigns to address: teen tobacco use, prescription drugs for seniors, medication assistance, health disparities, and obesity.

In 2003, the Commission unanimously voted to establish a study committee on childhood obesity called *Fit Families NC.* HWTF Commissioner Dr. Olson Huff, Senator William Purcell, and Representative Verla Insko agreed to lead this effort.

They were tasked with helping HWTF better understand the causes of childhood obesity and, more importantly, to develop practical recommendations for addressing this growing health concern in North Carolina. Committee members were strategically selected to represent broad diversity, both professionally and geographically.

To accomplish its objectives, the Study Committee took a multi-pronged, balanced approach that considered lessons learned from other states, and created a forum for *all* stakeholders to be heard. The inclusive nature of *Fit Families NC* included representatives from public health, business, education, academia, faith-based organizations and more.

During 2004-2005, the Study Committee held seven public hearings throughout the state that covered pertinent topics. Recommendations were received during the year-long study committee process and organized into two action areas: (1) Legislative Policy Proposals and (2) Proposals for State and Local Agencies, Organizations, Trade Groups etc.

The following policies directly resulted from *Fit Families NC* recommendations:

Revision of the State Board of Education's Healthy Active Children policy

- The State Board of Education voted unanimously to adopt a daily 30-minute physical activity requirement for all students, K-8. The first state in the nation to pass such a policy at the State Board level. This requirement will be implemented in the 2006-2007 school year.

School Nutrition Standards legislation (House Bill 855 – Sponsored by Rep. Verla Insko)

- Establishes a statewide nutrition standard for all school meals, a la cárte items, beverages, and the After School Snack Program in elementary, middle and high schools.
- Decreases foods high in total fat, trans-fat, saturated fat and sugar.
- Increases foods containing fruits, vegetables, and whole grain products.

School Vending Standards legislation (Senate Bill 961 – Sponsored by Sen. Bill Purcell)

- Bans soft drink and snack vending sales in elementary schools altogether.
- Prohibits sale of sugared carbonated beverages in middle schools and restricts soft drink sales in high schools.
- Requires that by 2006-2007 school year, 75% of snacks in middle and high schools have no more than 200 calories per package. The consensus work of *Fit Families NC* to develop this recommendation led the American Beverage Association to adopt a national voluntary policy that honors the provisions of this legislation.

While these policies are far from a solution to childhood obesity in North Carolina, each is an important step in the right direction. HWTF and *Fit Families NC* continue their work to ensure proper implementation of these policies, while remaining steadfast in our goal to make North Carolina's kids the healthiest in our nation.

For more information on the Health and Wellness Trust Fund or Fit Families NC, visit www.HealthWellNC.com.

Lt. Governor Beverly E. Perdue, Chair, NC Health and Wellness Trust Fund Commission. Telephone: 919-733-6137.

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A Periodic Feature to Inform North Carolina Healthcare Professionals
about Current Topics in Health Statistics

From the State Center for Health Statistics, NC Department of Health and Human Services
http://www.schs.state.nc.us/SCHS

Obesity and Overweight in North Carolina: Prevalence, Trends, and Risk Factors

Obesity and overweight are serious and increasing health problems in North Carolina and in the United States. According to the Behavioral Risk Factor Surveillance System (BRFSS) survey data for 2005, 24% of adults in the United States are obese. Although a national and North Carolina health objective for the year 2010 is to reduce the prevalence of obesity among adults to less than 15%, current data indicate that the situation is worsening rather than improving. While the prevalence of overweight among adults in North Carolina remained stable from 2000 to 2005 at 37%, obesity increased from 22% in 2000 to 26% in 2005 (NC BRFSS).[1] This increase in prevalence raises concern because of the implications for the future health of North Carolinians.

People who are obese are at increased risk for heart disease, high blood pressure, diabetes, arthritis-related disabilities, and some cancers. In addition, the prolonged illness and disability associated with many chronic diseases decrease the quality of life for millions of Americans. Much of the chronic disease burden is preventable.

Even more disturbing is the rapid increase in overweight among children and youth. Nationwide, the prevalence of overweight has more than tripled in adolescents from 5% in 1980 to 17% in 2004, and has more than doubled in children ages 6-11 from 7% in 1980 to 19% in 2004.[2] These trends are important to monitor because overweight children and adolescents are more likely than those of normal weight to become overweight or obese as adults,[3] and therefore be more at risk for associated chronic diseases.

Using data from the North Carolina Youth Risk Behavior Survey (YRBS), Table 1 shows consistent increases from 2001 to 2005 in the percentages of middle school and high school students who were overweight and at risk of overweight.

Table 1.
Prevalence of Overweight and At Risk for Overweight Among Middle and High School Students, 2001 and 2005 North Carolina YRBS

	Middle School		High School	
	2001	**2005**	**2001**	**2005**
Overweight	13%	16%	13%	14%
At Risk for Overweight	16%	18%	14%	16%

The Child Health Assessment and Monitoring Program (CHAMP) is a new tool in North Carolina that will help monitor child health status and identify child health problems, including overweight. Implemented in January 2005, this statewide representative survey gathers data from parents or caretakers of children ages 0-17. According to the 2005 baseline data, 12% of children and adolescents ages 0-17 are at risk for overweight and 16% are overweight.

Physical inactivity and poor diet are associated with overweight and obesity, as well as with heart disease, cancer, diabetes, and stroke. North Carolina BRFSS data for 2005 show that 58% of adults failed to meet recommended physical activity standards. Twenty-six percent of adults reported having no leisure time physical activity at all. North Carolina YRBS data indicate that 30% of high school youth spend less than 20 minutes per school day being

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physically active, and that 26% are physically active less than 20 minutes per weekend day. The recommended time is a minimum of 60 minutes per day.

North Carolina 2005 BRFSS data show that 77% of adults consumed less than the recommended five fruits and vegetables per day. Table 2 shows consumption of fruits and vegetables in children and youth as reported in the 2005 North Carolina YRBS and CHAMP surveys. Seventy-three percent of high school students reported that they consumed less than the recommended minimum of three servings of vegetables on a typical day and 47% consumed less than the recommended minimum of two servings of fruit. The CHAMP data, which are reported by parents or caretakers, show similar results for high school age children (ages 14-17). Seventy-four percent of all children ages 0-17 did not consume the recommended three servings of vegetables, while 37% did not consume the recommended level of fruits.

Table 2.
Consumption of Fruits and Vegetables in NC Children and High School Students

	YRBS	CHAMP	
	High School	Ages 14-17	Ages 0-17
< 3 vegetables / day	73%	76%	74%
< 2 fruits / day	47%	51%	37%

The CHAMP survey includes questions about sugar-sweetened beverages and hours of television viewing, two behaviors also associated with overweight. Parents or caretakers reported that 39% of children ages 0-17 drank two or more servings of sweetened beverages such as soda pop, sweet tea, fruit punch, Kool-aid, sports drinks or fruit drinks on a typical day. For adolescents ages 14-17 it was 56%. Fifty-three percent of children ages 0-17 were reported to watch television for two or more hours per day. For adolescents ages 14-17 it was 61%.

Both CDC and the national Institute of Medicine[5,6] have recognized that we cannot "fix" these problems by education alone, expecting individuals to change behaviors by themselves. Individual changes in behavior must be supported by changes in policies and environments in settings where people make everyday decisions. Information about public health efforts to address these issues can be accessed at http://eatsmartmovemorenc.com.

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4 BRFSS data are collected annually through random telephone interviews of adults age 18 and older. YRBS data are collected every two years in schools from middle and high school students via a written survey. Data from these sources are self-reported. CHAMP is a follow-up telephone survey of BRFSS households with children. NC BRFSS data can be accessed at http://www.schs.state.nc.us/SCHS/data/brfss.cfm, YRBS data (including some state-level data) at http://www.cdc.gov/HealthyYouth/yrbs/index.htm, and NC CHAMP data at http://www.schs.state.nc.us/SCHS/champ/index.html
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Contributed by Rosemary Ritzman and Lori Elmore
Chronic Disease and Injury Section, North Carolina Division of Public Health

Readers' Forum

To The Editor:

I would like to commend the contributors, editors, and publishers of the *North Carolina Medical Journal* for their last issue, "Covering the Uninsured." Few subjects are more important to our state's future than the exploding cost of healthcare and the more than 1.3 million uninsured North Carolinians. This problem is clearly not unique to our state, but it is one of many areas in which federal leadership is sorely lacking. As Adam Searing of the North Carolina Justice Center's Health Access Coalition rightly noted, there is little likelihood of major federal action until Washington puts its fiscal house in order.

If we are going to make a serious statewide effort to significantly reduce the number of uninsured North Carolinians, as I believe we should, then the expertise and knowledge of our state's leading healthcare and health policy experts must be leveraged. Doctors, hospitals, political leaders, insurance companies, and employers must join together to achieve the innovation, cooperation, and diligent work that such an initiative will require.

The alarming facts about the health of the uninsured alone should cause moral outrage. In almost every measurable health outcome, they fare worse than the insured. A number of contributors also demonstrated how everyone suffers when so many people are uninsured. School attendance and worker productivity decline, state costs for Medicaid and indigent care grow and divert resources, insurance premiums increase, our healthcare institutions face growing financial strains, and small business is stifled. All of this combines to drag down our state's economic growth.

Dr. Sandra Greene of the Cecil G. Sheps Center for Health Services Research at UNC-Chapel Hill provides a valuable analysis of the rapidly growing healthcare costs that cause insurance premiums to increase. There are many steps we can take to rein these costs in and expand coverage by making it more affordable.

Patients and insurers can help by participating in and creating new initiatives to promote generic drugs, preventive medicine, and increased consumer information and choice. The promotion of healthy lifestyles is one of the best long-term investments our state can make. I have been pleased to work with *Be Active North Carolina* to encourage physical activity and healthy living. As a member of the State Board of Education, I also led the effort to require daily physical activity in our public schools. Healthy habits must begin at a young age because healthy children perform better in the classroom and live longer and more productive lives.

North Carolina Hospital Association President William Pully is right that hospitals need help with reimbursement rates and a higher percentage of insured patients. I am happy to report that recently passed legislation supported by the Hospital Association and my office now allows public hospitals to invest funds via the State Treasurer's office. This will increase returns, decrease investment costs and provide additional financial resources. Hospitals and doctors are also suffering from higher malpractice premiums that lead to defensive medicine and threaten healthcare access, particularly in rural areas. It is imperative that all North Carolinians have the highest quality of healthcare available in their community. We must find solutions that preserve the rights of patients, end the waste of excess procedures, and improve access.

At the state level, our leaders must find new ways to immediately expand access to healthcare. The April 2006 report by the *North Carolina Task Force on Covering the Uninsured* convened by the North Carolina Institute of Medicine offers a number of good policy recommendations. I strongly agree that small businesses need help, as their employees are more likely to be uninsured and the obstacles they face are particularly difficult.

I also want to encourage our experts to consider bigger and bolder ideas for systemic change. While the policies working in other states might not always be feasible here, the inspiration for unique North Carolina solutions might be found anywhere. Massachusetts' new bipartisan legislation that requires all residents to purchase health insurance is a great example. Illinois recently passed legislation that will provide health insurance for every child. And a number of states are examining enhanced benefit accounts that incentivize weight management, smoking cessation and other healthy habits.

We need real leadership and innovation—here in North Carolina—to examine these kinds of big ideas and to take much-needed action on behalf of our families. To this end, I hope all of you will continue the dialogue that has been started on these pages and I thank all of the authors for their informative articles.

Richard Moore
Treasurer
State of North Carolina
Raleigh

To The Editor:

The May/June 2006 issue of the *North Carolina Medical Journal* included a thorough assessment of North Carolina's problems with people uninsured for healthcare. The authors made multiple points as to why the situation is detrimental to our state. The articles were timely and well done.

I would emphasize three basic parameters of our healthcare system that reflect a sad situation that affects all of us:

(a) Healthcare costs have progressively increased and we are spending far more per capita for healthcare than any other nation.
(b) The percentage of our population which is uninsured has risen progressively, now close to 1.5 million people in North Carolina.
(c) By various parameters measured by the World Health Organization, we show poor results, with our ranking 30th to 37th in the world for quality of healthcare.

Our technological advances have been remarkable, but we remain inconsistent with delivery of basic healthcare to our citizens. We need some degree of health insurance for all North Carolinians, but our per capita income is low by comparison with other states, and we have a larger percentage of people with no health insurance. Currently we cannot afford comprehensive healthcare for all persons, but we can take some steps to diminish the problem. Here are steps I think worthy of policy consideration:

(a) An adjustment in taxes that would enable individuals to pay premiums for health insurance with "before-tax" dollars.
(b) Tax credits that would encourage small employers to provide health insurance to their employees and their families.
(c) State government involvement in reinsurance underwriting to aid employers who might be self-funded for their health insurance.
(d) A consolidation of risk for high-risk individuals, such as was recently passed by the NC House of Representatives, but disapproved by the Senate. This measure would be a significant step toward affordability of health insurance by people who are not included in group insurance.

If these changes could occur, the benefits would include:

(1) Lower healthcare insurance premiums resulting from: (a) Less cost shifting in pricing by providers to recoup some of the expenses for care of the uninsured from those with insurance, (b) less utilization of the emergency department which is far more expensive for non-emergencies than care through a personal physician, and (c) less frequent in-patient admissions.
(2) Less days absent from school for children with a primary care physician.
(3) Increased productivity resulting from less time away from work.
(4) Earlier detection and more effective management of chronic problems and risk factors before disabling disease develops.
(5) Less frequent bankruptcies and emotional trauma for families with overwhelming medical bills in the face of no health-insurance.
(6) Less strain on healthcare providers and institutions as they strive to provide safety net care.

All of us in North Carolina, including those with health insurance and those who manage businesses, should push for improvements in our system that would be greatly enhanced if more people had some degree of health insurance coverage resulting in better access to more timely medical care.

Robert H. Bilbro, MD, FACP
Raleigh Medical Group

To The Editor:

Thank you for the interesting and thought provoking issue of the *North Carolina Medical Journal* of May/June 2006, on the topic of "Covering the Uninsured." Given your statistics, it appears more than four million North Carolinians do have some form of health insurance.

While some of the content in the various articles pertains to the mentally ill, the lack of specific attention is a glaring omission of your issue. How many of the four million plus who are covered have no, minimal or discriminatory coverage for mental illness?

All of the patients of a free psychotherapy clinic in Raleigh, where I served as Medical Director, lacked health insurance as well as permanent housing. One of the criteria for admission to the clinic was that applicants have no commercial insurance, Medicare or Medicaid, regardless of whether there was specific mental health coverage. During the 10 year life of the clinic we saw and treated hundreds of patients. Almost as many people with health coverage, but without mental health coverage were turned away. Over the course of treatment a large majority of patients acquired permanent housing and/or some form of health insurance, making them ineligible for our services and so were referred to private medical practitioners.

It is interesting your issue does pay specific attention to the dentally uninsured, also frequently not included by insurers and a major problem.

Evidence is clear that mental illness is a major health problem and a significant factor in many of the 15 conditions to which is attributed half of the increase in healthcare spending, including heart disease, obesity, smoking and problem drinking.

Nicholas E. Stratas, MD, DLFAPA
Raleigh, NC

To The Editor:

The March/April 2006 issue of the Journal included an excellent policy forum series on prostate cancer. One article in particular prompted me to ask a question. PSA and digital rectal examination are the key tests for detecting this disease. It is noted in several places in the forum that PSA may be affected by the patient's age, race and the presence of prostatitis, benign prostatic hypertrophy, and/or prostate cancer. Since there are so many men who could serve as the various reference groups for this test, why could we not have reference ranges specific for age, race and presence or absence of these disease states? This would, it seems, make the interpretation of a result much more definitive for a given patient.

Richard A. Dickey, MD
Hickory, NC

The Issue Brief Author Responds:

The issue of age and race-specific PSA reference ranges is an excellent one. Because PSA is a prostate marker and not a prostate cancer marker, many conditions influence the PSA value and its dynamics in individual patients. Many studies have reviewed the issue of age, race and inflammation and suggested reference ranges are reported in the literature.[1-5] Because these data are derived from large screening populations, no valid values have been agreed upon for absolute age- or race-related cut-offs. Indeed the lowest suspicious value has declined from 4.0 in the early PSA era to as low as 2.5 in the 21st century.[5]

A more accurate method of evaluating patients is, however, the rise in PSA over time or PSA velocity. While the exact PSA velocity values remain controversial, a rise of approximately 0.7 ng/dl per year is a good starting place.[6] The most important issue is regular screening of men over age 40 especially if they have a strong family history or are African American. Regular PSA levels will allow the physician to create a slope of PSA rise, and if that slope is associated with rapid PSA velocity, the physician can pursue a biopsy diagnosis of prostate cancer.

Culley C. Carson, MD
Professor and Chief
Division of Urology
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University of North Carolina at Chapel Hill

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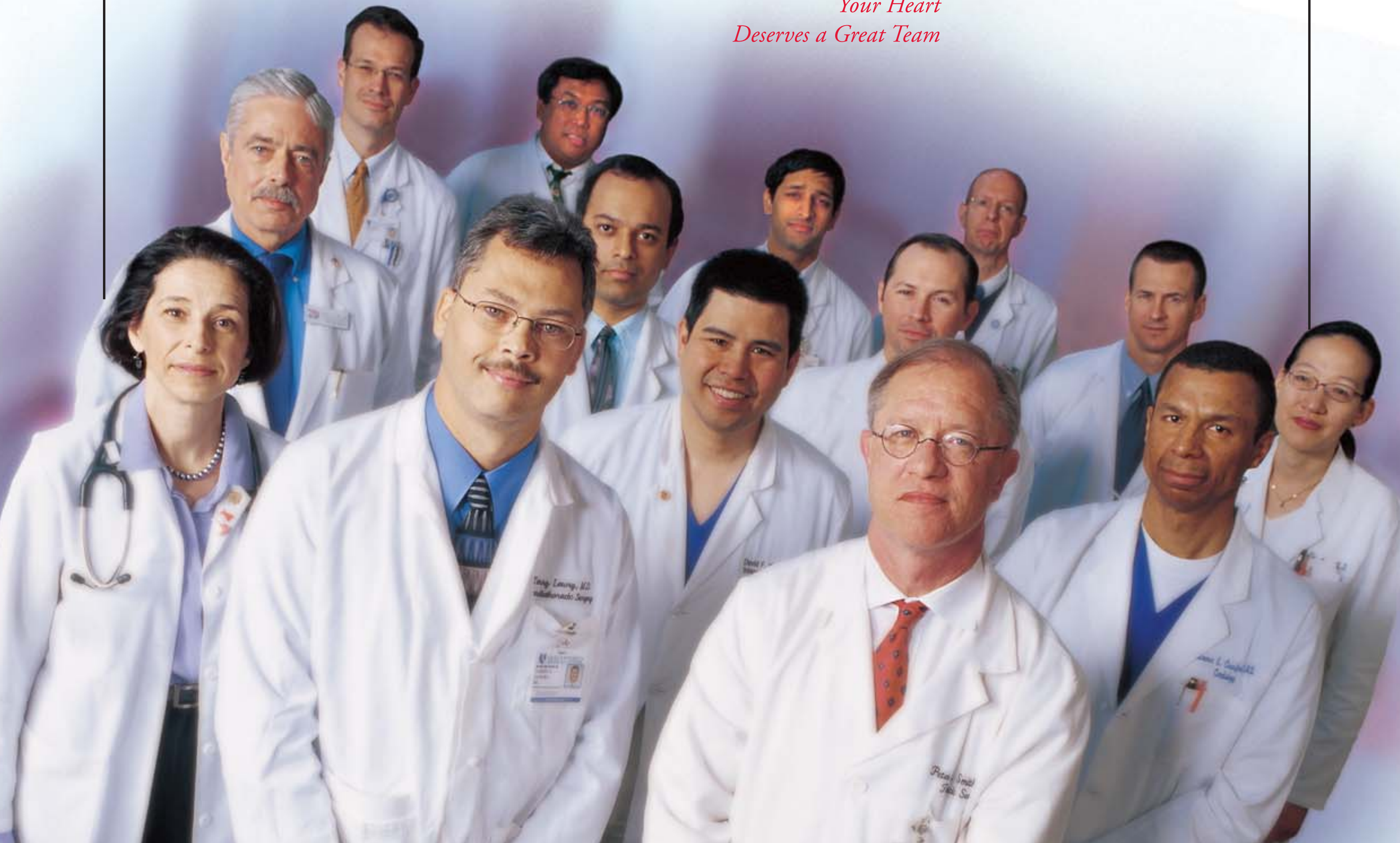

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Sexually Transmitted Disease: The Unspoken Epidemic

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September/October 2006, 67:5

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Tarheel Footprints in Healthcare

Recognizing unusual and often unsung contributions of individual citizens who have made healthcare for North Carolinians more accessible and of higher quality

Recognizing Samuel D. Cranford, Jr.
Asheboro, North Carolina


Samuel D. Cranford, Jr.

North Carolina hospitals, like so many voluntary and non-profit organizations in/outside the healthcare arena, depend for their governance and administrative leadership on the service of community members who give of their time and talents as hospital trustees. Hospitals are, for the communities they serve, important economic engines of community growth and development, and most are major employers in their respective counties. Lay trustees of these institutions bear an enormous responsibility for assuring the long-term stability of these institutions, and they help to shape the vision of hospital senior management regarding how these institutions can grow and continue to meet the increasing need for more, and more advanced, healthcare services and technology in the years ahead.

In this issue of the *North Carolina Medical Journal*, we are pleased to recognize the efforts of one of North Carolina's most outstanding hospital trustees, **Samuel D. Cranford, Jr.**, of Asheboro, who has served for over 30 years as a Director and member of the Executive Committee of Randolph Hospital, Inc., a private not-for-profit hospital in that community.

Sam Cranford is a well-known and highly regarded business executive. He served as President and Treasurer of a family owned ladies hosiery manufacturing company, Asheboro Hosiery Mills, Inc, until the family made the decision in 1998 to close the manufacturing plant in response to a shrinking market for its products. Since that time he has been actively engaged in other textile and clothing manufacturing businesses, as well as in the commercial and residential real estate business in Asheboro and surrounding areas. Sam Cranford has applied his business experience and skills in service to the greater Asheboro area by serving as the President and majority owner of a development company that negotiated Asheboro's first private housing unit for older adults, as well as other development efforts. He has served as Vice Chairman of First American Savings Bank and a director of First Peoples Savings and Loan, eventually helping to lead that organization to becoming the largest savings institution in the state of North Carolina. He was a board member of First National Bank & Trust and a founding board member and member of the executive committee of Bankers Trust of North Carolina (now a part of BB&T Corporation).

Like a number of trustees of North Carolina's community hospitals, Sam Cranford has a long history of volunteerism in his community. He was a founding member and officer of the YMCA of Randolph County; past president of the United Way of Randolph County; past president of United Way of North Carolina; past chairman of the Adolescent Pregnancy Prevention Coalition of North Carolina; and past president of Randolph Fellowship Home, non-profit organization offering emergency shelter and food assistance. He is past president of the Rotary Club of Asheboro and a former District Governor of Rotary International. For all of these voluntary activities, he has received the Distinguished Service Award of Randolph County and selected by the North Carolina Jaycees as one of five Outstanding Young Men of our state.

Because of his long tenure as a hospital trustee, his extensive business experience, and his numerous types of experience in serving the health and human services needs of his community, Sam Cranford was appointed by Governor Easley as a member of the State Health Planning Commission, for which he served as co-chair of the Preventive Health Subcommittee. The North Carolina Institute of Medicine asked him to serve as a member of its Task Force on the North Carolina Nursing Workforce and in this capacity he brought to the Task Force years of experience as a hospital trustee in dealing with these complicated professional and educational issues.

The President of Randolph Hospital, Robert E. Morrison, offered these comments: "Sam Cranford is an exceptionally valuable member of our board of directors. He has the ability to hear and see a number of different perspectives on a single issue, to ask challenging questions that others might not consider. He has served as one of our directors for many years, and he has had statewide health planning and policy experience on many levels. He is also committed to continuing education. Paid directors of large corporations rarely put so much energy into knowing their industries. Sam does it as a volunteer. Through these experiences he has become an expert in many of the most fundamental aspects of healthcare. Sam's attitude always has been to see where we are now, to start there, and see what it would take to get us to the next higher level. He is a champion of improvement. This attitude, plus his congenial manner and intellect have made him a valuable member of the leadership team in Randolph County and North Carolina generally."

For all of these many accomplishments, and for his steadfast and continuing role in his community and statewide in support of community-based healthcare services and facilities, as well as for his vision of *what might be possible* if healthcare systems were to operate with greater effectiveness and efficiency, the *North Carolina Medical Journal* is proud to recognize Samuel D. Cranford, Jr., and all hospital trustees, who have served us so well.

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ARTICLES

POLICY FORUM

Sexually Transmitted Diseases (STDs): Persistent Epidemic, Unspoken Topic, Missed Opportunities

COMMENTARIES

Measuring the Epidemic and Raising Public Concern

Responding to the Epidemic through Public Health and Clinical Medicine

SPECIAL ARTICLE

DEPARTMENTS

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ARTICLE

Key Attributes of Health Ministries in African American Churches:

An Exploratory Survey

Lori Carter-Edwards, PhD, Yhenneko B. Jallah, MS, Moses V. Goldmon, EdD, J.T. Roberson, Jr, PhD, and Cathrine Hoyo, PhD

Abstract

Background: *Church leaders are considered instrumental in the successful implementation of church-based health programs. However, it is unknown which program attributes they perceive as important and which program attributes exist in their congregations.*

Objective: *To explore the perceived importance and existence of health ministry-related attributes in predominately African American churches.*

Methods: *Cross-sectional survey, with a convenience sample of 98 registered church leaders attending a conference on health and spirituality in Raleigh, NC. Attendees were asked to complete a brief survey assessing perceived importance (very important vs. somewhat or not important) and existence (yes vs. no) of 20, health ministry-related attributes in their churches. Percent perceived as very important, percent existence, and their differences were assessed for each attribute.*

Results: *Seventy-two (73.5%) of the attendees completed the survey. Attributes perceived as very important were: displaying health information in churches (73.6%); hosting health fairs for church members (72.2%); pastoral, church-based Internet access (70.8%); willingness to receive foundation funding for activities (66.7%); and incorporating health messages in Sunday bulletins (65.3%). For each of these program attributes, there was a gap between the proportion rating them "very important" and existence of the attribute in their own congregations (range diff in %: -8.3 to -22.2).*

Limitations: *Lack of generalizability due to sample selection and homogeneity.*

Conclusions: *Among leaders surveyed, despite perceived importance, attributes did not exist for all. Future studies should evaluate whether attributes considered important by church leadership parallel an increase in the development and maintenance of health program activities, and are associated with congregation health behaviors and health outcomes.*

Key Words: *health ministry; African Americans; perceptions; churches*

Introduction

There has been an increased interest in African American churches as conduits for health information and program outreach to help prevent or reduce the burden of chronic diseases.[1,2] However, little is known about church attributes or infrastructures used to carry out health outreach and services to church congregations and their surrounding communities. Outreach services are typically conducted through health ministries, defined as special missions that integrate faith and health for their members and the communities they serve.[3] Health ministries are integral to the overall ministry of the church, and are organized to address health needs through activities and information dissemination related to spiritual, emotional, social, and physical health and wellness. They may be of particular importance to community-based health programs since millions frequently go to churches to find help for coping with life.[4]

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Despite the existence of church-based health ministries, little is published about them, including their characteristics, structures, or effectiveness. Even less is known about them in African American churches. Most literature on health ministries and their functions has been in the area of parish nurse programs. The recorded history of a health ministry model through the work of parish nurses dates back to 1836 in Kaiserwerth, Germany.[4] Rev. and Mrs. Fliedner established the "Deaconness" movement where, by 1900, over 25,000 trained nurses representing religious organizations served the ill in communities in Europe, the US, Egypt, Russia, and Hong Kong.[4]

Today, parish nurse programs continue to provide services to churches and local communities. Their success is largely dependent on church leadership. Pastors play key roles in the development and maintenance of parish nurse programs. If pastors are not interested, there is little hope for implementation.[4] However, for pastors who endorse such a program, they provide support by: assisting in the selection of congregation members to serve on a task force; helping the group bring the message to the congregation; helping to select and contact other pastors in the community who might be interested in such a program or collaboration; and providing the project with a strong biblical foundation for whole-person healthcare.[4] Once pastors select the parish nurse program leader, a health cabinet, typically comprised of the pastor, parish nurse, and other lay members, is formed to assist individuals and families in improving and maintaining their own health and that of their community, through worship, education, support networks, recreation, and fundraising.[4,5] Roles, needs, and challenges may differ across churches based on size,[6] location,[7] and program mission.[4]

As with these parish nurse programs, lay leaders and staff are key to the successful implementation of health programs in African American churches.[8] Such programs will exist only if pastors and their church leaders perceive them to be essential, efficacious in reducing disease risk, and consistent with the church mission.[9] However, it is not known whether attributes similar to those identified as essential in traditional parish nurse programs exist in health ministries in African American churches.[10] Furthermore, it is unknown what church leaders perceive to be important attributes for a health ministry, or whether these characteristics exist in their own congregations. This exploratory study describes the perceived importance of church-based health ministry attributes in a sample of leaders of predominantly African American churches, and the extent to which perceptions of importance diverged from reported existence of these attributes in their respective churches.

Methods

Study Sample

The study population was a convenience sample of 98 pastors, other ordained clergy, or lay leaders in predominantly African American churches in NC who were registered attendees of the 2004 Third Annual Health Enhancement through Medicine and Spirituality (HEMS) Conference, held in Raleigh, NC. This assembly was a collaborative effort between the Shaw University Divinity School, the oldest historically black university in the South, and the Old North State Medical Society, based in Durham, NC. The conference theme, "Building an Effective Ministry of Health and Healing," emphasized church accountability for the community's welfare and the need for collaboration between churches, academia, and other institutions to address African American health problems through effective outreach programs. The analysis sample included the 72 attendees (73.5%) who filled out an informed consent and health ministry assessment survey. The study's protocol and informed consent form were approved in 2004 by the Institutional Review Board at The University of North Carolina at Chapel Hill School of Public Health.

Health Ministry Assessment Survey

A health ministry assessment survey was administered to conference attendees and included questions on: respondent demographics (age, gender, marital status, and annual household income); church characteristics (respondent roles, denomination, church size and location); and the perceived *importance* and *existence* of 20 health ministry attributes in the church or congregation represented by the respondent. Since no scale to date has been published that captures parish nurse program or health ministry attributes, the HEMS conference organizers compiled an exploratory list of health ministry attributes based on literature on parish nurse programs,[4-6] church-based studies,[2,9-14] and attributes deemed important based on the conference theme of leadership, outreach, and collaboration (e.g., technological attributes for collaboration and outreach). Attributes were grouped into four areas: *leadership and staffing* (leadership decisions, appointments, personnel roles, responsibilities, and expertise, and working relationships with other church groups that may impact behaviors related to chronic disease [e.g., the kitchen committee's food choices and preparation practices]);[4-6,10-14] *function* (activities that may be conducted by a health ministry, whether part of the church health infrastructure or through outreach);[4-6,9] *technology and funding* (characteristics associated with Internet access for quick acquisition of health ministry-related information as well as information on capital development and fundraising);[4-6,15] and *collaboration* (research partnerships with academic institutions and local community organizations, such as health agencies, outreach programs, and foundations).[1,5]

For each attribute, respondents rated the *level of importance* (very; somewhat; not at all) and current *existence* in their church (yes; no; don't know). It was anticipated that the number of potential respondents would have been no greater than 100, which represented the approximate number of persons who pre-registered for the conference. Thus, for importance, a three-level, rather than a standard five-level, response category was created to minimize potentially small cell sizes in the analysis. Existence measured an individual respondent's perceived existence of the attribute in the church of which he/she was a member. To maximize anonymity of respondents, data were not collected on the name of church; so more than one respondent may represent some churches.

Variable Measurement and Analysis

Sample demographics and levels of importance and existence of health ministry attributes were evaluated. The proportion of attendees for which each attribute was very important (versus somewhat important and not at all important) and corresponding level of existence (percent existence among the entire analysis sample) are reported. McNemar's test of differences in proportions was used to compare differences in percentages of importance and existence of the 20 attributes. Where attributes were rated as very important, Fisher's exact test was used to evaluate individual effects of clergy status (pastor and other clergy vs. non-clergy or laity),[4,5] geographic location (urban vs. rural),[7] and church size (300 members (large) vs. <300 members (medium and small)).[6,17] It was hypothesized that the percent difference in attribute importance and existence would differ for: clergy and non-clergy members of urban compared to rural churches; and for larger versus smaller or medium-sized churches.

Results

Of the 72 respondents, 43 (59.7%) were women (Table 1). Approximately 39% of the sample were clergy (senior pastors or associate ministers). Most were members of large Baptist churches located in urban communities.

Among the 20 attributes (Table 2), the display of health information at the church was the attribute most frequently rated as very important (73.6%). Other attributes ranking high in importance were: hosting health fairs for members (72.2%); pastoral access to the Internet (70.8%); willingness to receive foundation funding for activities (66.7%); and incorporating health messages in Sunday bulletins (65.3%). The pastor leading the health ministry and making all of the decisions was perceived as being the least important (25.0%). A higher proportion reported an attribute as being important than existent in their churches for 18 of the 20 attributes. For the five most frequently rated as very important, the difference in percentage between existence and importance ranged from –8.3% to –22.2%. For all 18 attributes, differences in percentages between existence and importance ranged from –5.5%, where the health ministry is headed by a healthcare professional (p=0.359) to –27.8%, where the health ministry has a system for keeping track of the church members' health status or specific health indicators (p<0.001).

Limited associations of clergy status, church geographic location, and church size on existence of the 20, health ministry attributes were found; therefore full results are not shown. More clergy than non-clergy perceived access to the Internet as very important (p=0.02). More leaders from larger than smaller churches identified hosting community health fairs as very important (p=0.01). Urban compared to rural leaders perceived having a health professional head the health ministry as very important (p<0.001).

Table 1.
Sample Demographics (N=72)

Characteristics	N (%)
Gender	
% Male	21 (29.2)
% Female	43 (59.7)
Missing	8 (11.1)
Church Role	
Senior Pastor	10 (13.9)
Associate Minister/Ordained Clergy	18 (25.0)
Auxiliary/Board Member	10 (13.9)
Other	29 (40.3)
Missing	5 (6.9)
Denomination	
Baptist[a]	28 (38.9)
Other Denomination[b]	25 (34.7)
Non-Denominational	9 (12.5)
Missing	10 (13.9)
Church Membership Size	
Small (<100)	9 (12.5)
Medium (100-299)	17 (23.6)
Large (300+)	33 (45.8)
Missing	13 (18.1)
Church Geographic Location	
Urban	33 (45.8)
Rural	18 (25.0)
Suburban	11 (15.3)
Missing	10 (13.9)

[a] Baptist includes: National Baptist Convention of America, National Baptist Convention USA, Inc., National Missionary Baptist Convention of America, and Progressive National Baptist Convention, Inc.

[b] Other Denomination includes: African Methodist Episcopal, African Methodist Episcopal Zion, Christian Methodist Episcopal, Church of God in Christ, and other denominations.

Discussion

In this exploratory study, display of health information was deemed most important, emphasizing, as in other studies, a continued interest in health information dissemination and education in African American churches.[9,11] The other attributes considered most important by at least 65% of the sample were in the areas of function/technology and funding. Reasons these particular attributes may be considered most important is that they can reach a large number of people at one time and/or open up financial and collaborative opportunities for gathering and using information to help sustain church-based or church-sponsored health programs.[16,17] For attributes considered least important, findings reveal that research may be less of a priority for health ministries than practice (as indicated through functional attributes). In addition, despite the recognized importance of pastoral approval before implementing a health ministry leadership structure,[1,4,5,18] this sample may be comfortable with church members, rather than the pastor, making daily decisions and fulfilling the responsibilities of a health ministry. This may be a necessity for pastors since their multiple commitments to their own families, congregations, and colleagues can make additional time commitments to such activities challenging.[19]

Table 2.
Differences in Existence and Perceived Importance of Health Ministry Attributes (N=72)

Attribute	Attribute Area	% (N) Exist[b]	% (N) Very Important[a]	Difference in %[c]	p-value[d]
1. Church displays health information (pamphlets)	Function	65.3 (47)	73.6 (53)	-8.3	0.359
2. Church hosts health fairs for members	Function	58.3 (42)	72.2 (52)	-13.9	0.064
3. Pastor has access to Internet at church	Technology and Funding	63.9 (46)	70.8 (51)	-6.9	0.109
4. Church is willing to receive foundation funds for its health ministry	Technology and Funding	52.8 (38)	66.7 (48)	-13.9	0.013
5. Health messages/announcements are in Sunday bulletins at least once per month	Function	43.1 (31)	65.3 (47)	-22.2	0.006
6. Church hosts health fairs for the community	Function	38.9 (28)	63.9 (46)	-25.0	<.001
7. Health ministry uses biblical scripture with members	Function	52.8 (38)	62.5 (45)	-9.7	0.442
8. Pastor appoints member to be head of the health ministry	Leadership and Staffing	65.3 (47)	58.3 (42)	7.0	0.664
9. Pastor incorporates health messages in sermons monthly	Function	44.4 (32)	58.3 (42)	-13.9	0.286
10. Church has earmarked funds specifically for health ministry	Technology and Funding	30.6 (22)	58.3 (42)	-27.7	0.002
11. Church is willing to receive government funds for its health ministry[e]	Technology and Funding	45.8 (33)	58.3 (42)	-12.5	—
12. Health ministry works with the kitchen committee	Leadership and Staffing	34.7 (25)	56.9 (41)	-22.2	0.007
13. Health ministry is headed by a healthcare professional	Leadership and Staffing	51.4 (37)	56.9 (41)	-5.5	0.359
14. Church has separate 501c3 for outreach ministries	Technology and Funding	31.9 (23)	56.9 (41)	-25.0	<.001
15. Members have access to Internet at church	Technology and Funding	27.8 (20)	48.6 (35)	-20.8	<.001
16. Health ministry has system for keeping track of members health	Function	19.4 (14)	47.2 (34)	-27.8	<.001
17. Church participates in research with local community organizations	Collaboration	31.9 (23)	47.2 (34)	-15.3	0.011
18. Church participates in research studies with universities	Collaboration	23.6 (17)	41.7 (30)	-18.1	0.013
19. Health ministry occasionally provides members transportation to physicians office or health centers[e]	Function	23.6 (17)	37.5 (27)	-13.9	—
20. Pastor leads ministry and makes all of the decisions	Leadership and Staffing	36.1 (26)	25.0 (18)	11.1	0.122

[a] Percentage is computed as ([number very important/total n of 72 respondents] x 100).
[b] Percentage is computed as ([number exist in the church/total n of 72 respondents] x 100).
[c] Difference in % is an absolute difference computed as (%exist - %very important).
[d] Two–sided exact p-value obtained from McNemar's test of difference in proportions of perceived very important and exists within the church.
[e] No statistics computed due to missing or zero values in cross tabulation table.

For most of the attributes, the proportion of the sample perceiving them as very important was greater than the proportion reporting the attributes existed in their churches. These findings, coupled with their attendance at the HEMS conference, whose theme focused on health ministries, reflect a potential interest to increase these attributes. Additionally, significant differences between perceived importance and existence across all four attribute categories imply that characteristics for effective health ministry service and outreach may be multi-dimensional.[20] Formal assessment of functional activities, technological access, and collaborative partnerships may lead to an increase and improvement in the churches' attributes and help shape and implement effective church-based interventions in the future.

Limitations

There are limitations to this study. The convenience sample of predominantly Baptist conference attendees limits the generalizability of the findings. Another limitation is lack of information on both the church attended and whether an established health ministry existed in their churches. It is possible that more than one respondent attended the same church, hence a clustering (or inter-correlation) in responses. Non-response is another limitation. Some attendees (24%) did not complete the survey, raising the concern that respondents may have different perceptions or prevalence of existence of these health ministry attributes than non-respondents. Additionally, some who filled out the survey did not complete all of the demographic questions, making it difficult to determine whether the results would have been different by clergy status, urbanity, or church size. Despite these limitations, the study's findings are useful for generating hypotheses about key attributes and their implementation in predominantly African American churches.

Conclusions

Churches represent the oldest institution among African Americans.[21,22] Compared to other organizations, they are typically better able to disseminate information within the wider African American community,[1,20,22] and are also associated with an increased likelihood of positive healthcare practices.[23] This exploratory study represents new evidence on health ministry attributes in this sample of church leaders. Further understanding of these and other attributes, including how well they operate and are implemented, and whether they parallel an increase in the development and maintenance of health ministry program activities, will provide valuable information for designing subsequent church-based observational studies and interventions and assessing improvement in congregation behaviors and health outcomes. **NCMedJ**

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POLICY FORUM

Sexually Transmitted Diseases (STDs): Persistent Epidemic, Unspoken Topic, Missed Opportunities

> *"STD and HIV programs remain highly controversial, lack strong public approval, are significantly underfunded, and are frequently fractured at service delivery points."*

INTRODUCTION

Policy Forum:

Sexually Transmitted Diseases (STDs): Persistent Epidemic, Unspoken Topic, Missed Opportunities

One of the characteristic aspects of public health, but one rarely the focus in the lay media coverage of the field, is the persistence of some of the problems to which public health has devoted significant attention over its long history. Sexually transmitted disease is one of these categories of public health issues, as Dr. Steven Cline, Deputy Director of Public Health of the NC Department of Health and Human Services, has pointed out in his Issue Brief, which never seems to "go away." Despite the existence of numerous programs to screen for these conditions, to trace the sexual contacts of those diagnosed, or to educate our population, especially those at highest risk, of the dangers of these diseases and how they may be prevented, the incidence and prevalence of these diseases remain a matter of constant concern across our state and the nation as a whole.

One would have thought that the discovery of acquired immunodeficiency syndrome (AIDS) and the risk associated with the human immunodeficiency virus (HIV) would have cast such a wide alarm that public awareness of the dangers of unprotected sexual encounters would have had the effect of significantly reducing both the incidence and the prevalence of these conditions. As the papers in this issue of the *North Carolina Medical Journal* indicate, sexually transmitted diseases (STDs) remain one of the most difficult and demanding of the public health challenges in our state. Yet, the good news is that when we devote appropriate financial support and public commitment to the effort, change is possible.

Despite the enormity of the epidemic of STDs, the worldwide (though periodic) media attention to the spread of HIV/AIDS, and the impact of the several varieties of sexually transmitted diseases among many different segments of our population, only scant or passing attention seems to be given to these issues in discussions of community public health, in legislative deliberations of funding for essential public health programs, or in the curricula of our public schools where human reproductive and sexual health issues could be addressed.

In this issue of the Journal, we have invited persons who have led the effort of our state and local public health and education agencies in confronting the problems of STDs to describe the problems faced in this area, as well as some of the programs and initiatives they have sponsored to address these problems. It is not always either easy or straightforward to determine the incidence or prevalence of each of the types of STDs reportable in our state, as Lynne Sampson describes in her Running the Numbers section. But, as Drs. Arlene Sena and Marcia Hobbs point out, screening technologies for most STDs have greatly improved in recent years. Dr. Peter Leone describes current science and best practice for the detection and clinical management of acute HIV infection and makes the case for early intervention by healthcare professionals to prevent the spread of this disease. We are fortunate that Dr. P. Frederick Sparling, one of the nation's leading specialists in infectious disease research, has contributed a brief overview of the prospects for vaccines to protect and prevent these diseases in the future.

Given the fact that nearly half of all newly diagnosed STDs (including HIV) in our state occur among adolescents between the ages of 15 and 24, there is an urgent need for additional attention to these issues through our public schools. North Carolina is one of the states where concerted action with regard to STDs appears to be most urgently needed. It is alarming to read, as one can in Dr. Cline's Issue Brief, that of the 28 US counties reporting over 50 percent of the nation's primary and secondary syphilis cases in 1998, five of these counties were in North Carolina! Special attention to the efforts in two of these counties (Guilford and Robeson) among sex workers are described in this issue, but one can see from reading these accounts just how complicated and frustrating these efforts can be.

We hope by bringing more attention to these issues through these pages that we can see in the year ahead a renewed commitment to address the difficult challenge of STDs in our state and our communities where these problems are most evident.

Gordon H. DeFriese, PhD
Editor-in-Chief

Sexually Transmitted Diseases:
Will This Problem Ever Go Away?

J. Steven Cline, DDS, MPH

One of the oldest professions in the world may also be related to one of the oldest public health problems in the world—sexually transmitted diseases. In 2005, more than 18 million new cases of STDs (sexually transmitted diseases) were reported in the United States, with 54,500 cases in North Carolina alone. While these diseases are of epidemic proportion, we actually see surprising little about them in the media and we talk about them even less. A 1997 national Institute of Medicine report stated that "sexually transmitted diseases (STDs) are hidden epidemics of tremendous health and economic consequence in the United States. They are hidden from public view because many Americans are reluctant to address sexual issues in an open way and because of the biological and social factors associated with these diseases."[1] According to this report, in 1995 the United States had the highest rates of curable STDs in the developed world, with approximately 12 million new cases of STDs annually, three million of them occurring among teenagers. Little public outcry has been heard since then and little progress has been made in the last ten years.

> *"Why can't we make this problem go away?"*

Historically, it is easy to accept that STDs were a problem before we even understood the germ theory of how infections are spread. Similarly, in 1918, at the time of the Spanish flu epidemic, infections such as influenza and STDs were common, but not commonly understood. However, now the United States has the most advanced healthcare system in the world, a wide variety of powerful antibiotics, modern infection control practices, and a multitude of tried and true methods individuals can use to prevent STDs. Most sexually transmitted diseases and conditions are entirely preventable and many curable. Obviously, this is not just a problem of healthcare. As a practicing public health professional in North Carolina and a parent to four teenagers who are soon to enter the "at risk" population, I consider this to be unacceptable.

Why can't we make this problem go away?

The Problems Presented by STDs

STDs are transmitted through unprotected sex with someone who has the disease. Since many STDs are asymptomatic, STDs are frequently transmitted by persons who unknowingly are infected. Any person who is sexually active or who becomes sexually active is at risk.

In North Carolina, there are nine sexually transmitted diseases or conditions that are reportable to state and local public health agencies. They include: chlamydia, gonorrhea, syphilis (all stages and types), chancroid, granuloma inguinale, hepatitis B, HIV/AIDS, lymphogranuloma venereum (LGV), and nongonococcal urethritis (NGU). Historically, North Carolina has experienced consistently high rates of syphilis, gonorrhea, chlamydia, and HIV/AIDS when compared to other states.[2] There are also a number of sexually transmitted illnesses such as human papillomavirus (HPV) that are not reportable in North Carolina. The "Running the Numbers" department of this issue of the *North Carolina Medical Journal* includes a discussion authored by Lynne Sampson describing the problems of drawing inferences about the prevalence of STDs from available reportable data.[3]

There are 30 known strains of HPV, some strains causing no symptoms, others causing genital warts, and still others that cause cervical cancer. HPV is a leading cause of cervical cancer in the United States. It is believed to be implicated in an average of 300 cases of cervical cancer reported in North Carolina each year. The Centers for Disease Control and Prevention (CDC) estimates that over 50 % of sexually active adults will acquire HPV at some point in their lives.[4] Genital herpes is also common, but not reportable. An estimated 45 million cases of genital herpes, primarily caused by type 2 herpes simplex virus (HSV-2), occur each year in the United States,[5] but few states require reporting of these cases. Other STDs not reportable in North Carolina include trichomoniasis and bacterial vaginosis.

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Table 1.
North Carolina Reportable Sexually Transmitted Diseases, 2005

	Sex			
	Male	Female	Unknown	Total
Chlamydia (lab-confirmed)	5,481	25,702	0	31,183
Gonorrhea	7,529	7,546	0	15,075
Syphilis				
Primary Syphilis	81	15	0	96
Secondary Syphilis	135	43	0	178
Early Latent Syphilis	127	88	0	215
Late Syphilis	80	71	0	151
Late Latent Syphilis	34	25	0	59
Late Syphilis w/symptoms	0	0	0	0
Neurosyphilis	0	2	0	2
Congenital Syphilis	5	5	1	11
Syndromic Diagnoses				
Nongonococcal Urethritis (NGU)	5,318	n/a	0	5,318
Mucopurulent Cervicitis (MPC)	n/a	24	0	24
Pelvic Inflammatory Disease (PID)	n/a	382	0	382
Other STDs				
Chancroid	5	0	0	5
Granuloma Inguinale	1	3	0	4
Lymphogranuloma Venereum (LGV)	3	0	0	3
Opthalmia Neonatorum (gonorrhea)	0	0	0	0

Undiagnosed and/or untreated STDs contribute to the higher than average rates of infant mortality and preterm births in North Carolina and are a leading cause of infertility across the country. Other common, yet serious, medical implications of STDs include such things as syphilitic meningitis, neurosyphilis, chronic hepatitis, cirrhosis, liver cancer, endometritis, and even death. Despite advances in healthcare, HIV infection remains a fatal disease. We're not just talking about a curable STD rash, but serious infections with serious potential consequences for individual and community health.

According to data collected by the HIV/STD Prevention and Care Branch of the Division of Public Health, over 54,500 new STDs were reported in North Carolina in 2005. These included 11 cases of congenital syphilis and 1,806 new cases of HIV disease. Specific disease trends vary by disease and from year-to-year. Some STDs, such as gonorrhea, have actually declined over the last ten years while the number of reported chlamydia cases has increased among 20 to 29 year olds. It is important to note that screening for chlamydia has increased in publicly-funded clinics over the past several years, and in May of 2004 the State Laboratory of Public Health began using a more sensitive screening test. This likely accounts for the increase in detected cases. Hepatitis A, B and C, often not appreciated as STDs, accounted for an additional 1,100 STD case reports in 2005. STD screening and reporting varies from provider-to-provider, therefore performing a statewide STD trend analysis can be challenging.

The high rates of STDs affecting North Carolina are typical across the predominantly rural South. For the past decade, southern states consistently led the nation in reported cases of syphilis, chlamydia, gonorrhea, and new AIDS cases.[6] In 2002, the CDC reported that seven of the states with the highest AIDS case rates in the nation were located in the South. Similarly, in 2000, all of the states with the highest rates of gonorrhea and nine of the top ten states with regard to infectious syphilis were in the South.[7] These trends are still true today. The direct and indirect human and economic costs associated with these diseases in the rural South have been well documented by state and national organizations, public health experts, and healthcare researchers. Higher rates in the South are influenced by differences in the racial and ethnic distribution of the population. These differences are linked to higher rates of poverty and the availability and quality of healthcare services.[7] STDs, including HIV/AIDS, disproportionately and unacceptably affect persons of color, particularly across the South. Poverty, access to quality healthcare (including prevention services and education), cultural factors such as the lack of trust for the healthcare system, and social stigma are all strongly linked to high rates of STDs and HIV/AIDS among persons of color.

CHALLENGES: Why Is This So Difficult?

Missed Opportunities

There are two myths that are prevalent in North Carolina. The first is the belief that STDs, including HIV, only happen to people who do bad things or make bad choices. The second is that only the people who have these conditions are directly affected by them. These beliefs, whether openly expressed or quietly implied, keep individuals from seeking rapid treatment for themselves and their sexual partners. The fear of being stigmatized, and the lack of awareness about the true risks of acquiring an STD, keep the epidemic alive in our communities.

The false assumptions about who is at risk for HIV/STD infections affect screening and counseling practices of public and private healthcare providers. While STD and HIV screening and counseling are a regular part of the standard of care in local public health departments and community health centers, it is normally not a part of routine screening in many private practices.

For example, one North Carolina study found that among primary care providers in Wake County in 1997 less than 25% offered routine screening for chlamydia, despite the fact that this disease is the most frequently reported bacterial STD and one that is easily treated.[7] Preventing and treating STDs is also critical because of the strong evidence that a person with a STD is more likely to acquire HIV infection, and if an individual is co-infected, they are more likely to transmit their HIV infection to others.[8] Early diagnosis and treatment of STDs is a critical public health strategy to reduce the spread of new HIV/AIDS in both the public and private healthcare sectors. CDC just released new guidelines to strongly encourage that HIV screening become a regular and routine part of all healthcare settings in this country.

Access to Care and Cultural Competency

Access to care and the ability to provide culturally-appropriate health services are inextricably tied together. Traditional barriers to care, such as being un- or under-insured, lack of transportation, lack of providers in many rural areas, and inconvenient hours of operation are common for most health services, and certainly impact STD care as well. But, even if patients are able to seek care in their communities, the issues of stigmatization, confidentiality, and cultural differences make STD care particularly challenging for providers and patients.

Adolescent Sexual Health

Nearly half of all the new sexually transmitted diseases and HIV infections occur in youth between the ages of 15 and 24. Adolescents are at increased risk because of their risk-taking behaviors and lack of awareness about HIV/STDs. In 2005, North Carolina high school students participated in the 2005 Youth Risk Behavior Survey (YRBS) that assessed the behaviors that put them at risk for various health problems. These behaviors included diet, exercise, tobacco use, and sexual behavior.[9] The results revealed that 50.8 % of all high school students and 63% of high school seniors self-reported that they had experienced sexual intercourse. Eight percent of students reported having sex before the age of 13. In four of the five risk-taking categories examined, the percentage of North Carolina adolescents engaging in risky sexual behaviors was greater than the national average.[9]

The debate about how North Carolina should address these alarming statistics is strongly mixed. While most people believe that parents/guardians and schools should play a strong role in educating our young people about HIV/STD and teen pregnancy prevention, there is conflict about what the prevention messages should be, how often they should be taught, and at what ages. The role of public education in meeting the challenges of the STD epidemic is the focus of the commentary in this issue of the *North Carolina Medical Journal* by Sherry Lehman.[b]

The North Carolina General Assembly enacted the Abstinence Until Marriage Law in 1995 which instructs the State Board of Education about what to include in the health curriculum taught in North Carolina public schools. The Healthful Living Standard Course of Study sets the goals and objectives by grade for human sexuality education for North Carolina in accordance with the Abstinence Until Marriage Law. This law promotes "abstinence only" education in grades 7 through 12. Many people are concerned that sexually active adolescents are not being provided with all the information they need to reduce their risks of getting a STD or HIV infection. Still others argue that the only message North Carolina teens should get in school is that abstinence is the only absolute way to prevent getting these diseases. They believe that talking about other risk reduction methods (i.e., condom use) is not appropriate. This is a critical conversation for North Carolina. We need to seriously examine this question in light of the fact that many adolescents are having unprotected, high-risk sex and experiencing high rates of STDs, including HIV, not to mention unplanned adolescent pregnancies. In early 2002, North Carolina uncovered a previously unrecognized HIV outbreak among young adults attending college or linked to students attending college. This outbreak received national attention and it supports the notion that North Carolina's young adults are not hearing (or paying attention to) our HIV/STD prevention messages.

Racial and Ethnic Disparities

Syphilis—Syphilis disproportionately affects minority communities in North Carolina. Rates for African Americans, American Indians/Alaska natives, and Hispanics are many times higher than for corresponding white groups. A complex combination of healthcare access, poverty, racism, and the composition of sexual networks produces this disparity in syphilis rates. In 2005 rates among African American males were four times higher than among whites. Hispanic rates were two times higher than for whites. Racial disparities in male syphilis rates have improved slightly over the past five years due in part to decreasing syphilis rates in minorities generally, and increasing rates among white men. Syphilis rates among all women regardless of color have declined dramatically over the past five years from 10.5 cases/100,000 in 2001 to 3.4 cases/100,000 in 1005. There has been a modest improvement in the disparity between white and black female rates as well. In 2005, the early syphilis rate for African American women was approximately 10.5 times the rate for white women. By 2005, African American female rates had declined to approximately 8.5 times the rate for white females.[2]

Unfortunately, North Carolina continues to suffer from cases of congenital syphilis. In both 2004 and 2005, eleven infants were born to mothers who had active or inadequately treated cases of syphilis, the majority of whom were African American. This is down from previous years (21 infants in 2003, 15 in 2002, and 19 in 2001), but remains unacceptably high. Six of the eleven women in 2004 did not have any prenatal care (PNC) prior to delivery and an additional three had less than five total PNC visits. Women who do not receive adequate PNC services often miss opportunities for screening. According to the North Carolina Pregnancy Risk Assessment Monitoring System (PRAMS) survey for 2003, 18.4% of North Carolina mothers reported a barrier to receiving prenatal care services.[11] Younger mothers and those of African American or Hispanic race/ethnicity were most likely to report barriers to prenatal care.

Gonorrhea—There is some good news in that severe racial disparities in gonorrhea incidence rates are on the decline among males. In 2001, rates among African American males were 32 times the rates for white males. The disparity decreased to 22 times higher in 2005. Disparities among females have remained relatively steady, with African American female gonorrhea rates 10 to 14 times higher than rates for white females over the five-year period.

Chlamydia—Racial disparities in female chlamydia reports have remained stable over the past five years (2001-2005), with seven-to-eight times more cases reported among African American females and three-to-five times more cases among American Indian/Alaska Native and Hispanic females.

HIV/AIDS—An estimated 29,500 persons were living with HIV or AIDS in North Carolina (including persons who may be unaware of their infection) as of December 31, 2005. In 2005, the rate of HIV infection for non-Hispanic blacks (61.4 per 100,000) was more than seven times greater than for non-Hispanic whites (8.6 per 100,000). The rate of infection for Hispanics (24.1 per 100,000) was almost three times greater than for whites, and the rate of infection for American Indians (20.6 per 100,000) was over twice the rate for whites. The highest rate of HIV infection in 2005 was among African American non-Hispanic males, at 88.6 per 100,000. This was more than six times more than white non-Hispanic males (14.4/100,000). The greatest disparity observed in 2005 was for African American non-Hispanic females, with a rate of HIV infection (37.3 per 100,000) that was over 12 times higher than for white non-Hispanic females (3.0 per 100,000).

NOTEWORTHY SUCCESSES: What is Working?

Despite the challenges, North Carolina has made progress on several important fronts. The following section describes several efforts that are showing positive results in reducing the rates of these diseases.

STD Services in Local Health Departments

In North Carolina, all 100 local health departments offer free and confidential STD and HIV/AIDS services. Many community, academic, and faith-based organizations also offer STD and HIV/AIDS screening and counseling. Faith-based organizations have been very successful in some communities in linking persons into care and prevention services, or in offering some HIV/STD screening. North Carolina academic and research partners have continued to play enormous roles in developing best practice models and keeping STD and HIV/AIDS on the radar screen nationally. North Carolina was the first state to implement an acute HIV screening program, which allows for the detection of HIV in individuals even before they have had a chance to mount an antibody response.[12] Peter Leone describes these efforts in a commentary in this issue of the *North Carolina Medical Journal.*[13] Successful North Carolina interventions are the subject of a subsequent article by Evelyn Foust in this issue of the *North Carolina Medical Journal.*[14]

Syphilis Elimination

In 1998 CDC reported that over 50% of all the United States primary and secondary syphilis cases were reported from just 28 counties. Five of those counties were in North Carolina, a number greater than for any other state. The counties were Forsyth, Guilford, Mecklenburg, Robeson, and Wake. Many of these cases occur among sex workers in these communities. To assist in addressing the evident need, CDC awarded the North Carolina Division of Public Health additional funding to participate in the National Plan to Eliminate Syphilis.[15] Due to the efforts of NC's local county health departments, community-based organizations, and state disease intervention staff, early syphilis now has been reduced by 69%. North Carolina has been able to demonstrate that community-based interventions, combined with traditional approaches, are effective in reducing STDs.

Commentaries by Merle Green and Jonathan Lucas of Guilford County and by Melissa Packer, April Oxedine, and Karen Woodell of Robeson County in this issue of the *North Carolina Medical Journal* describe the extensive, community-based efforts required to address the epidemic of syphilis among NC sex workers.[16,17]

Vaccines Against STDs

In May of 2001, the Food and Drug Administration (FDA) licensed a combined hepatitis A and B vaccine (Twinrix®) for use in persons over the age of 18. Currently, the vaccine is available at almost all (96%) of the local health department STD clinics across the state. The vaccine is administered as a three-dose series. This project was started in 2003 by HIV/STD Prevention and Care Branch staff in collaboration with the State Immunization Branch. Healthcare providers were educated about the importance of this new combination vaccine and strongly encouraged to offer the vaccine to everyone over 18 years of age who is seen for an STD visit. Targeted risk factors include HIV positive status, Hepatitis C virus positive status, injecting drug use, men who have sex with other men, anyone having a male sex partner, and incarceration. Based on utilization from January through June of this year, it is estimated that approximately 5,600 persons will be vaccinated. Frederick Sparling, a distinguished infectious disease scientist from the University of North Carolina at Chapel Hill, addresses the prospect for vaccines to prevent STDs in this issue of the *North Carolina Medical Journal.*[18]

In June of 2006, the first vaccine for human papillomavirus (HPV) was recommended by the Advisory Committee on Immunization Practices for use in the prevention of cervical cancer caused by four of the HPV types. The HPV types included in the vaccine (Gardasil®) are responsible for approximately 70% of the cervical cancers and 90% of genital warts. Currently the vaccine is recommended for 11-to12 year-old girls, but it can be used in girls as young as 9 years old and up to age 26 at the provider's discretion. It is recommended for girls/women who have not been immunized against HPV. Ideally, immunization would be provided before sexual activity begins, since it will be ineffective if the individual has already been exposed to an HPV type covered by the vaccine. The vaccine is not effective as a treatment for existing HPV, genital warts, cervical cancers or precancers.

The Center for HIV-AIDS Vaccine Immunology (CHAVI) is a major component to the Global HIV Vaccine Enterprise. In July 2005, the National Institute of Allergy and Infectious Diseases (NIAID) awarded the CHAVI grant to a consortium of investigators from Duke University, Beth Israel Deaconess Medical Center, the Dana-Farber Cancer Institute, the University of Alabama-Birmingham, and Oxford University. Dr. Barton Haynes at Duke University is the CHAVI principal investigator and the consortium consists of a group of investigators who are well known as having made significant scientific contributions to HIV vaccine design and to the current basis of knowledge of HIV transmission and infection. The initial research focus will be on understanding the host immune response in the acute stages of infection. Other lead investigators in North Carolina include David Goldstein of Duke University and Myron Cohen of the University of North Carolina at Chapel Hill.

Screening Pregnant Women for HIV

Since 1994, there has been a requirement that pregnant women be offered testing for HIV as a part of regular prenatal care. The North Carolina Administrative Code was modified in 2003 so that all pregnant women would be tested unless they specifically declined such testing. This "opt out" approach to prenatal testing is very effective at promoting testing for women who have prenatal care; however, it does not improve testing for women who do not receive routine prenatal care. The benefit of prenatal testing, especially when combined with the program for acute HIV screening, is undeniable. In the North Carolina State Laboratory of Public Health (SLPH), in addition to the typical HIV antibody testing, patient lab samples are screened for the presence of genetic material (RNA) that would indicate possible HIV infection prior to the development of antibodies. This is innovative new testing technology that is discussed in greater detail in a subsequent article by Arlene Sena and Marcia Hobbs in this issue of the *North Carolina Medical Journal*.[19] Since the implementation of the acute HIV screening program through the SLPH, five pregnant women have been identified with acute HIV infection. These women were tested as the rule requires, and under the previous testing algorithm would have been told they were negative. They would likely have progressed through pregnancy and delivered HIV-exposed infants. Given the likely 25-30% vertical transmission for mothers who are not provided prenatal antiretroviral therapy, it is probable that at least one of the babies would have been infected. However, since the woman's HIV infection was determined and all were provided appropriate prenatal antiretroviral medication, all five babies have been determined not to be infected.

Jail Screening

As part of the Syphilis Elimination Project (SEP), syphilis screening was initiated in the seven county jails in the six SEP counties (Durham, Forsyth, Guilford, Mecklenburg, Robeson, and Wake). Inmates are given counseling on syphilis and other STDs and blood is collected for screening by a nurse or trained phlebotomist. Data collection began in 2002 and analysis shows that the screening is highly effective in identifying new cases. From 2002 to 2004 the program screened 20,552 inmates (17.5% female). There were 742 seropositives, which yielded 121 new cases of syphilis. Screening female inmates seems to be of particular value because they are more likely to be seropositive (8.11% compared to 2.65% for males) and more likely to be new cases (0.97% compared to 0.51% for males). The effort to address the STD epidemic among incarcerated populations is described by Lynne A. Sampson in this issue of the *North Carolina Medical Journal*.[20]

Conclusions

Despite the undisputed impact of STDs, and how much we have learned about how to treat and prevent them, North Carolina public health authorities still struggle to ensure that STD/HIV prevention and control strategies remain high priorities in both private and public healthcare clinics. Most sexually transmitted diseases and conditions are preventable and many curable. However, the establishment of routine screening, and successful prevention and education programs are challenged by lack of resources and public awareness.

Sexually transmitted diseases are a serious problem in North Carolina that won't go away. This is the case of a traditional public health problem that the traditional way of thinking will not solve. Societal attitudes, false beliefs, fears, and our inability to talk honestly and openly about sexual behaviors are getting in the way. STDs are not reserved for a small subset of our society. STDs are equal opportunity infections. The bottom line is that infection with either HIV or another STD is a risk for any sexually active individual. Early education and risk reduction counseling for all sexually active individuals is a must, regardless of age. Routine screening and counseling for these diseases should be the standard of care for all patients in all healthcare settings.

STD and HIV/AIDS programs at the state and local levels remain highly controversial, lack strong public approval, are significantly underfunded, and are frequently fractured at service delivery points. With a father who is a public health professional, my own children have heard this sad story all too often. The risks they face are real and the consequences of ignoring them can be fatal. We can, and we MUST, do better. **NCMedJ**

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Current and Best Practices for Testing of Sexually Transmitted Diseases

Arlene C. Sena, MD, MPH, and Marcia Hobbs, PhD

Effective diagnosis and treatment of infected persons is a critical component of sexually transmitted diseases (STDs) prevention and control. STD diagnostic methods that are sensitive, rapid and inexpensive are ideal for testing of individuals presenting with genitourinary symptoms and screening of asymptomatic individuals in high risk populations. Fortunately, recent advances in STD diagnostics have provided nucleic acid amplification tests (NAATs) with increased sensitivity compared to older tests and rapid "point-of-care" (POC) tests, with quick turn-around time for results. However, despite their ability to improve best practices for STD management, NAATs and POC tests have not been widely adopted into public and privately funded practices. This may in part be due to barriers ranging from the cost and complexity of some of these methods to unfamiliarity with application of these new technologies for the testing and screening of at-risk patients.

> *"A recent national survey of physicians, in which the majority practice in private clinics, reported that fewer than one-third routinely screened men or women (pregnant or non-pregnant) for STDs."*

Although federal resources for the control and prevention of STDs are primarily distributed to state and local health departments, the National Health and Social Life Survey reported that STDs are frequently treated in private practice settings.[1] Therefore, consideration of the ideal STD testing methods to use in the apparently low prevalence populations evaluated in private clinics is as crucial as application of these technologies in high prevalence populations presenting to STD clinics and emergency rooms.

New STD Diagnostic Methods

Currently available NAATs for Neisseria gonorrhoeae and Chlamydia trachomatis are based on new technologies, including polymerase chain reaction (PCR), DNA strand displacement assays (SDA), or transcription-mediated amplification (TMA) using vaginal, cervical, urethral or first-void urine specimens (Table 1).[2] Self-collected vaginal swabs may also be used in settings where physical examinations are limited for women.[3] Diagnosis of gonorrhea and chlamydia was previously reliant on cultures, enzyme immune assays (EIA), and non-amplification DNA probe assays to detect these organisms. The use of NAATs is now considered the "gold standard" for C. trachomatis; however, despite the availability of NAATs for gonorrhea, culture remains in widespread use since it allows assessment of antimicrobial susceptibility which is currently unavailable with amplification tests. Combination NAATs are available for N. gonorrhoeae and C. trachomatis using a single patient specimen,[4] which is advantageous among high-risk populations in light of the frequency of co-infections with these pathogens. However, NAATs are not approved for detection of gonorrhea or chlamydia in rectal or pharyngeal specimens.

NAATs also hold promise in the future for diagnosis of other STDs. PCR and TMA for Trichomonas vaginalis are more sensitive than culture for diagnosis of trichomoniasis in

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Table 1.
Common STD Syndromes, Most Likely STD Etiologies and Performance Estimates of Selected Available Diagnostic Technologies [2,4,7,10-13]

STD Syndrome	Most Likely STD Etiologies	Available Diagnostic Technologies	Estimated Sensitivity (%): Specific (%)*
Vaginitis/ cervicitis	Trichomonas vaginalis	Wet mount microscopy	30-60; 100
		Culture	80-90; 100
		Rapid antigen test	78-83; 98-99
	Chlamydia trachomatis	Enzyme immunoassay	53-76; 95
		Direct fluorescent antibody	80-85; >99
		Probe hybridization	65-83; 99
		Polymerase chain reaction (cervical)	90; 99
		Strand displacement assay (cervical)	93; 98
		Transcription-mediated amplification (cervical)	94; 98
	Neisseria gonorrhoeae	Culture (Thayer-Martin)	80-95; 100
		Probe hybridization	93-96; 99
		Polymerase chain reaction (cervical) (urine)	92; 100 65; 100
		Strand displacement assay (cervical) (urine)	97; 98 -100 85; 99-100
		Transcription-mediated amplification (cervical) (urine)	99; 99 91; 99
Urethritis (males)	Chlamydia trachomatis	Enzyme immunoassay Direct fluorescent antibody Probe hybridization	As above
		Polymerase chain reaction (urethral) (urine)	96; 99 90; 98
		Strand displacement assay (urethral) (urine)	95; 94 93; 94
		Transcription-mediated amplification (urethal) (urine)	95; 98 97; 99
	Neisseria gonorrhoeae	Culture Probe hybridization	As above
		Polymerase chain reaction (urethral) (urine)	97; 97 94; 100
		Strand displacement assay (urethral) (urine)	99; 92-100 98; 93-100
		Transcription-mediated amplification (urethral) (urine)	99; 98 97; 100
	Trichomonas vaginalis	Culture	50; 100
Genital ulcers	Herpes simplex virus	Culture	73-100; 100
		Type-specific ELISA serology	81-100; 96-99
		Rapid antibody test (HSV-2)	93-96; 95-98
		Polymerase chain reaction	98-100; 98-100
	Treponema pallidum	Non-treponemal tests	78-86; 98
		Treponemal tests	87-100;
		Rapid antigen tests	70-88; 100
		Enzyme immune assay	71; 98

* Ranges for test performance of the diagnostic technologies reflect broad differences in reference standards and patient populations.

both men and women, but these molecular tests are available only in clinical research settings.[5] PCR and TMA assays have been developed for Mycoplasma genitalium, which has been recently established as a case of non-gonococcal urethritis (NGU) in men, but the future clinical application of these tests is uncertain.[6] For the evaluation of genital ulcer disease, a PCR for herpes simplex virus (HSV) has enhanced performance over viral isolation with culture, but is not yet approved by the Food and Drug Admininistration (FDA) for testing of genital specimens.[7] A multiplex PCR test for HSV, Treponema pallidum (syphilis), and Haemophilus ducreyi (chancroid) has been developed and continues to be investigated for clinical application.[8]

For human papilloma virus (HPV), there is a commercially available signal-amplified nucleic acid assay and PCR to detect high-risk HPV types associated with cervical cancer.[9] These HPV DNA tests are currently being considered for cervical cancer prevention (along with the Pap smear) including primary screening for high-grade lesions among women >30 years of age. They are not intended to assist in the diagnosis of external genital warts which are primarily associated with benign HPV types.

There are several STD rapid tests which have the advantage of immediate diagnosis in clinics serving both high- and low-prevalence populations. For T. vaginalis, a POC test that uses an immunochromatographic capillary flow (dipstick) assay to detect parasite antigens in vaginal specimens can provide results in 10 minutes.[10] Compared to culture, this rapid test for trichomoniasis has a sensitivity and specificity which is superior to wet mount microscopy (Table 1), but is only approved for use in women. Rapid syphilis tests have also been introduced using an immunochromatographic strip with finger-stick or whole blood to detect antibodies to T. pallidum antigens.[11] However, these tests would be reactive in all patients with prior syphilis, which limits their potential use for testing or screening in low prevalence clinic populations.

There are several new serologic tests for diagnosis of syphilis and HSV that are worth noting. Recently, an immunoglobulin G (IgG) EIA has become available as a diagnostic test for syphilis.[12] This test, which detects treponema-specific antibodies, has the potential to be automated and produces an objective result without requiring confirmation (unlike the reactive plasma reagin [RPR] or other non-treponemal tests). Clinicians now have a choice of several type-specific HSV antibody tests based on the glycoprotein G antigens of HSV-1 and HSV-2.[13] These serologic tests in an enzyme-linked immunosorbent assay (ELISA) format can be used to supplement culture and physical examinations to confirm a clinical diagnosis, to diagnose a person with unrecognized infection, and to manage sexual partners of persons with genital herpes. In addition, rapid POC tests for HSV-2 antibodies (not HSV-1) using capillary blood or serum are also available and can provide results within six minutes.

Current Practices for STD Testing

Unfortunately, publicly-funded STD clinics in North Carolina that evaluate large numbers of patients with suspected STDs have limited access to these advanced technologies for routine STD testing and screening. Currently, evaluation of vaginitis still relies on insensitive wet mount microscopy for diagnosis of candidiasis, bacterial vaginosis, and trichomoniasis. While a urethral Gram stain is typically performed in the evaluation of NGU, pathogens other than C. trachomatis, including T. vaginalis and M. genitalium, are not usually tested for in men. Testing for gonorrhea and chlamydia still rely on culture or DNA hybridization probes in many public clinics. Targeted screening for chlamydia is frequently performed based on age or gender due to limited funds. Initial testing for syphilis consists of the non-treponemal tests, which require confirmation at the state laboratory (which recently switched to the IgG EIA for T. pallidum for confirmatory testing). Some local public health department laboratories have the capability to perform stat RPRs with available results in 15 minutes and darkfield microscopy for direct visualization of treponemes. Diagnosis of HSV or HPV is often based on clinical presentations, since HSV viral cultures that can be sent to the state laboratory are usually reserved for atypical lesions.

Emergency rooms and private clinics may be better able to use newer technologies for detecting bacterial STDs, including gonorrhea, chlamydia, and syphilis. However, a national survey of physicians conducted in 2002 found that only 1.3% and 1.8% of clinicians used newer urine-based tests for gonorrhea and chlamydia, respectively, although these tests are less invasive and more acceptable to patients.[14] In general, there is little to no information in the literature on the use of newer diagnostic methods for the other bacterial and viral STDs in these clinical settings.

Although some emergency rooms that serve a large number of high-risk patients in urban areas have been reported to have a high prevalence of STDs like gonorrhea ranging from 1.7-11.0%,[15] screening rates in these settings are typically lower than in other settings. A recent national survey of physicians, in which the majority practice in private clinics, reported that fewer than one-third routinely screened men or women (pregnant or non-pregnant) for STDs.[14] The survey found that screening rates among non-pregnant women ranged from 20-35% and were slightly higher for pregnant women at 30-32%. Physicians in the survey who saw male patients rarely screened for syphilis, gonorrhea or chlamydia.

Opportunities for Best Practices

With the increasing availability of improved technologies for STD diagnosis, including highly sensitive and rapid tests, we now have the opportunity to improve current practices for STD testing and screening in various clinical practices as well as non-traditional settings. However, the costs and complexities of the NAATs for gonorrhea and chlamydia are barriers to their widespread application, especially in STD clinics with limited funding or small private practices without access to advanced laboratories. Although they are less sensitive than NAATs, POC tests may be more affordable and easier to implement. Positive results from these tests eliminate the need for a return visit and increase treatment rates; therefore, POC tests should be strongly considered, especially in the diagnosis of T. vaginalis and HSV-2 infections which are the most common STDs.

Public STD clinics clearly need access to sensitive molecular diagnostic tests for gonorrhea and chlamydia among all high-risk patients, including men. However, N. gonorrhoeae cultures would still be useful in cases of persistent infections in order to test for antimicrobial resistance. T. vaginalis testing should become routine in both men and women using culture or rapid antigen tests; wet mount microscopy alone is clearly suboptimal for organism detection. Use of the HSV type-specific serology and the POC test for HSV-2 could greatly enhance the diagnosis and management of patients with atypical lesions as well as their sexual partners. The availability of the multiplex PCR test for detection of T. pallidum, HSV, and H. ducreyi would assist in the differential diagnosis of genital ulcers which are frequently seen in these clinics.

STD management in emergency rooms and private clinics could be optimized with the use of urine-based NAATs for N. gonorrhoeae and C. trachomatis and POC tests for T. vaginalis and T. pallidum for testing of symptomatic persons. Utilization of POC tests that can be performed in less than 30 minutes in the emergency room or a doctor's office would allow rapid diagnosis and treatment without a need for subsequent follow-up appointments.

Emergency rooms and private practices present an opportunity for targeted STD screening among asymptomatic at-risk patients, who can be easily determined by adding a brief sexual history as part of their clinic encounters. Adolescents, substance abusers, and persons who report multiple sexual partners should be strongly considered for screening, at least for the bacterial STDs using non-invasive molecular assays or POC tests. The positive predictive values of NAATs , like that of all diagnostic tests, is reduced in low prevalence populations with a greater potential for false-positive tests. However, their increased sensitivity compared to culture make NAATs particularly useful in detecting asymptomatic infections among persons with lower organism burdens.Although STD screening of sexually active women should be prioritized, screening of high-risk asymptomatic men for the most common STDs is important to prevent transmission of undetected infections to their sexual partners.

Approximately 1.3 million cases of bacterial STDs (gonorrhea, chlamydia, early syphilis) were reported in the United States in 2004, and roughly 47,000 cases were reported in North Carolina in 2005.[16-17] In 1994, the total costs for the most common STDs and their sequelae, including pelvic inflammatory disease and adverse pregnancy outcomes, were estimated to be approximately $10 billion dollars annually.[18] The epidemiologic and biologic associations between STDs and HIV infection underscore the importance of STD management as an HIV preventive strategy. We need to prioritize funds and efforts towards increased utilization of the newer STD diagnostic tests in public and privately-funded practices to maximize the detection, treatment and prevention of these highly prevalent infections and their subsequent complications. **NCMedJ**

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Public Health Approaches to North Carolina's STD Epidemic

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The National Vision

The Institute of Medicine's Committee on Prevention and Control of Sexually Transmitted Diseases in their 1997 report The Hidden Epidemic, *Confronting Sexually Transmitted Diseases*, concluded that an effective national system of STD Prevention did not exist.[1] As they discussed gaps, new approaches and collaborations, they developed the following vision statement to guide their work:

"An effective system of services and information that supports individuals, families, and communities in preventing STDs, including HIV infection, and ensures comprehensive, high-quality STD related health services for all persons."[1]

This vision recognizes that successful STD prevention systems must insure individual and community participation, and coordination of related programs. While identifying and commiting adequate local and statewide resources and support to implement STD programs are critical, successful STD programs are built upon collaborations which involve a wide variety of stakeholders.

Components of North Carolina's STD and HIV programs are frequently cited as national models. North Carolina's STD and HIV programs are a mix of traditional and community-based approaches. This mix, combined with strong program-to-program collaborations and strategies, have strengthened our collective ability to prevent the spread of STDs, including HIV/AIDS, despite our serious funding challenges.

Traditional Collaborations That Work: Local Health Departments And Disease Intervention Specialists (DIS)

Communicable disease programs, like STD programs, are primarily designed to protect the public health by identifying and treating infected individuals and by notifying and (when appropriate) treating exposed partners, households, networks, or all the above. The confidential nature of this work is protected by law. North Carolina confidentiality provisions are specific and are designed to both prevent the inappropriate release of medical information pertaining to infected and exposed individuals and to protect the public health by allowing for the release of information under specific circumstances. There is a delicate balance between protecting the rights of individuals and protecting the public health.

Traditional "shoe leather" epidemiology starts with timely disease reporting by diagnosing physicians and/or laboratories. North Carolina has a strong public health system and an even stronger commitment to supporting local public health authorities. North Carolina public health law and rules provide local health departments with clear authority and responsibilities pertaining to the reporting and investigation of communicable diseases. North Carolina is fortunate to have a local health department presence in all 100 counties. This presence helps insure that North Carolina public health laws are followed by individuals infected with and /or exposed to a communicable

"...North Carolina relies on partnerships and collaborations to advance STD prevention work. Often the best examples of model STD practices are those that pull traditional providers and community-based partners together."

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disease (through enforcement of control measures) and in conjunction with physicians, hospitals, labs and community providers through whom diagnosis and treatment of people with STDs are available. Local health departments also provide confidential medical and counseling services that include STD and HIV disease diagnosis, treatment, referral, partner notification, community outreach and health education.

For STDs like syphilis and HIV/AIDS, local health departments often use Disease Intervention Specialists (DIS) to find persons who are infected and bring them to treatment, or find and notify partners that they may have unknowingly been exposed to a STD. Local health departments are often assisted in the performance of their investigation and control responsibilities by the state's HIV/STD Prevention and Care Branch Field Services staff. The state DISs are located regionally and are trained by the state and/or the Centers for Disease Control and Prevention (CDC) to work with local authorities, private providers, community-based organizations, and hospitals to insure that persons newly diagnosed with syphilis and/or HIV/AIDS understand their diagnosis, are referred to care, and are given appropriate counseling and control measures. These staff also provide confidential partner notification services and often draw blood samples in the field to assist the partner in determining their health status. In 2005, 15% of the named partners exposed to HIV and 20% of the named partners to syphilis-infected individuals who were notified by state DIS were newly infected with HIV or syphilis, respectively. Given the rurality of our state, a mobile DIS workforce is critical.

A Community-Based Collaboration Model that Works

"Cape Fear Regional Bureau For Community Action, Closing The Gap" Program
Jail-Based Strategic HIV/Syphilis Prevention and Support Project
Cumberland County North Carolina

Background and Morbidity

The Cape Fear Regional Bureau for Community Action was founded by Ashley Rozier II and is one of the oldest grassroots HIV/AIDS/Substance Abuse street outreach, community-based organizations (CBOs) in North Carolina. Since 1989, the Bureau has provided prevention counseling, testing and referral services for HIV/AIDS, STDs, substance abuse, hepatitis and many other chronic needs to African Americans, as well as high-risk minorities and the disenfranchised, in the Cumberland County Cape Fear Region. In the NC 2004 HIV/STD Epidemiologic Profile, Cumberland County ranked 6th among the state's 100 counties for cumulative reports of HIV disease (1983-2004) with 1,246 cases. In Cumberland County, African Americans represent only 39% of its population, but an alarming 75% of HIV cases. Additionally, African Americans represented 63% of chlamydia cases, 79% of gonorrhea cases, and 70% of early syphilis cases in 2004.

In January 2006, after collaboration with local and state partners, the Bureau, the Cumberland County Sheriff and the Cumberland County Health Director initiated the "Closing The Gap" program. This program offers traditional jail screening and a community outreach component. Bureau staff are trained to conduct HIV/syphilis counseling and testing and target incarcerated men and women. HIV/STD education and testing is offered on Friday, Saturday and Sunday evenings from 7:00 pm to 11:00 pm. HIV and syphilis blood specimens are processed through the Cumberland County Health Department and test results are provided to the client regardless of whether they are still incarcerated. Those inmates testing positive for HIV and/or syphilis are interviewed for partner notification purposes and are given relevant referrals. This program focuses on 1) early identification of HIV and syphilis, 2) linking clients to appropriate medical care and prevention services, including identification and enrollment of high-risk women in prenatal care programs, and 3) supporting positive clients in adhering to treatment regimens and in adopting and sustaining HIV risk reduction behavior.

Exceeding Their Goals

From January 1-June 15, 2006, the Bureau tested 821 inmates for HIV, of which three HIV-positive cases were identified. For the same time period, 824 inmates were tested for syphilis and six new cases were identified. Seventy-nine percent of those tested for HIV were post-test counseled. All positive HIV and syphilis clients were referred for medical care/treatment, partner notification services and case management services.

In addition to the work within the detention facility, the Bureau has an active outreach program that includes testing in Fayetteville at 110 1/2 Gillespie Street (main office), local bars/clubs, field/street outreach, and in Hoke County. From January 1-June 15, 2006, 137 persons were tested for HIV, of which three HIV-positive cases were identified. For the same time period, 132 persons were tested for syphilis and two new cases were identified. All positive HIV and syphilis clients were referred for medical care/treatment, partner notification services and case management services.

Two Program-To-Program Collaborations that Work

A. Hepatitis A and B Vaccination Program
State Immunization Branch and HIV/STD Prevention Care Branch

In 2002, hepatitis A rates increased dramatically in five North Carolina counties (Wake, Forsyth, Guilford, Mecklenburg, and Robeson). A 4.5 fold increase in the number of men self-reporting recent sexual contact with men was noted when compared to the average over the 1997 to 2001 time period. The increase was largely attributable to men who have sex with men (MSM) activity, especially in white males in the 25-44 age groups. In terms of hepatitis B, it is well-known that it is a sexually transmitted disease, 100 times more infectious than HIV. Unvaccinated adults who engage in unprotected sex with multiple partners are especially vulnerable to this vaccine-preventable disease.

Based on data indicating high rates of hepatitis infection, a statewide strategy to prevent and control hepatitis A and B infection through vaccination was needed. CDC offered grant money to programs designed to increase vaccination rates in high-risk populations. After applying for and receiving funds from a CDC grant, the Immunization Branch made the decision to purchase, a combination hepatitis A and B vaccine, under the trade name Twinrix.® This vaccine is manufactured and distributed by GlaxoSmithKline Biologicals. Through a limited pilot project in 2003, adults at high risk for both hepatitis A and B, including those infected with hepatitis C, were targeted for vaccination.

The HIV/STD Branch staff in collaboration with the Women's and Children's Health Section (WCHS) Immunization Branch, announced the availability of state-supplied hepatitis A and B vaccine to all local health departments effective January 2, 2004. This project continues as an ongoing routine vaccination opportunity. Considered a standard of care, hepatitis A and B vaccine is available statewide to high-risk adults served in health department STD clinics. Since the beginning of the calendar year 2006, administration of hepatitis A and B vaccinations at local health departments has increased (see table below). Communicable disease nurses at the health departments have received correspondence, verbal encouragement to use the vaccine and consistent education about the importance of offering/administering the vaccine from both the hepatitis B and C coordinators. The nurses are strongly encouraged to offer the vaccine to all unvaccinated patients over 18 years of age who are seen in their STD clinic. Targeted risk factors include HIV positive status, HCV positive status,

IDU (Intravenous Drug Users), MSM, MSP (Multiple Sex Partners), and past incarceration. High vaccination coverage will reduce transmission of hepatitis A and B infection in the community by immunizing persons at highest risk for infection.

The Branch Quality Assurance, Training, and Development Team (QATD) regularly conducts site assessments at local health department HIV/STD clinics to assess the uptake of hepatitis A and B vaccinations at the sites. Future plans are to increase the focus on increasing initial acceptance and completion rates of vaccine.

B. *Chlamydia and gonorrhea-screening programs targeting high-risk adolescents entering Assessment and Treatment Planning Centers*

Background

Asymptomatic chlamydia and gonorrhea infections are common among both adolescent males and females and are especially high for those entering detention facilities. According to the CDC STD Surveillance 2002 Special Focus Profile "STDs in Persons Entering Corrections Facilities:"

- The positivity for chlamydia and gonorrhea among women was higher in juvenile facilities than in adult facilities. Among adolescent women entering juvenile detention facilities, the median positivity for chlamydia was 15% (range, 1.5% to 28.9%); positivity was greater than 10% in 17 (71%) of 24 facilities reporting data.
- The median positivity for gonorrhea among women entering juvenile facilities was 4.9% (range, 0.5% to 13.0%); positivity was greater than 4% in 11 (73%) of 15 juvenile facilities. The median positivity for chlamydial infection among men entering juvenile facilities in 30 counties was 6.6% (range, 0.9% to 13.0%).

To address this issue in North Carolina, the HIV/STD Prevention and Care Branch is working in partnership with the Department of Juvenile Justice and Delinquency Prevention (DJJDP) to implement an STD screening program targeting high-risk adolescents entering two state-level Assessment and Treatment Planning Centers. The program reaches adolescents entering one Youth Development Center for Females (approximately 100/year) and one Youth Development Center for Males (approximately 500/year). Center medical staff collect demographic information (age, race, gender) and urine samples for gonorrhea and chlamydia screening using an FDA-approved NAAT testing procedure.

Status

Testing was initiated in October, 2003 for males and females entering the two Youth Development Centers. As of June 31, 2006 the project has screened 1,257 (1,071 males and 186 females) between the ages of 13 and 17. Of those screened, 138 (103 males and 35 females) tested positive for chlamydia and 19 (eight males and 11 females) tested positive for gonorrhea. All of those who tested positive were treated in accordance with NC treatment recommendations and were counseled on risk reduction behaviors to

Table 1.
Total Doses of Hepatitis A and B Vaccines Ordered by 93 Local and Regional Health Departments

2004	15,695	(includes pilot project period)
2005	13,685	
2006 January-June (actual)	8,395	
2006 Estimated total (projected)	16,790	
Using the above numbers and the assumption that all vaccine recipients have received or will receive the required 3-dose series,* it can be estimated that the following number of clients were/will be vaccinated:		
2004	5,230	
2005	4,529	
2006	5,600	(Estimated total for the year)

*NOTE: Many clients received at least one or two more doses of vaccine than estimated. All received the first dose of the vaccine, but the percentage of those returning for their 2nd and 3rd doses is usually around 25% and 5%, respectively.

prevent future infections. This model program is a great example of the benefit of adding routine STD screening to programs serving at-risk adolescents. These young people can be treated quickly and the likelihood of complications such as epididymitis, infertility and pelvic inflammatory disease are greatly reduced.

As can be seen from the above examples, North Carolina relies on partnerships and collaborations to advance STD prevention work. Often the best examples of model STD practices are those that pull traditional providers and community-based partners together. The best example of this is North Carolina's Syphilis Elimination Project.

The Syphilis Elimination Project (NCSEP) began in 1998 with CDC funds given to the HIV/STD Prevention and Care Branch to reduce the levels of syphilis in North Carolina, which has had one of the highest primary and secondary syphilis rates in the United States. The NCSEP program is comprised of six counties: Durham, Forsyth, Guilford, Mecklenburg, Robeson and Wake. Through this program, each county hired a Syphilis Elimination Coordinator devoted to syphilis elimination activities, conducted an evaluation project and convened a community task force to develop a syphilis elimination plan unique to their county. Each county conducts syphilis outreach and education, screening of high-risk persons, jail screening programs, establishes and supports condom distribution centers, and conducts social marketing. A crucial element of syphilis elimination is the partnership formed between CDC, the state, county health departments and community-based organizations (CBOs). CDC in fact made collaboration with CBOs a requirement and thirty per cent of the CDC grant award was designated for use by community-based organizations.

North Carolina has made substantial progress toward controlling syphilis since the inception of the Syphilis Elimination Project (NCSEP) in 1998. Since that time infectious syphilis in North Carolina has declined by 62% and the state rate has dropped from 9.6 to 3.2 in 2005. In 1998 North Carolina led the nation in the number of counties reporting infectious syphilis cases, and was the only state in the nation with five of the twenty-eight counties reporting more than 50% of the nation's morbidity of infectious syphilis. In 2005, only one North Carolina County (Mecklenburg) remains on the National listing of the top counties with syphilis. The NCSEP program has been successful because of the partnership between community-based organizations, local healthcare providers and local/state health staff. This partnership supported the use of locally tailored, innovative strategies and "after hours" screening in non-traditional venues.

SYNERGY

Definition

(1) SYNERGISM; broadly: combined action or operation (2) a mutually advantageous conjunction or compatibility of distinct business participants or elements (as resources or efforts).[2]

North Carolina's approach to effective implementation of programs and activities designed to impact HIV/AIDS and other sexually transmitted diseases is one rooted in the synergistic character of our programs. Our activities are designed to draw upon the strength of other similar program activities, both at the local as well as at the state level. The Division of Public Health is a full partner with our local health departments as well as community-based organizations and providers. The HIV/STD Prevention and Care Branch recognized several years ago that in order to effectively address the burgeoning HIV and STD impact on communities in our state, it was necessary to form partnerships with key leaders and stakeholders in those communities and to provide resources as well as mentoring to improve delivery of services. Together we are stronger than we are alone. **NCMedJ**

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Responding with Treatment to Those Acutely Infected with HIV:

No Time to Lose

Peter Leone, MD, MPH

Acute HIV infection (AHI) refers to the brief period after HIV infection when HIV RNA first appears in the blood, but before HIV-specific antibodies are detectable. Individuals with AHI have increased HIV transmissibility due to the increased viral load in both blood and genital secretions, making it critically important for prevention of secondary HIV transmission.[1] While some patients with acute infection have a viral syndrome (known as acute retroviral syndrome or primary HIV), the mild and non-specific nature of acute retroviral syndrome complicates effective screening.[2] A significant barrier to diagnosis of AHI is the non-specific nature of the signs and symptoms associated with the acute retroviral syndrome. Unless a clinician entertains the diagnosis in the differential and orders an appropriate diagnostic test, the diagnosis will be missed. It is vital to have clinicians consider AHI in young adults with fever and diffuse lymphadenopathy and that clinicians also know to include a viral-specific test and not just an HIV antibody as diagnostic tests. Methods to incorporate HIV RNA screening of all HIV antibody negative bloods for testing populations may reduce the number of missed diagnoses for AHI. Specimen pooling and nucleic acid amplification methodologies have proven to be a feasible and effective method of acute HIV infection screening of at-risk populations such as individuals seen in Sexually Transmitted Disease clinics, Emergency Departments, and at other locations where HIV testing is routinely provided or individuals at risk for HIV infection may seek care.[3]

> *"Early HIV therapy presents a potential window of opportunity to improve immune function and slow the progression to AIDS, and more trials are underway now to determine the clinical benefits of early HIV therapy."*

Diagnosing AHI is of benefit at the level of the individual patient and at the level of the general public as part of HIV disease control efforts. Early HIV therapy presents a potential window of opportunity to improve immune function and slow the progression to AIDS, and more trials are underway now to determine the clinical benefits of early HIV therapy.[4,5] Transmission of HIV is principally driven by the quantity of the HIV inoculum in either blood or genital secretions. This brief period of extremely high HIV viral load and uncontrolled viral replication in AHI last for less than eight weeks. Therapy with ARV can precipitously drop the serum and genital secretion viral load and potentially render the individual "non-infectious" should the viral load drop below detection. Brief interventions that alter HIV high-risk activities for even a brief period of time can tremendously reduce the transmission of HIV among discordant partnerships. Additional public health benefits of early intervention include epidemiologic information about incidence rates in communities,[6] case clustering,[7] information on trends in drug resistance,[8] identification of high risk periods and places,[9,10] molecular characterization to better define core populations and sexual risk,[11] identification of marginalized and otherwise hidden high risk groups,[12] and a unique opportunity to disrupt active HIV transmission networks.

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The Period of Acute HIV Infection

The kinetics of HIV transmission and diagnosis has profound implications for disease control efforts. Both the biological progression and behavioral characteristics leading to AHI exacerbate the risk of secondary HIV transmission (Figure 1). As higher viral loads correlate to greater risk of HIV transmission, the increased viral burden in blood and genital secretions associated with AHI increase the probability of transmission.[1,23] "Look-back" studies investigating transmission rates,[24] case series showing rapid secondary transmission,[25] and prospective sero-discordant couple studies[26] all strongly suggest a greater likelihood of transmission per sex act during acute HIV infection. Our own data from the North Carolina AHI program (STAT) suggest transmission of HIV during acute infection occurred >1:13 to 1:18 unprotected coital acts. Beyond the increased risk of transmission from an individual with AHI, the partners subsequently infected during this period are also at an increased risk of transmitting HIV, creating a chain of secondary transmission among core populations.[27]

Figure 1.
AHI and Symptoms

- **49-89% "Symptomatic" within 3 Months**
  (Schacker TW, et al., AIM 1996 125:257-264)
- **Symptoms**

	Schacker	Kinloch-de Loes	NCSTD
Fever	93%	87%	48%
Fatigue	93	26	37
Pharyngitis	70	48	30
Headache	55	39	26
Rash	–	–	15
GI Symptoms	–	–	37

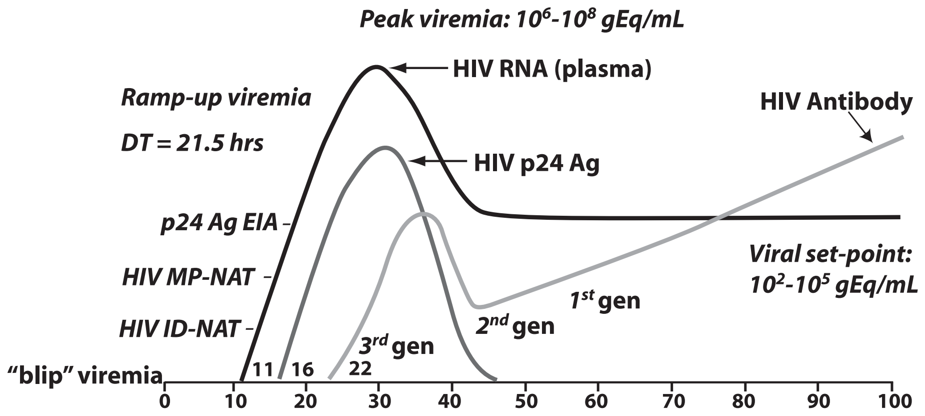
In addition to this heightened biological risk of HIV derived from increased viremia among specific populations, increased behavioral risk has also been suggested during the AHI. Studies analyzing men who have sex with men (MSM) who recently seroconverted revealed behaviors during the period of acute HIV infection which likely facilitated HIV transmission, and declined soon after diagnosis.[20] This behavioral component of HIV risk is independent of viremia, but importantly seems to correspond to a similar period of high-risk behavior. Recall bias interferes with locating active HIV transmission networks since it tends to increase as time elapses from sexual encounter.[28] Finding individuals with AHI at the earliest time following infection is a matter of urgent public health and individual importance.

A recent publication described the epidemiologic and clinical characteristics of a cohort of patients with AHI who were followed prospectively. This represented nearly three percent of all new HIV infections diagnosed during a seven-year time period. The symptoms were nonspecific, with only fever and asthenia being nearly universal (98% and 86% respectively).[30] Prior studies suggest symptoms of an acute retroviral syndrome occur in 40-90% of patients.[13] Our own experience in North Carolina found that 70% of individuals developed an acute retroviral illness, but that less than 50% had symptoms at the time of diagnosis. Anecdotally, even when patients have presented to clinicians with signs and symptoms of the acute retroviral syndrome, the diagnosis was either never considered or the wrong HIV diagnostic test was ordered. Clearly there is a need to educate clinicians concerning the subtle presentations of AHI and consideration given to appropriate diagnostic testing and follow up. Barriers to the initiation of universal HIV testing must be addressed in settings for which clinicians have been hesitant to order HIV testing. Such settings include emergency departments and urgent care settings where clinicians have been reluctant to order HIV tests, let alone screening for AHI with HIV viral load testing, due to lack of reimbursement for counseling, an inadequate referral base for HIV care and the requirements for HIV post-test counseling.

The development of symptoms is associated with high-level viremia and the initial immune response to HIV. Much is unknown regarding the prognostic significance of the acute retroviral syndrome, but the severity of illness may reflect difficulty of the host immune response to control viral replication and has been correlated with a more rapid progression of disease.[13] Sued, et al., provide further support for this conclusion with the more rapid progression of disease reported in those who did not receive ART (42.3% vs. 12.3%).[30] It is, for this reason, disturbing that the percentage of individuals starting on ART decreased during the observed period from 79% to 49%. The high rate of dyslipidemia and lipodistrophy may be attributable to the choice of ART or reflect a "defect" in the host immune response with poor response to viral replication since the majority of the individuals in the cohort had an acute retroviral syndrome.

The timing of HIV diagnosis is central to subsequent public health response and preventing unknowing transmission of HIV. Depending on the threshold used for a true positive, nucleic acid amplification testing (NAAT) used for acute HIV surveillance can be positive within the first week of infection. Some third-generation ELISA tests may be positive as early as three weeks following HIV infection, compared to the two weeks needed for positive p24 antigenemia (Figure 1).[29] The sensitivity of assay used to detect either HIV or HIV-specific antibody response is only one factor in diagnosing acute HIV. The frequency of repeat HIV testing in high-risk groups will also impact the ability to diagnose individuals during the AHI period. Clinician awareness of the presentation of AHI as well as a high index of suspicion is also critical since detectable antibodies levels may not be present at the maximal height of viremia and the onset of symptoms. Appropriate clinical history, such as sexual risk factors, reported intravenous drug use, coupled with physical signs and symptoms of an acute retroviral illness, should prompt the ordering of appropriate diagnostic tests with either a NAAT HIV RNA or HIV p24 assay (Figure 2). Sued and colleagues looked for evidence of AHI in this high risk population and therefore were able to recognize and diagnose AHI. We can and must do better in considering AHI in all sexually active young adults who present with a non-specific mononucleosis-like illness.

Figure 2.
HIV Viremia During Early Infection



The University of North Carolina Hospitals recently implemented routine HIV RNA screening of all HIV ELISA antibody negative or Western Blot indeterminate blood as a way of reducing clinician oversight of AHI. When used with specimen pooling, HIV NAAT offers a sensitive and specific method for detection of acute HIV infection before the period of greatest transmissibility.[3] North Carolina's STAT program illustrates how acute HIV surveillance is critically time-dependent. During the period November 2002 to September 2006, 78 patients from 110 public counseling and testing sites were RNA positive and antibody negative. During this same period, over 90 community-identified cases of AHI were referred into the North Carolina STAT program. Finding individuals with acute HIV infection and their recent sexual partners provides insight about HIV sexual networks at the leading edge of the epidemic. From a public health perspective, the evidence to support increased HIV transmissibility during acute infection justifies closely related case finding and prevention activities.

Conclusion

The clinical presentation of AHI is, at best, non-specific and can closely resemble a host of other "viral-like" illnesses. A history of recent unprotected sexual intercourse or injecting drug use, coupled with characteristic signs/symptoms, such as fever, rash or lymphadenopathy, should alert clinicians to consideration of the diagnosis. Education of clinicians and patients concerning acute retroviral syndrome and access to frequent HIV testing is critical for identification of AHI.

Closing the window period between acquisition and diagnosis of HIV infection via routine acute HIV infection screening is a major public health opportunity that demands further study and consideration. Case interviewing needs to be better connected to HIV prevention, given what we know about the increased HIV transmissibility associated with acute HIV infection. In most parts of the world, physicians fail to diagnose acute HIV infection, case interviewing is underutilized, and disease control based on acute HIV surveillance remains a theoretical benefit. Since the increased HIV transmissibility associated with acute HIV infection is supported by North Carolina's STAT program[3] and transmission data, identifying acute HIV infections and tracing their partners should be further considered. Analyzing the high-risk people/places/periods involved in active HIV transmission needs to be considered in other locations, as a complementary strategy alongside the sensitive-to—less-sensitive HIV testing. Despite support from the CDC and work in the field, routine detection of acute HIV infection and case interviewing has not yet been broadly applied.

Some have persistent doubts about acute HIV-centered testing and disease control. Limitations to the proposed approach include higher testing costs, NAAT test performance issues, and a requisite for venous blood draw. In addition, the need for follow-up Western Blot confirmation for presumably positive clients makes delayed testing less desirable in settings where acute healthcare alone is provided. Rapid HIV testing can be coupled with screening for AHI should the rapid test prove HIV antibody negative. Rapid HIV testing and AHI screening are not mutually exclusive propositions. Given the increased uptake associated with rapid HIV testing, the longer follow-up and potentially greater refusal of blood draws required for acute HIV screening, strategies to incorporate AHI screening seems justified. North Carolina's STAT program has shown that identification of acute HIV infections and disease control can be implemented on a very large scale while preserving test performance and low cost. Sued and associates demonstrate an additional approach by prospective following of high-risk groups with the hope of recognizing AHI. Even with the increased cost and potentially higher refusal rate associated with either strategy, the public health advantages demand further study and consideration of these new approaches. With five years of ongoing increases in the new diagnoses of HIV among North Carolinians, new approaches for prevention must be encouraged. We are clearly missing most cases of AHI. Approximately 60% of all new diagnoses of HIV occur in the private medical sector. It is imperative that an extensive education campaign for AHI be instituted for clinicians and new partnerships for follow-up and referral links for AHI cases be strengthened at the state and local health department level. These activities should also be implemented with simultaneous education of high-risk HIV communities, such as men who have sex with men (MSM) and injecting drug users so that healthcare is sought with the first presentation of AHI signs and symptoms.

Extensive public health experience with syphilis control suggests that disease control-focused epidemiologic investigations linked to active transmission among core high-risk groups may be a more effective public health approach to HIV control than merely recommending universal HIV testing. While traditional HIV surveillance systems provide broader estimates of overall HIV incidence, such surveys are very unlikely to adequately sample either populations that deny high-risk behaviors or high morbidity areas to provide the type of detailed information essential to stopping active transmission networks.

Acute HIV infection detection and disease control systems allow clinicians and public health authorities to get a more detailed and comprehensive understanding of the when, where, why, and who of new HIV infections. Routine detection of acute HIV and disease control offers a new blueprint for organizing HIV testing, bringing HIV acquisition and diagnosis closer, and expanding potential prevention programs. Several lines of evidence support a new paradigm of acute HIV detection and disease control, but more investigation and further replication are necessary. **NCMedJ**

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Responding to the Epidemic of STDs through Public Education and Community Intervention

Sherry Lehman

In 2005, 50.8% of high school students in North Carolina had engaged in sexual intercourse according to the Centers for Disease Control and Prevention (CDC), Division of Adolescent and School Health's Youth Risk Behavior Survey (YRBS). While this is a relatively new statistic, teen pregnancy rates and the prevalence of chlamydia and gonorrhea among teens demonstrates that youth in North Carolina have been involved in risky sexual behaviors for a long time. In 1995, the state legislature recognized this fact and took steps to get the schools involved in HIV/STD and teen pregnancy prevention.

Prior to 1995, there were no state statutes or state school board policies that dictated what local school systems should teach regarding sexuality education in the classroom. In 1995, the legislature amended the Basic Education Statute 115C-81 to require abstinence until marriage for HIV/STD prevention as the expected standard for all school-aged children. The North Carolina State Board of Education used the statute as a guide to update the Healthful Living Standard Course of Study, which mandates age-appropriate learning objectives on sexuality education. The amendment of the statute and the course of study created conflict and controversy and changed the way sexuality education was taught in North Carolina.

Overnight, school systems became leery of letting health education teachers teach information about condoms and birth control. Masturbation, abortion, and sexual orientation became taboo subjects for discussion in the classroom. The great tragedy of the transition was that school systems were interpreting the state statute too conservatively and safer sex education was deleted from the scope of knowledge provided to students.

Recognition of the misinterpretation has been a slow, but steady progress has been made. Informed educators from the Department of Public Instruction and the North Carolina Comprehensive School Health Training Center have provided ongoing workshops to local school boards, school administrators, health teachers, community health educators, and parents on the accurate translation of the guidelines. Primary concepts of the workshops include: (1) the allowance of the statute and the mandate of the course of study for seventh and eighth grade health teachers to teach the effectiveness and failure rates of condoms and other birth control methods; (2) the right for parents to opt their students out of the sexuality portion of the Healthful Living curriculum without penalty (or prejudice) to the student; (3) the right of the local school system to go beyond the scope of the statute and hold a public hearing to approve teaching comprehensive sexuality education, which could include classroom demonstration of condoms; and (4) the primary difference between the statute and the course of study (and holding a public hearing) rests with the ability to demonstrate condoms in the classroom. Despite the fact that the statute is known across the state as the "abstinence until marriage" law, the statute allows for great flexibility in teaching an "abstinence plus" curriculum.

The North Carolina Comprehensive School Health

> *"Making A Difference is an abstinence-based middle school curriculum that has been aligned with the Healthful Living Standard Course of Study, and when implemented with fidelity has demonstrated positive behavior change in adolescents."*

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Training Center provides professional development to school systems or community-based organizations that want evidence-based HIV/STD prevention curricula that meet the state statute *and* the course of study requirements. *Making A Difference*[1] is an abstinence-based middle school curriculum that has been aligned with the Healthful Living Standard Course of Study, and when implemented with fidelity has demonstrated positive behavior change in adolescents. *Successfully Teaching Middle School Health*[2] and *Successfully Teaching High School Health*[3] are two manuals produced by the professional organization, North Carolina Association for the Advancement of Health, which provides six-step lesson plans for every health learning objective, including HIV/STD and teen pregnancy prevention. Staffs of after-school programs and community-based programs, which are not held to the terms of the statute or the course of study, may receive training in such evidence-based curricula as *Focus on Kids*[4] and *Making Proud Choices*.[5] All of the above curricula are highly interactive and promote communication, negotiation, and refusal skills that delay the initiation of sexual intercourse and stress the importance of abstinence.

With the appropriate teacher training, North Carolina can have highly effective health education in the classroom. However, several issues jeopardize the future of school health education. The high stakes pressure of adequate yearly progress and student achievement is forcing health education out of the school day with the need for remedial math, reading, and writing time. The recent Healthy Active Children state board policy, which requires 30 minutes of daily physical activity in elementary and middle schools, is placing an emphasis on physical activity, sometimes at the expense of health education. Without an end-of-course test for health education there is no accountability for the teaching of health, and specifically HIV/STD and teen pregnancy prevention, in the classroom. It is the responsibility of parents and the greater community to advocate for appropriate school health education and disease prevention. Without the watch-dogs of community involvement, the sexual risk-taking behaviors of North Carolina youth may put them in the cross hairs of HIV/AIDS. **NCMedJ**

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Opportunities for Addressing the STD Epidemic through Interventions Targeted to North Carolina's Incarcerated Populations

Lynne A. Sampson, MPH

The prevalence of sexually transmitted diseases (STDs) among inmates of jails, prisons, and juvenile detention facilities is many times higher than among the general population. Surveillance projects at the Centers for Disease Control and Prevention (CDC) have found high rates of chlamydial infection, gonorrhea, and reactive syphilis serology among inmates entering both adult and juvenile correctional facilities (Table 1).[1] The Bureau of Justice Statistics also reports that 1.8% of male prison inmates and 2.6% of female prison inmates in the US are infected with HIV.[2]

The association of STDs with incarcerated populations should not, however, imply that the infections were acquired in prison or jail. Although transmission can occur within such facilities, it is not common. Rather, correctional settings represent a unique opportunity to access populations that have a high risk for STD infections and offer screening, treatment, and education.

Why Are Incarcerated Populations at High Risk?

The risk of acquiring sexually transmitted infections has long been associated with illicit behaviors, such as prostitution and drug use. This pattern is especially true for syphilis and HIV infection which have occurred in similar populations since the earliest days of the HIV epidemic. Studies of HIV-infected populations have documented high rates of incident syphilis infection[3,4] and syphilis studies have established HIV infection as a consistent risk factor.[5-8] Syphilis and HIV have both been found to be associated with trading sex for drugs or money,[9-11] use of illegal drugs,[9-14] and a history of incarceration.[6,14] These risks are, in themselves, related as prostitution and drug possession/sale are among the most common reasons for arrest.[15]

Jail Versus Prison Settings – Implications for Screening Programs

Because STDs are highly prevalent in incarcerated populations, screening programs to identify new infections have been proposed and/or implemented in jails and prisons across the United States. Inmates are generally screened upon entry to the facility and receive treatment and/or referrals for any STDs detected. Screening in jails and prisons each has different goals and benefits, therefore it is important to distinguish the difference between these two types of institutions.

> *"...correctional settings represent a unique opportunity to access populations that have a high risk for STD infections and offer screening, treatment,*

Jails are locally operated (city or county) and serve to house persons arrested and awaiting trial as well as those sentenced to short terms of generally less than one year. The average inmate stays in jail for less than two days,[16] most posting bond and awaiting trial outside jail. In North Carolina, only about 23% of the jail population at any given time is serving sentences; the remainder are pre-trial detainees.[17]

Because most jail detainees are housed for only a matter of days, conditions are crowded and opportunities for inmate recreation are limited, decreasing the opportunities for sexual contact (and ongoing transmission) within the institution. In

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Table 1.
Median Prevalence of Sexually Transmitted Diseases among Populations Screened in US Correctional Facilities, 2004.

	Males		Females	
	Median %	Range %	Median %	Range %
ADULT				
Chlamydia	10.2	0.7 – 30.0	7.2	1.2 – 22.7
Gonorrhea	2.6	0.0 – 33.8	3.0	0.0 – 8.4
Syphilis	2.7	0.2 – 5.9	5.3	0.0 – 19.0
JUVENILE				
Chlamydia	5.8	1.0 – 27.5	14.0	2.4 – 26.5
Gonorrhea	0.8	0.0 – 18.2	4.5	0.0 – 16.5
Syphilis	0.5	0.0 – 2.4	0.7	0.0 – 5.1

Source: CDC STD Surveillance 2004[1]

such settings, STD screening programs serve as community-level screenings, reaching a population that often has limited contact with other healthcare services and screening opportunities. The net benefit of such programs is very much to the non-incarcerated community to which the detainees return.

Prisons are generally under state or federal control and are designed to house inmates sentenced to terms of one year or longer. Essentially all prison inmates will have spent some time in jail before trial, sentencing, and finally entering prison. Screening for STDs in these settings has very different functions: to maintain the health of the inmate population while they are in custody and to prevent ongoing transmission within the facility. Inmates benefit directly from detection and treatment of their disease. Upon release, the benefit transfers to communities where the risk of infection from a newly released inmate is decreased.

STDs in North Carolina Correctional Facilities

The prevalence of STDs among North Carolina's incarcerated populations is difficult to assess because few screening programs currently exist. In 2005, 256 cases of sexually transmitted diseases were reported from the state's correctional facilities (Table 2). These data should be viewed as an extremely low estimate of the true number of STD cases among incarcerated populations in North Carolina. Most reported cases are likely to be the result of sick inmates seeking care. Since the most prevalent reportable STD (chlamydia) is asymptomatic, most cases are not detected unless a screening program is in place. Inmates entering Department of Corrections (prison) custody are screened for syphilis. HIV testing is also offered on a voluntary basis. Screening programs in jails are far less common.

There are also some reporting issues associated with this data. Internal surveillance audits at the Branch have found that some STD reports listed as coming from county health departments were actually cases detected through the local jail. This occurs sometimes when a jail is not able to provide treatment on site and inmates are temporarily transferred to the local health department for care. The STD case report may be filled out at that time and come in to the Branch as a health department case. This bias does not appear to be present in reports coming from prison facilities.

Expansion of STD screening programs, especially in jails and juvenile justice settings, would likely detect a large number of cases of treatable STDs and contribute to decreases in ongoing transmission in the community. The HIV/STD Prevention and Care Branch has two major screening efforts underway that can provide a model for future programs.

Juvenile Justice Screening in North Carolina

Since October of 2003 the HIV/STD Prevention and Care Branch of the North Carolina Division of Public Health has partnered with the State Laboratory of Public Health and the Department of Juvenile Justice and Delinquency Prevention (DJJDP) to provide STD screening in several long-term facilities. Females at the Samarkand Facility and males at C.A. Dillon are screened upon entry for chlamydia, gonorrhea, and syphilis. In 2005, 371 young men were screened. Of these, 40 (10.8%) were found positive for chlamydia and two (0.5%) were positive for gonorrhea. The problem is even more pronounced among young women. Out of 48 screened in 2005, 10 (20.8%) tested positive for chlamydia, and two (4.2%) tested positive for gonorrhea. All of the juveniles were immediately treated for their infections. No cases of syphilis were detected.

The HIV/STD Prevention and Care Branch hopes to secure additional funds to allow for expansion of this program to additional facilities within DJJDP.

Syphilis Elimination Jail Screening in North Carolina

In 1998 CDC found that over 50% of reported primary and secondary syphilis cases in the United States came from just 28 counties. They launched an extensive campaign called the Syphilis Elimination Effort (SEE) in 1999 in response. North Carolina had five counties on that list, more than any other state, and has expanded the program to include six counties.

As part of the enhanced surveillance objective of SEE, North Carolina has instituted syphilis screening in seven jails in all six of the SEE counties. Several counties began screening in the early project years (1999-2001). However, it was not until 2002 that good data collection and evaluation procedures were put into place. By September 2002, all seven jails were screening for syphilis and collecting data for evaluation. Two of the jails also added HIV testing to their programs. Data from 2002-2004 indicate that 98% of inmates who agree to having their blood drawn for syphilis testing also agree to having an extra tube drawn for HIV testing. During that time period the project identified 47 HIV-positive inmates (out of 4,655 screened) of which 25 were new reports.

From 2002-2005, the jail screening program tested 25,069 detainees for syphilis (20,311 males and 4,758 females). Overall, 932 inmates tested reactive and of these, 156 new cases of syphilis were identified (20 primary & secondary, 55 early latent, and 81 late syphilis). Females were more likely to be reactive than males (8.2% vs. 2.7%) and more likely to be a new case (1.2% vs. 0.5%). Female cases were also more likely to be primary, secondary or early latent (60% vs. 41% for males). In addition to greater rates of case detection, screening female inmates has a major additional benefit in that treatment can prevent possible cases of congenital syphilis.

Table 2.
Sexually Transmitted Diseases Reported in North Carolina, 2005

	Males			Females		
	All Cases	Corrections		All Cases	Corrections	
	N	N	%	N	N	%
Chlamydia	5,481	36	0.7	25,702	37	0.1
Gonorrhea	7,529	36	0.5	7,546	12	0.2
Early Syphilis*	343	22	6.4	146	18	12.3
HIV Disease**	1,308	79	6.0	498	16	3.2

Source: NC HIV/STD Prevention and Care Branch

* Early Syphilis = Primary, Secondary, & Early Latent Syphilis (<1 year duration)
** HIV Disease = First report of HIV infection, regardless of stage (includes some cases first reported as AIDS cases)

The Syphilis Elimination jail screening project has been fruitful in identifying 156 previously undiagnosed cases of syphilis and 25 new cases of HIV infection. Undoubtedly many others were also identified through partner notification and contact tracing of those jail cases. The North Carolina Syphilis Elimination team has used the results of the evaluation to adjust our screening by increasing our emphasis on female inmates. We plan to continue syphilis screening in the jails and hope to expand the HIV screening component to additional jails.

Policy Recommendations

Due to the high prevalence of sexually transmitted diseases among incarcerated populations, correctional settings provide a unique opportunity to reach a group of people at high risk and provide testing and treatment for their infections. Such programs benefit the inmates themselves, who may otherwise have poor access to healthcare, and the communities to which they return. This is particularly true for jail screening programs because detainees are often released within a matter of days. Expansion of the existing syphilis and HIV jail screening programs should be a major policy goal. Addition of chlamydia and gonorrhea screening to adult jail screening programs would likely detect a large number of cases and should also be explored. Younger populations are highly affected by these two STDs and special effort should be made to expand chlamydia and gonorrhea screening in juvenile correctional settings. **NCMedJ**

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Guilford County's Syphilis Elimination Program:
People Stopping Syphilis Today (PSST)

Merle Green, MPH, MBA, and Jonathan Paul Lucas, MPH

Similar to many of the nation's mid-sized communities, Guilford County, North Carolina (including Greensboro) is battling a growing number of health-related social challenges. Guilford, the state's third largest county, is constantly looking for ways to decrease the number of sexually transmitted infections (STI) in its community that proudly houses eight institutions of higher learning and over 100 public primary and secondary schools. Guilford has battled growing numbers of syphilis cases, one of the state's leading causes of disease and disability. Until three years ago, NC had the highest rate of syphilis in the nation, and Guilford was highest in the state, for nearly a decade.

In 1997, Guilford County's largest cities, Greensboro and High Point, had the disturbing recognition of leading the nation in the rate of syphilis infection. With this news came a determined effort to battle this health issue and turn these numbers around. Health Educators and Disease Intervention Specialists from the local health department knew that one of the keys to any successful behavior change intervention should begin with buy-in from the affected communities. They also knew that matters of human sexuality were often met with secrecy and the attitude that "good boys and girls don't talk about that." With little time for changing human nature in this southern town, the local human service workers joined in an effort to respect the "privacy" attitude of the local community, while aggressively tackling this growing public health threat.

> *"In other words, when the planning was driven by the community, we experienced more success than we did when the agency staff made plans and then took them to the community to buy into."*

One of the initial interventions was to convene and host a community coalition. The coalition was then charged with two ambitious goals. These goals were to lower HIV infection rates, and eliminate syphilis by the year 2010.

The coalition named itself People Stopping Syphilis Today (PSST) in order to candidly acknowledge the southern "manners" under which they would be forced to operate. PSST sought and was awarded funding in 1998 from the North Carolina HIV/STD Prevention and Care Branch of the North Carolina Department of Health and Human Services. The Branch had successfully secured community targeted funding through a grant from the Centers for Disease Control and Prevention (CDC), and subsequently awarded mini-grants to local communities. As it continues to exist today, PSST is a partnership that is organized and led by the Guilford County Department of Public Health (GCDPH), but depends heavily on local residents and other local human service agencies and non-profit groups to staff and manage the many activities aimed at reducing HIV and eliminating syphilis infection.

Coalition participants include public service organizations, community based organizations (CBOs), churches, concerned residents, and non-profit health organizations. After learning about best-practice models across the nation, the group realized that the most effective strategies to lower rates of HIV transmission and eliminate syphilis were intensive "street outreach" to offer

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free counseling and referrals, expanded testing services, and community education programs.

Lessons Learned, Strategy Change

After operating with mixed results for about seven years, the organizers noticed that their successes appeared to be heavily weighted in favor of the interventions that involved less agency intervention, and more direct planning and implementation by local grass roots workers. In other words, when the planning was driven by the community, we experienced more success than we did when the agency staff made plans and then took them to the community to buy into. With these data in mind, PSST purposely began to evolve into a program that was completely community driven. In 2004, community members developed and administered a community demonstration project named the Rapid Ethnographic Community Assessment Process (RECAP). In collaboration with the Centers for Disease Control and Prevention (CDC), this assessment was conducted quickly, required little money, and asked communities at risk their opinions on how best to solve the syphilis epidemic in Guilford County. The assessment identified three key groups who were at highest risk for syphilis and HIV infection. The target groups identified were (a) people who use crack cocaine, (b) people who exchange sex for money or drugs, and (c) the customers of people who exchange sex for drugs or money.

Targeting At-Risk Groups

Building on the work of the assessment, the PSST program began to target local Commercial Sex Workers (CSWs) as a core group at risk for the transmission of HIV and other sexually transmitted infections (STIs). A review of public health records and confidential patient interviews confirmed high HIV and syphilis infection rates as well as large numbers of sexual partners among CSWs. The interviews also confirmed that a large majority of the CSWs are often poor, homeless, young, have a history of childhood abuse, and are likely to be drug or alcohol dependent. These issues are common among CSWs across the nation.[1] A study of childhood trauma and adult prostitution behavior by Merrano, Hatch, Zule and Desmond found that emotional and physical abuse were significant factors in predicting increased risk of prostitution.[2] In a study of juvenile and adult women who were street prostitutes, two-thirds were sexually abused, and, of those abused, 70% felt that the abuse affected their decision to become a prostitute.[2] Drug-addicted people may turn to commercial sex work to earn money to pay for the high cost of illegal drugs.[1] Many homeless youth have no education or means of support, and rely on commercial sex work for survival.[3] Attention to the more immediate concerns of food, housing, and addiction often takes priority over future concerns of HIV and syphilis infection.[3] A cross sectional interview-based survey of seventy-one CSWs found that rates of STIs were nine to 60 times higher than for people in the general population.[3]

To prevent HIV infection among CSWs, it is essential to address the context in which sex work is transacted, as well as the specific practices of the CSWs. Placing the major burden for HIV and syphilis prevention on CSWs themselves may not be the most effective tactic.[4] Men who solicit CSWs play a major role in transmitting disease to their other sex partners and thus into the general population. As such, the clients of sex workers are an important target group in direct STI prevention programs. The regular partners, or non-commercial partners, of CSWs and their clients are another important core group for HIV and syphilis prevention programs to target.

Building Relationships with the Sex Worker Community

PSST collaborates with CSWs to educate their customers and their colleagues (other CSWs) about the signs, symptoms, and prevention of STIs. Outreach workers walk the streets Tuesdays through Fridays and as needed on weekends (in conjunction with special testing events) to educate CSWs, their customers and drug dealers on safer sex practices. Outreach workers also focus on peer education. They spend time educating community gate-keepers and preparing them to educate other community members. Outreach teams provide condoms, personal lubricants, other personal safety products, and written materials about STIs. They discuss the syphilis and HIV epidemic with those they encounter, and provide individual risk reduction counseling to concerned community residents. Outreach workers also provide testing for syphilis and HIV at the request of community members. Outreach staff make referrals to a variety of social service agencies when appropriate. Providing such street outreach eliminates many of the barriers that people have to accessing healthcare, including transportation, childcare, and fear of being recognized at a public clinic.

PSST has set up six fixed sites for testing throughout the county in neighborhoods identified by morbidity maps and deemed "hot-spots" for HIV and syphilis infection. These locations have heavy drug traffic and are often frequented by CSWs. PSST sponsors or assists with about 50 special neighborhood screenings a year in locations with high syphilis morbidity rates to target these individuals who exchange sex for drugs or money. These events are done in collaboration with several other community-based organizations (CBOs), and public and private health organizations. At these events, STI testing is offered along with a number of other medical services that include, but are not limited to, blood pressure, glucose, cholesterol and dental/vision screening. Food and other incentives are provided at these community events. Community members assist with planning, advertising, and implementation of these health clinics. Often, community members alsoprovide food for these events. Services provided are always free, so cost is never a barrier for individuals receiving medical care at these events.

Behaviors that increase some women's risk of HIV commonly put them at risk of being incarcerated. As such, female detainees in the prison system often have STIs and/or are at risk for infections.[5] In a sexual behavior and drug use survey done at the Cook County Department of Corrections in Chicago, researchers collected data on 940 women.[5] Of those women interviewed 27% had two or three partners in the past year and 27% had more than four partners. Between 32% and 74% had not used protection in the last year and one third had traded sex for money or drugs.[5]

Collaborations Between Public Health and Law Enforcement Agencies

With this information in mind, PSST works with law enforcement agencies to reach CSWs and the customers of CSWs through education, screening, and treatment. Representatives from the sheriff's department, Prison Health Services, and city police departments serve on PSST. Officers have agreed to discuss the risk of STI infection with people they arrest, especially those arrested for soliciting CSWs. This increases awareness about the HIV and syphilis epidemic in Guilford County and increases access to education about STIs as an interruption to behavior that could lead to disease transmission. PSST also collaborated with law enforcement to produce an educational video for inmates. The video was designed by inmates and discusses syphilis in "street language." The video is shown to arrestees at booking and also to individuals who are waiting for arraignment.

HIV and syphilis testing is another important component of the collaboration with local law enforcement. Guilford County Detention Centers (GCDC) consistently report more syphilis and HIV than any other reporting location in Guilford County. In spite of the overcrowding county facilities are experiencing, medial personnel in detention centers still manage to provide testing to detainees. Arrestees are screened for tuberculosis when they are booked and the syphilis elimination program offers syphilis and HIV testing at that time as well. Unfortunately, due to overcrowding and understaffing, the nursing staff in detention centers could not provide adequate syphilis and HIV testing. To cover this gap, PSST provides syphilis and HIV testing in the jail through a unique partnership with the Sickle Cell Disease Association of the Piedmont (SCDAP). SCDAP employees provide testing and risk reduction counseling at booking and in the jail pods. GCDC nursing staff also offers the test at 14 days when they perform a standard physical. SCDAP provides weekly educational sessions to inmates about STIs. This partnership increases the likelihood that inmates get tested and treated before they are released back into the community.

The Benefits of the Collaborative Model

Guilford County has had a long history of using the community coalition model as a way to address health problems affecting county residents. PSST has been no exception, and the syphilis elimination program is one in a long line of programs successful at increasing access to care in Guilford County. PSST is a success because of its flexibility and service providers' willingness to listen to those individuals served by the program. Guilford was the first county chosen by CDC to conduct a community assessment (RECAP) around syphilis and one of the first to conduct a strategic planning process, which was accomplished entirely by PSST. Many other high morbidity areas have replicated the assessment and planning process. Guilford County remains one of the few places that have gone beyond the assessment process by creating and implementing a strategic plan based on community input at every stage. The result has been better access to quality care for Guilford County's most disenfranchised citizens. **NCMedJ**

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Syphilis Elimination in Robeson County:
Challenges of Addressing the Problem among Sex Workers

Melissa Packer, BS, April Oxendine, BS, MEd, and Karen Woodell, BS

All Is Not Fair with the My Fair Lady Project

In 2004, the Robeson County Health Department received funding through the North Carolina HIV/STD Prevention and Care Branch to implement the highly ambitious My Fair Lady Project, a comprehensive three-year project targeting STD reduction through prostitute rehabilitation.

Greeted with great expectations, the project was the first of its kind funded by the state. With a goal of reducing the occurrence of HIV and other sexually transmitted diseases by decreasing the number of commercial sex workers, My Fair Lady made headlines with local, state, and national media coverage.

The project focused on three key components: *recruitment, rehabilitation and reintroduction*. Commercial sex workers were to be recruited into the program, extensively rehabilitated, and then reintroduced into their former environments with the new skills necessary to encourage positive behavior changes among their past peers.

Unfortunately, despite the media hype and high expectations, the My Fair Lady Project has documented only limited success in reducing sex trade activity in Robeson County. Several distinct and interrelated social problems have led to the near demise of the once ambitious undertaking. With less than one year remaining in the three-year grant, organizers are uncertain of their new directions and whether funding for projects of this nature will be awarded to the Robeson County Health Department in the near or distant future. However, one certainty remains: interventions targeting commercial sex workers must continue in Robeson County.

> *"Commercial sex workers were to be recruited into the program, extensively rehabilitated, and then reintroduced into their former environments with the new skills necessary to encourage positive behavior changes among their past peers."*

Substance Abuse and Mental Health Issues Create a Revolving Door For Peer Outreach Sex Workers

In the first two years of the project, two former commercial sex workers failed in their extensive rehabilitation attempts. These aspiring peer educators and their public health mentors struggled to disentangle the interwoven issues of substance abuse and mental health problems. The most positive phase was the recruitment process, with an initial panel of eight qualified candidates to select from.

The substance abuse challenges faced by sex workers in Robeson County are comparable to those documented in rehabilitation programs across the nation. Studies show that almost all women working in prostitution use drugs and alcohol heavily. Many start using these substances or increase their usage in order to deal with the stress and emotional

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issues of the trade. Others begin to prostitute themselves to fund their drug habits or those of their partners or family members.[1]

State-employed Disease Intervention Specialists working in Robeson County identified the predominant drug of choice for the local commercial sex worker as smoked crack cocaine. Since crack cocaine appeared in urban areas in the United States in the mid-1980s, reports have suggested that crack smokers may be at increased risk of sexually transmitted diseases (STDs), including infection with HIV, because they have multiple sex partners, trade sex for money or drugs, and rarely use condoms.[2] Consistent with the majority of sex workers in Robeson County, smoked crack cocaine was the drug of choice for the two unsuccessful program participants. One of the participants had been substance-free for 14 months and the other had abstained for five months. Prior to employment with the project, both had experienced recurring relapses. One of the women had once led a substance free lifestyle for a five-year period prior to an unfortunate setback. Despite repeated attempts to redirect the paths of these two women, both were released from their duties. This clearly demonstrates the intractable nature that some substance abuse problems present.

Research indicates that cocaine use is the most common drug problem of patients entering treatment for illicit drug use. According to the 1999 Drug Abuse Treatment Outcome Studies (DATOS) funded by the National Institute on Drug Abuse (NIDA), about three-fourths of all admissions to non-methadone treatment programs in the United States are for cocaine dependence.[3] In a national sample from 55 treatment programs, the problem severity of patients at admission was found to be directly related to cocaine relapse in the year following discharge. Treatment retention also was a significant predictor among moderate-to-high problem groups. Among highest severity patients, 90 days or longer in residential programs was needed to improve outcomes. Cocaine treatment outcomes in the year after discharge indicated that 52% relapsed to drug use with 23% going back to "weekly" cocaine use, 19% to "occasional" cocaine nd 10% to "other drugs." Another 4% had alcohol problems and 11% re-entered treatment without relapse. Overall, 67% had problems during the follow-up period.[3] Having discussed that the first two peer educators relapsed during their course of employment, it should also be noted that both had completed inpatient treatment programs less than 90 days in duration.

Aside from drug addiction, one of the participants suffered from bi-polar disorder. Poor compliance with prescribed medications resulted in excessive absenteeism and lack of communication with project coordinators and community-based partners. Multiple interventions were initiated over an extended period, but each proved unsuccessful. Despite her progressively poor performance, this participant initially exhibited remarkable energy and charisma in her public relations efforts. Her communications skills were considered a "plus" for this "first of its kind" project and garnered a wealth of media attention. Her uninhibited approach to public speaking was applauded by all audiences, both lay and professional. It is unfortunate that she was unable to continue progressing, due to stressors encountered on her road to rehabilitation.

Currently, coordinators, in partnership with Palmer Prevention, a local substance abuse prevention center, have recruited two new peer outreach candidates. The director of Palmer Prevention was actively involved in the recruitment efforts of the project. Though grant funds will soon cease, coordinators anticipate closing the My Fair Lady Project on a more positive note. Like the two former Fair Ladies, both new recruits have a history of smoked crack cocaine addiction. And, reminiscent of the first two, they also have a limited duration of "clean time". Strikingly different are their candid communications concerning fears associated with returning to their former work environments as peer educators. Considering their vulnerability as well as the experiences of their predecessors, project coordinators anticipate consistent supervision during all community outreach activities.

Another variation in strategy involves the primary agency where the participants will report daily. Based upon past experiences and the issue of drug relapse, project coordinators have opted to station the two new employees at Palmer Prevention, rather than the health department. Initially, the health department had elected to "outstation" the My Fair Lady peer educators. This was considered the best approach due to confidentiality concerns, as well as media and public scrutiny. When attendance and performance issues spiraled out of control, the faith-based community partners regretfully suggested the workers move back "home" to the health department.

Now back on track with their original concept, coordinators predict the new linkage with Palmer Prevention will support closer monitoring of the rehabilitation and recovery outcomes of both young women. Improved results are highly anticipated; however, existing grant funds are insufficient to pay for clinical substance abuse counseling.

The project's conclusion may be inevitable, but the capacity of the My Fair Lady Advisory Council has grown significantly. The Council is a diverse group with representation including community, faith-based groups, law enforcement, substance abuse counselors, and the Lumbee Tribal Government. The panel offers a wealth of expertise to the project. Organizers predict group sustainability and support of local interventions long after the My Fair Lady Project has ended.

Project Challenges beyond Drug Addiction and Mental Health Problems

Aside from the aforementioned issues, the My Fair Lady Project has faced some additional challenges. Insufficient funding for full-scale implementation has proven a major obstacle. Increased funding is needed to address the full range of problems commercial sex workers (CSWs) face, both on and off the streets, especially for programs staffed and managed by peers. Drug treatment, housing, child care, and skills training for CSWs are essential. Better healthcare services are needed for CSWs, including diagnosis and treatment for STDs/HIV, care for injuries due to violence, and mental health care.[5]

When the My Fair Lady Project proposal was submitted in 2004, the total original funding request was $480,271, which would have funded a 15-member outreach team over a three-year grant cycle. In the original model, the proposed outreach team included a full-time project coordinator, two rehabilitated commercial sex workers/peer educators during the first year, and the extensive rehabilitation and addition of 12 new peer educators by the conclusion of the project in year three.

The original My Fair Lady Project targeted an audience of 126 known commercial sex workers in Robeson County (as documented in 2004 by state Disease Intervention Specialists stationed in Robeson). The project extended to include some 500 individuals within the periphery of services available through partnering agencies.

Grant reviewers favored the project's novelty, but due to budget constraints the project was awarded a total of $90,000 total with $30,000 awarded per year over a three-year period. Resisting the inclination to decline partial funding, health department staff and their community partners downsized their approach. Without funding for a full-time project coordinator, project oversight fell upon the department's existing Syphilis Elimination Coordinator. And, with insufficient funds to recruit, rehabilitate and reintroduce 14 former commercial sex workers, the "novel approach" was reduced to just two peer educators. Only one peer educator's salary was to be paid from the My Fair Lady grant. The second educator would be recruited by the first paid employee and connected with the rehabilitation and education necessary for skilled employment.

Despite the fact that both of the original women succumbed to their former drug addictions, the project was initiated as planned. The first Fair Lady participant recruited the second who was enrolled in the Certified Nursing Assistant Program at the local community college at the time of her dismissal due to drug relapse. The costs of her tuition and books were covered by grant funds.

Effective Supervision of Dual Projects Proves Difficult

Though the Syphilis Elimination Program and the My Fair Lady Project share a common goal, single supervision of double duties has proven disadvantageous. Newly rehabilitated substance abusers and commercial sex trade workers lacked the self-assurance needed to return to their old environments without consistent public health companionship. Frequently, the Syphilis Elimination Coordinator was unable to accompany the peer educators in their daily street outreach activities, due to her full-time job obligations.

Another setback to successful implementation involved staff training. A deficient budget prohibited training using the Real AIDS Prevention Project (RAPP©) intervention model. RAPP© is a community mobilization program designed to reduce risk for HIV and unintended pregnancies among women in communities at high risk by increasing condom use. This intervention relies on peer-led activities, including: outreach/one-on-one brief conversations with brochures, referrals, and condom distribution; small group safer sex discussions and presentations.[4]

Lessons Learned

As previously detailed, Robeson County public health officials and community partners have learned valuable lessons regarding recruitment, rehabilitation, and reintroduction of former CSWs. Project shortfalls should not be viewed as failures, rather they should guide the course for those seeking to reduce the occurrence of HIV and other sexually transmitted diseases through decreasing the number of commercial sex workers. **NCMedJ**

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A Vaccine for Genital HPV:

A Time to Rejoice!

P. Frederick Sparling, MD

In this issue of the journal, Dr. Steven Cline discusses in his Issue Brief the newly licensed and approved vaccine "Gardasil" for human genital papilloma viruses (HPV) types 16, 18, 6 and 11, produced and marketed by Merck.[1] The vaccine requires three parenteral injections over six months, and is expensive ($360). It is approved by the FDA for use in females ages 9-26. A similar vaccine is in development by GlaxoSmithKline, and may be presented for approval in a year. This is an exciting development because HPV types 16 and 18 are the principal causes of cancer of the cervix, accounting for about 70% of such cancers in the developed world and about 60% in less well developed areas of the world. HPV types 6 and 11 are responsible for about 90% of benign genital warts. Clinical studies of the Merck vaccine were about two years in duration, long enough to document remarkable protection against persistent infection and the early cytological changes (cervical intraepithelial neoplasia, or CIN-II and III) that are the prelude to cancer.[2] The clinical studies were limited to women ages 15-26 but studies of immunogenicity in girls 9-15 show the vaccine is equally immunogenic in children. It is extremely likely that the vaccine will prevent HPV 16 and 18 associated cancers that typically follow persistent HPV infection by many years. The Glaxo vaccine consists of only HPV types 16 and 18 only, but appears equally efficacious in preventing incident HPV infection by the type strains in the vaccine, and seems to provide durable immunity at least up to five years.[3]

It has been clear for decades that cervical cancer is associated with sexually transmitted diseases. Extensive basic and clinical research finally narrowed the cause down to the minority of HPV infections in which HPV DNA integrates into host DNA, persisting for years, down-regulating two important tumor suppressor genes, and eventually leading to cancer. Most incident HPV infections clear due to immune responses in less than two years, but persistent infection is dangerous.

How the Vaccine Works

The vaccine is composed of a combination of viral-like particles (VLPs), made up from recombinant HPV protein L1 prepared from each of types 6, 11, 16 and 18. Protein L1 self-assembles into an empty viral capsid (VLP), and lacking any other viral proteins or DNA, is entirely safe. Conformational L1 epitopes are expressed in the VLPs, undoubtedly important to the vaccine's efficacy. The vaccine is quite immunogenic, and stimulates an antibody response that blocks initiation of infection. Remarkably, the vaccine was almost 100% effective in the clinical trials in prevention of infection by the covered types of HPV, but has little effect against most other HPV types. It also has no effect on already established infection. The Glaxo vaccine, which uses a different adjuvant, also results in a cellular immune response against the vaccine strains and a few very closely related HPV types, and may have limited effects against a few other HPV types.[4]

> *"Public acceptance of this vaccine should help pave the way for acceptance of other STD vaccines, when they become available."*

When Must Vaccination Take Place?

The question is, will the HPV vaccines be accepted and widely used? For them to be effective, they must be used before women acquire HPV, which happens soon after onset of sexual activity. Sexual activity often commences in adolescence,

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whether parents approve or not. Some have worried that a vaccine for a sexually transmitted disease will only serve to promote sexual activity among the young and susceptible. A recent meeting of the Centers for Disease Control and Prevention's (CDC's) Advisory Committee for Immunization Practices (ACIP) recommended widespread deployment of the vaccine in school aged girls 12 and older, and noted that it may be used in girls as young as nine, so as to prevent acquisition of HPV before onset of sexual activity. Clearly this is crucial, since the vaccine has no therapeutic activity for established infection, and must be used before exposure to the virus. This recommendation was hailed by most public health authorities, and the stage is set to find out just how well the public accepts this new vaccine.

Remaining Questions

Many questions about the HPV vaccine remain, including how it can be deployed in populations in the United States, and especially abroad, who are unable to afford its cost. How durable is the immune response? Will booster immunization prove necessary? Will women continue to undergo regular Pap smear testing, which will be necessary because all HPV types associated with cancer are not included in the vaccine? Although the vaccines appear very safe, will large scale use reveal rare and unanticipated side effects? Will use of a vaccine that includes HPV types 6 and 11 lead to use in men, to prevent socially unacceptable, visible genital warts? Will use in men have an impact on their female sexual partner's risk of acquiring genital HPV? On the longer range horizon, can other vaccines be developed that are effective against established HPV infection?

What about the Prospects for Vaccines to Prevent Other STDs?

The triumph of this development effort, culminating a huge effort by scientists across the globe for well over 20 years, raises the question of whether other vaccines for STDs are imminent. Unfortunately, the answer is "no" with perhaps one exception. A huge effort to discover a vaccine for HIV has been entirely fruitless to date. Although there is a bit of experimental evidence that a vaccine for syphilis might be possible, basic research demonstrating antigenic variation of a key surface protein is one of many arguments that a vaccine will be difficult to discover and even more difficult to develop. Gonorrhea and genital chlamydia have stirred only a modicum of vaccine interest, and the results have not been encouraging. The gonococcus is a master at immune evasion and perhaps also immune suppression, and a few small efforts to develop a vaccine have failed completely. There is no enthusiasm among pharmaceutical companies for development of such vaccines, in part because of their difficulty and expense of development, and also undoubtedly because of market considerations. That is unfortunate, because gonorrhea and chlamydia are common diseases in much of the world, with significant sequelae, and in the case of the gonococcus at least, resistance to antibiotics is spreading rapidly.

The one bright spot on the horizon is herpes simplex virus (HSV). This common and debilitating disease, the cause of so much angst in the pre-HIV era, is still very common. It is one of the major causes of genital ulcers that promote the sexual transmission of HIV. A recombinant surface glycoprotein D is undergoing an extensive phase III trial against genital HSV. Early results showed promise in prevention of disease in women who were seronegative for both HSV-1 and HSV-2, although there was little or no effect in women previously exposed to the virus, or in men.[5]

Challenges Ahead

We should rejoice in the advent of a vaccine for HPV. One hopes that concerns of social conservatives about the possible effects of a vaccine for a sexually transmitted disease on sexual behaviors will not limit use of the vaccine, and that means to pay for the vaccine in those who most need it will be found. Recent evidence suggests both the HPV vaccine and a potential HSV vaccine will be widely acceptable to adolescents and their parents.[6] Public acceptance of this vaccine should help pave the way for acceptance of other STD vaccines, when they become available. The HPV vaccine is the second vaccine to enter clinical use that prevents an important human cancer, joining the hepatitis B vaccine. **NCMedJ**

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What North Carolinians Can Expect from the Healthcare System:

Eleven Things Learned During a "Special" Month of Residency Training

Harriett Ravenel Purves, MD, MPH

Most days, residency overwhelms me. To begin with, I am constantly reminded of how much I still have to learn. Despite the years of college and medical school and two years of residency, there are always questions I still cannot answer. Then, there are the long workdays. And, while they are admittedly not as long as they used to be, they proceed at a frantic pace. I almost wish I were allowed to stay in the hospital longer so I could just slow things down, but I am expected to complete my work within an average of eighty hours per week and I am gently scolded when I don't. And finally, there's everything in between—running to code blues, reassuring worried families, returning calls from nurses, social workers and pharmacists, documenting all of the above into the medical record.

Occasionally, during my "good" months, I can get past the hectic days and the intellectual insecurity, but I am left with something equally unsettling. When I have the luxury of time to think about my profession—what I do and the system within which I do it—I am overwhelmed again. I began thinking harder about my profession earlier this year when my father got sick. He was admitted into the hospital twice. He represents a truly fortunate patient—he is well-insured, well-educated, even medically-trained (though he gave up clinical medicine long ago) and he had excellent outcomes. Yet, through two hospitalizations, and weeks of recovery, he had just as much trouble navigating the healthcare system as patients like my non-English speaking, poorly-educated patient from Honduras. It made me wonder: how can this be?

The more I thought about it, the more I wanted an answer. My father's illness came up in conversation with other physicians and I kept prodding them for ideas. My colleagues had plenty of examples of the mysterious ways in which the healthcare system works (or fails to work). I decided to investigate further. As part of my second year training, I had a really good month, a "special" month (as it appeared on my web-based residency schedule) coming up. These special months are built into training to allow residents to pursue research, design a focused rotation or work in another city or country. So, for my special month, I set about to ask and answer my question: "How can this be?"

> *"My colleagues had plenty of examples of the mysterious ways in which the healthcare system works (or fails to work)."*

I phrased the question in general terms. I asked, "What can North Carolinians expect from the healthcare system in the coming years?" I emailed the question to different healthcare professionals I thought would have strong opinions on the matter. I asked them to meet with me to discuss their thoughts. I also asked them to suggest reading material and the names of other people who might be willing to talk with me. The response surprised me. Almost everyone I asked agreed to sit down with me for thirty minutes—which inevitably turned into an hour. They were extremely generous with their time and gave me a lot to consider.

Among the people I interviewed were department chairs, heads of professional societies, health services researchers, public health employees, and primary care physicians. Each person I interviewed had a different perspective, but there were overlapping themes. Though many were pessimistic about the state of the

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healthcare system, I was inspired by the thoughtfulness of their answers and the glimpses of hope I found in each interview. I chose eleven ideas that came from the interviews to write about in this article. Because I realized it would be impossible to attribute each point to a single interview, I have thanked the interviewees collectively at the end. But what I learned did not come solely from my conversations with them; I must also acknowledge and thank my father, who has recovered completely and is in good health; the rest of my family, who provide me with plenty of fodder; and my patients, who bravely put up with the healthcare system in the face of illness and who have taught me the most of all.

1. The Healthcare System is Broken.

I am sorry to say that the word "broken" was used most often to describe the healthcare system during my special-month discussions. Other words often used to describe the healthcare system: complex, unpredictable, chaotic, fragmented, flawed, inaccessible, out-of-control, and worst-in-the-world. (Some of the people I interviewed were more pessimistic than others.) I am sure there are some out there who think things are just fine with healthcare, but I suspect those people work in some subsection of healthcare that has managed to remain unaffected by the larger system. And, I am sure some healthcare workers actually make a point of avoiding the larger system—those who have gone into "concierge medicine" where they explicitly spend more time with patients and often accept only cash payments so as to avoid the reimbursement systems. Everyone I spoke with, however, works under the umbrella of the larger healthcare system and they had plenty of stories to back up their use of the word "broken."

I came into the month with my own stories about the shortcomings of today's healthcare system—my stroke patient who needs physical therapy, but cannot find anyone to provide it because she is uninsured; my hepatitis C patient who does not qualify for a liver transplant because of her weight, but can't afford any weight-loss programs; my newborn baby diagnosed prenatally with abnormal kidneys, but whose parents never followed up because of transportation issues.[1] In some cases, I blamed myself as much as the system for these shortcomings. I should be able to work around these obstacles. Surely I could find a physical therapist who would do pro bono work if I looked hard enough. And there must be some way to help my hepatitis C patient lose weight without a costly program. Maybe, with experience, I will learn all the tricks required to get around these system roadblocks.

But the people I interviewed, despite their experience, had as many frustrations as I did. One pediatrician who works at one of the very few clinics that provides care for a large number of Spanish-speaking patients told me that the hospitals in the area refer almost exclusively to her clinic when Spanish-speaking patients need primary care. That means she and her partners get almost all of the newborn babies from the local hospitals born to Spanish-speaking patients. So their appointment book fills with newborn and well-baby appointments (since babies need far more visits in the first year of life than their later years). With all the well-baby appointments, there is not much room left for "sick" visits. So, when a child who is an established patient of her clinic gets an ear infection, instead of being able to make an appointment for an $85 clinic visit, he may wind up in the emergency room where his parents will likely get charged as much as $600.

To make things worse, if that child is uninsured his family will be responsible for the full amount. If the child is insured (by an insurance company with a negotiated rate for its beneficiaries), on the other hand, the hospital may accept as little as $200 as payment in full from the insurance company.[2] What's more—and to add to the potential complexity of this hypothetical example—the child with the ear infection may get antibiotics as treatment or he may get a prescription for antibiotics and recommendations about when to fill it or his parents may get reassurance and be asked to follow-up in a few days. All three options are acceptable under the AAP (American Academy of Pediatrics) guidelines regarding treatment of acute otitis media.[3]

While this example highlights the unpredictable and inefficient way things happen, at least the child will get treated. There are plenty of places in the world where healthcare is not even an option. Most everyone I interviewed qualified their (horror) stories about the healthcare system by saying that it is still possible to get good healthcare in the United States. In fact, depending on the medical problem, you may be able to get some of the best care in the world. Even if your illness is routine, there are doctors who go above and beyond to make things happen in spite of the system. Within the broken system, there are success stories and I heard some during my conversations, just not as many.

2. In Order to get Good Care, You Need to know How to Work the System.

As I mentioned in my introduction, my father got sick earlier this year. He had high fevers and did not feel well at all. Eventually, when he could no longer work (the ability to work being his and many patients' measure of health) he went to an urgent care clinic. It was a Saturday, and his primary care office was not open. From Urgent Care, he was sent to the hospital emergency room. No one there could figure out exactly what was wrong with him, but he appeared seriously ill and, much to my family's relief, he was admitted to the hospital. There were not many clues to go on, but in rather short order, his doctors discovered he had a liver abscess, ultimately of unknown etiology. He underwent CT-guided drainage and started on a long course of intravenous antibiotics. His story falls into the category of a "success story." Before he left the hospital, in a moment I try to remember when I'm deep in the grunt-work of residency, he told the attending physician, "You saved my life."

He never complained about the care he received, but there were plenty of bumps on the road to recovery. At home, when his drain stopped working, he asked me who he should call. The system has changed a lot since he was in medical school and he didn't know who was "in charge" of his outpatient care.

I asked him where his doctors had scheduled him to follow up. He had an appointment in the infectious diseases clinic, so I suggested he call there. Fortunately, he works at the same institution where he got his care and he knew the infectious diseases attending physician who was assigned to his case. He paged the attending to let him know about the blocked drain and another CT was arranged to see if the abscess had drained completely.

I wonder what would have happened if he'd called the office number and had to go through the secretary and nurse. It might have worked out, but it helped that he could go straight to the person who could make things happen. Even when patients are not connected in the traditional sense, they sometimes get lucky and make connections. One of my patients, for example, has figured out that the hospital operator will page me directly if she calls during business hours. I am not sure if she says something special—I would think more patients would call me this way—but she always gets a hold of me. Many more patients, I am afraid, are getting the run-around…endless automated messages; unhelpful, overburdened secretaries answering their calls; appointments made months in the future. Even when I decide to make some of the phone calls myself—to make a subspecialty appointment, for example—it seems I'm just as likely get the run-around. (And, from what I hear around the hospital, it doesn't seem to change even when you are an attending.)

I spent a lot of time during my special month pondering what it means to have "connections" and how people have learned to "work the system." The examples I came up with reminded me of the time I've spent in developing countries. In my travels, I found that having connections is sometimes the only way to get anything done—not just in health matters. Realizing that working the healthcare system in the United States is not that different from making more mundane things happen in the third world made me wonder how long will it be before the overburdened secretaries start accepting bribes to get people seen sooner. If things don't change, it might not be too long until the equivalent of a healthcare black market emerges in which the only way to get things done efficiently is to go around the official system.

3. In America, Healthcare is a Commodity.

In all of my interviews, the topic of healthcare inevitably turned, at some point, into a conversation about business and economics. No matter what your perspective, discussing our healthcare system inside a capitalist framework is inevitable. For better or for worse, it is impossible to separate the humanitarian aspect of caring for the patient from the financial aspect. In medical school, I learned from one preceptor that I should not ask about a patient's insurance status because it should have nothing to do with the way I would treat them. That made sense to me; I shouldn't treat a patient any differently based on his/her ability to pay. A few years later, though, I learned from another preceptor—this time at a community health center—that she essentially asks all her patients about finances. Though she had found an indirect way of getting that information—by asking, "How do you get your medicines?" She didn't want patients to think she might treat them differently if they did not have insurance, but she also wanted to make sure they had a way of getting the medicines she prescribed. That made sense to me as well; what is the point of prescribing something that the patient has no hope of getting? It comes back to the same question: who is going to pay?

Healthcare as a commodity has some strange effects on our practice of medicine. One physician described the "perverse incentives" generated by the healthcare market. The business goal is, "to get as many procedures done as quickly as possible." Maybe, we decided, if you are an aesthetic dermatologist, this philosophy makes sense. Both you and your patients would benefit from the increased number of procedures. In most instances, though, the goal of "throughput"—getting patients through the system and generating the highest number of procedures—may not be such a good idea…especially if you can't be sure how much your procedures actually benefit your patients. And knowing which patients will benefit from which procedures is not as straightforward as I once thought. It takes time to investigate a patient's history and to decide, given his specific circumstances, if he should go through with a certain procedure.

What may appear to be an obvious answer to an obvious problem is not always clear. For example, if a patient has blockages in his coronary arteries, surgery to bypass those blockages seems the obvious answer. Having done two months of adult cardiology as a resident, it came as a shock to me that some physicians argue, based on existing evidence, that very few people should undergo coronary artery bypass grafting.[4] The argument is that bypass grafting may not really change how long a patient lives and, there are significant risks associated with bypass operations. I can appreciate this argument because I have now seen many instances where the effects of treatment ended up being worse than the disease. Debates like this one make me question the interventions I advocate on a daily basis in the name of cure. Depending on my mood, I start to wonder if I am accomplishing what I set out to do—that is, am I helping people? Or am I just an unwitting cog in a system set up to generate money? The business aspect of medicine certainly adds several degrees of complexity to the system.

On the other hand, if it weren't for the business of medicine we wouldn't have some of the state-of-the-art treatments that make a real difference to certain patients. Plus, using a business framework to improve healthcare has proven useful again and again. Many quality improvement plans, for example, are based on business concepts utilized by car manufacturers and air flight controllers to obtain higher quality. One such concept is that variation is a sign of poor quality. Collecting and analyzing data about variation within a business is critical to the process of improvement.[5] Hence the innumerable guidelines now published on a variety of disease entities, which are meant to reduce variation in the practice of medicine. So, treating healthcare as a commodity and the healthcare system as a business has its advantages. In fact, after thinking more about it, I realized that maybe we need to convince more patients to think of health itself as a commodity.

4. Patients Don't Desire Health the Same Way They Desire an Ipod.

For most people, health is an abstract concept. When we are healthy, health is something we almost never think about. We are not actively seeking health in the same way that we might seek the latest MP3 player or flat-screen TV. It surprises me when I meet patients who plan their lives around staying healthy, people who, for years on end, exercise daily and eat the recommended number of vegetable servings, etc. The occasional patient may simply be wired that way, but most people don't make dramatic lifestyle changes until actually experiencing illness in one way or another. I have a patient who finally quit smoking when his wife was diagnosed with lung cancer, for example. The female rap star, Missy Elliott, worked to lose a significant amount of weight after her doctor told her she had high blood pressure. Fear of illness can be a tremendous motivator. But can we motivate "well" people to actively seek health?

One pediatrician I interviewed said that if she taught in the elementary schools, she would make every child bring in a family tree that included medical histories of each relative. She would use the trees to talk about why the children should want to control their cholesterol and weight. I'm afraid that even a family tree might still be too abstract. Studies examining the use of smoking prevention and cessation techniques with kids found that seeing pictures of atherosclerotic aortas and smoke-blackened lungs scared some children into healthy lifestyles, but not the majority of them.[6] Another pediatrician talked about showing pictures from an era gone by to the young parents who don't want their kids to be immunized—pictures of when children were devastated by vaccine-preventable diseases. He thought it might change their minds. But if direct visual examples don't work for kids, I'm not sure they will work for their parents.

So how do we motivate people to actively seek health? And if we decide that scaring people about the prospect of illness is the most effective technique we have, are we willing to accept the consequences of instilling those fears? Acting on fears may backfire in ways that are difficult to predict as the example in the next section points out.

5. People Avoid Changing Jobs for Fear of Losing Health Insurance.

The fact that people stay in jobs because of wage-related benefits is not a new observation. It's probably been as true for workers in the distant past as it is now. But the trend is more worrisome now because, these days, business relies more heavily on the flexibility of the workforce. If workers are reluctant to move into new positions—positions available to them presumably because they have skills that could be put to effective use—jobs for skilled workers remain unfilled and our economy is less efficient. There is good reason to think twice before leaving a job that has health insurance: fewer businesses are offering health coverage and even if a new job promises insurance, it will likely cost you more.[7]

Another problem with new employer-based health insurance is that its benefits may not kick-in right away. Since we know that insufficient insurance can end up costing the system more money, waiting for benefits to kick in must cost the system, too. As an example—my own insurance. Until this year, medical residents in my training program were not eligible for the Family Medical Leave coverage (or the equivalent) until they had been working at the hospital for at least one year.[8] Accordingly, first-year residents in the past may have consciously delayed childbearing. I recognize that there are many other reasons a woman might delay childbearing; but, for some, this was probably an important one. I can imagine that for the unlucky individual, waiting a year could mean the difference between fertility and infertility. And that could mean the difference between a straightforward pregnancy/delivery and a more complicated, expensive pregnancy and delivery. During my special-month interviews, I realized that the link between jobs and insurance is increasingly problematic.

6. Big Business will Lead the Way to Reform.

Wal-Mart has been the target of much criticism about its benefit programs, specifically its healthcare benefits.[9] In 2004, it was even the target of an advertising campaign to drum up support for California's Proposition 72, legislation that would have expanded healthcare coverage in that state. The ads criticized Wal-Mart for not offering affordable healthcare to its employees. The company decided to get involved in the debate.[10] Healthcare expenditure is a big deal for all large corporations—not just because it costs them money, but also because healthy workers are more productive than sick ones. Because of this, more companies are joining the debate about who should pay for healthcare. Some companies, like Chrysler, have publicly supported universal, national health coverage.[11] Others have an interest in keeping the healthcare system more or less the way it is.

Big corporations spending a significant amount of money on healthcare for their employees should have an interest in reform. But, I would expect insurance and pharmaceutical companies, whose profit margins depend on the money spent on healthcare coverage—to support the status quo. I learned, however, during one of my interviews, that Dr. Jean-Paul Garnier, the Philadelphia-based CEO of GlaxoSmithKline (GSK), supports a national healthcare system. What he proposes would cover catastrophic care and help cover people who are between jobs or whose employers do not provide coverage.[12] I suppose that having more people insured—even if it only includes bare-bones coverage—would free up more of a patient's income to pay for his medicines. This could explain why Garnier would be in favor of such a plan. And maybe it is wise to advocate for this plan before another type of plan—one that would allow the government to get big discounts on GSK pharmaceuticals, for example—comes up for debate.

Still, his support of some type of national healthcare system suggests that there is a will on the part of big business (and there is certainly the power) to lead the way to reform. So, we had better make sure big business's way jibes with what physicians and other healthcare professionals want. Accordingly, several of the people I interviewed stressed the importance of allying ourselves (in the medical profession) with business. North Carolina has worked hard to attract big business to the state. Now that big business is here, maybe we should work harder to align our goals on issues that affect us both equally—issues like healthcare.

7. Technology has Increased Costs and Caused Physicians to Specialize.

During my special month, the theme of technology came up just as much as the theme of business. "It used to be that premies born before a certain gestational age just died," one pediatrician reminded me. Technology has changed that. Now we keep babies alive who spent just over half the usual time in their mothers' wombs. And many of them (depending on your perspective of what percentage constitutes "many") grow up with no measurable deficits. Not long ago, one of the ER nurses told me that she is a former 27-week premie. "They told my parents I would be blind, but I see just fine. They also told them there could be mental delays…the jury's still out on that," she joked. Thanks to ventilators that can pump air into their fragile, tiny lungs in just the right way, these babies are much more likely to survive. Likewise, it is not just "any pediatrician" who helps them make it into childhood. Most often, it is a neonatologist, a specially trained pediatrician, who understands those ventilators inside and out, among other things.

It is hard enough to keep abreast of the new technologies available in a single field such as neonatology; it is impossible to keep abreast of all fields in medicine. There are a few souls who appear to know everything (there is one sitting in every morning report I have ever been to), but they must not sleep or eat. No normal human being can keep up with all the information out there. More commonly, and more understandably, I meet specialists who know everything there is to know about their specialty, but may not have kept up in other areas.

A specialist is responsible for knowing a limited set of diagnoses, treatments and management guidelines. A primary care physician, on the other hand, may not have to learn new technologies, but has to keep track of all the guidelines to make sure that the patient is getting the recommended care—whether it comes from the primary care physician or from the specialist. The primary care physician has to coordinate and synthesize the care from a multitude of specialists who may be working with a single patient. That task requires intense organization, clear communication and quite a bit of time and patience. As a resident, I respect the power of technology and the knowledge of specialists, but I also have newfound respect for primary care providers.

8. Physicians Don't Go into Primary Care Because They Dread It.

It finally dawned on me why residents, as a rule, dread going to clinic. Most residents spend a half-day a week in clinic. The rest of the time we are in the hospital. The outpatient world operates differently and it requires a separate skill set. I cannot speak for all residents, but my visits to clinic are just frequent enough to make me painfully aware of my inadequacies. Give me the eighty-year-old Alzheimer's patient who has been rejected by every nursing home in the tri-county area and I will find placement. Give me the new-start dialysis patient and I will make sure vascular interventional radiology places a permcath before the day is out. But, give me an otherwise healthy young woman with sinus problems and I am clueless. I am never quite sure of my role when caring for my clinic patients. How much should I do for them? How much should I expect them to do for themselves?

One internist explained the problem to me this way, "With inpatient medicine, there's a sense of control. If you're in the medical ICU you can control a patient's blood pressure, his breathing, his blood sugar. With outpatient medicine, you have no control. You don't know if a patient will take the medicine you've prescribed or go for the mammogram you scheduled. It's a psychological issue." By psychological, he meant that, in the hospital, you have a completely different mindset and it's hard to turn it off and on. While the rewards of outpatient medicine seem greater (I cannot describe how great I felt when my first patient told me she quit smoking because of something I said to her), the frustrations also seem greater (I also cannot describe how guilty I felt when I failed to prevent my obese, diabetic patient with coronary artery disease from going into the hospital each time—seven times in the past year). The same physician who told me about the psychology of control reassured me, "You have to realize that there are 10-15% of patients who won't do well…even if you're Sir William Osler and Mother Theresa all in one."

9. Doctors Can Make a Difference.

If you have gotten this far, despite all the discouraging news, relax…here comes the uplifting part. Several of my interviewees reminded me that doctors do make a difference. We may learn tomorrow that for the past twenty years we have been treating [insert any number of disease processes here] all wrong, but we will likely still make a difference to the patient suffering from that disorder just by supporting him/her through it. I think it means a lot to a patient simply to learn about what ails him/her—it gives him more control. For the families struggling with a loved one compromised by illness, doctors can also offer great comfort. Many have written about the patient-doctor relationship and, though I will not dwell on it here, despite the chaotic system in which we work, I came away from my special month convinced doctors can and do make a difference.

10. We Need to Get Smart, Old People Energized.

This piece of advice came from a newcomer to North Carolina who told me that the fastest growing population in our state is the one made up of older adults. This surprised me since my background includes work with the Latino population and a commonly touted fact is that North Carolina has the fastest growing Latino population in the country. The latter fact may be true, but the elderly population is larger and growing at an even faster rate. The baby boomers are aging into this population and elders from other states are migrating to North Carolina. Of course, not every person over "retirement age" is retired. And the working elderly population may be one of the most respected and influential groups in the state. It also happens to be a group that relies more heavily on the healthcare system.

To add to this idea, I would say that we need to get smart, old doctors energized. I don't mean to offend and reader with my choice of wording—I only say it this way to point out that there is a fair number of retired physicians in North Carolina's older population. And who better to advocate for change than those who are intimately familiar with the provision of healthcare? Retired doctors (in my mind) have "special months" one after the other. So they might have time to push legislators on these issues. And I would like to issue a challenge to them to complain.

The same person who spoke to me about the retired population —a Yankee—remarked how little North Carolinians seem to complain. For example, if more people of my father's generation started to make a stink about the hoops they jump through to get an appointment or prescription drugs, change might happen sooner. After thinking about this more, the thought of driving to the nearest retirement community (there is one less than half a mile from my house) to encourage elders to complain crossed my mind. But all good (and "special") months come to an end. Before I knew it, I was back in the hospital most of my waking hours. Starting a movement did not appear feasible anymore. Fortunately, I had come up with another way to do something that I can do even on my bad and even really bad months.

11. Participate in Professional Societies.

There were mixed opinions about this advice, but more of the people I interviewed supported it than not. Part of my motivation in designing my special month stemmed from my growing obsession with choosing a career path. Without explicitly using the words, the question, "What should I do with my life?" came up implicitly in every interview. I tried to explain my general goals to see if the interviewee would come up with a specific job description. One physician swiftly diagnosed me, "You have the same disease I do. You want to change the world." I have been accused of this in the past and even been mocked for it. It may be naïve, but I still have hope.

Before my special month, I believed that a single, carefully chosen job would allow me to accomplish my divergent and unwieldy goals, which include knowing everything I possibly can about internal medicine and pediatrics, becoming a trusted doctor for a wide range of patients, staying in touch with healthcare trends and policies, and maintaining a balanced lifestyle. Again, I freely admit the naivete behind this belief. Fortunately, this last piece of advice may have saved me, particularly with regard to staying in touch. There just may be a way to step back and keep abreast of what is happening generally in medicine and the healthcare system—even, when I spend every fourth night in the MICU or, later, when I become an attending…namely, participating in an organized group of my professional peers.

For the past two years, I have shamelessly deleted the email invitations to local meetings of the different state and local medical societies because I thought it would take away too much of my prized free time. But I am going to try a meeting or two because I realized during my special month that contact with other people interested in the challenges of the healthcare system—importantly, outside of the hospital and clinic—reenergized me. I may not have found all the answers during my special-month interviews, but I was inspired and motivated by the thoughtfulness of the excellent clinicians and thinkers who spoke with me. I hope to have many chances to continue the conversations we started. **NCMedJ**

Acknowledgements: The people I interviewed all contributed significantly to my month and to my education in general. I am truly grateful. In alphabetical order, they are: John Buse, Chief of the Division of Internal Medicine and Clinical Epidemiology, UNC-CH; Timothy Carey, Kenan Professor of Medicine and Director, Cecil G. Sheps Center for Health Services Research, UNC-CH; Darren DeWalt, Assistant Professor of Medicine, UNC-CH; Robert Gutman, Durham Nephrology Associates; Nortin Hadler, Professor of Medicine and Microbiology/Immunology, UNC-CH; Harvey Hamrick, Director, Pediatric Resident Training Program, UNC-CH; Peter Morris, Medical Director, Wake Human Services; Rick Mumford, Senior Assistant to the State Health Director for Health Disparities and Workforce Development; Thomas Ricketts, Professor of Health Policy & Administraton and Deputy Director, Cecil G. Sheps Center for Health Services Research, UNC-CH; Marschall Runge, Chairman, Department of Medicine, UNC-CH; Steve Shore, Executive Director, North Carolina Pediatric Society; Evelyn Schmidt, Director, Lincoln Community Health Center, Durham; Pam Silberman, President & CEO, North Carolina Institute of Medicine; Alan Stiles, Chairman, Department of Pediatrics, UNC-CH; Elizabeth Tilson, Medical Director, Community Care of Wake/Johnston County; Brian Toomey, Chief Executive Officer, Piedmont Health Services; and Charles Willson, President, North Carolina Medical Society and Department of Pediatrics, East Carolina University, Greenville.

REFERENCES

1 My sister, a social worker, pointed out that the stroke patient and the obstetric patient might qualify for Medicaid, the first because she is disabled and the second because she was pregnant. Unfortunately the first patient is not a citizen and therefore does not qualify for Medicaid. The second, also not a citizen, probably did qualify for Emergency Medicaid, which covers many costs of prenatal care and delivery for noncitizens. She may have been able to get Medicaid van services during her pregnancy, but if she was, she was unaware of this possibility and did not show for a repeat ultrasound.

2 There are some very good examples presented in: Rosenbaum, Michael. Hospitals: Is the Price Right? 60 Minutes March 5, 2006. CBS Broadcasting. Available at: http://www.cbsnews.com/stories/2006/03/02/60minutes/main1362808.shtml.Accessed April 2006.

3 It depends on your interpretation, but I think all three possibilities seem to be consistent with the guidelines. See American Academy of Pediatrics Subcommittee on Management of Acute Otitis Media. Diagnosis and management of acute otitis media. Pediatrics. 2004;113(5):1451-65.

4 One notably vocal physician advocating this stance, and one of my inerviewees, is Norton Hadler. See Hadler, NM. The Last Well Person: How to Stay Well Despite the Health-Care System. Montreal: McGill-Queen's University Press, 2004.

5 One such project being piloted in North Carolina is called Improving Performance in Practice, personal communication with Darren DeWalt.

6 Historically, it is difficult to assess the specific strategy of using scare tactics in a field such as smoking prevention. Analyses of programs targeted at adolescents usually include those that include scare tactics into a broader category making it hard to know which tactic produces which effect.

7 The Kaiser Family Foundation conducts an annual survey about Employer Health Benefits. The 2005 survey documenting these facts is available at http://www.kff.org/insurance/7315/index.cfm. Accessed June 2006.

8 Now the residency program will cover leave from your first day of employment, though it does not technically count as leave under the Family Medical Leave Act until you have worked there 1040 hours. The new policy is available at: http://www.unchealthcare.org/site/residency_home/resForms/04_fmla.doc. Accessed June 2006. I confirmed the old policy via telephone with the UNC Office of Graduate Medical Education on 6/27/06.

9 A summary of some of the criticisms can be found in a November 2004 Frontline piece, available at http://www.pbs.org/wgbh/pages/frontline/shows/walmart/transform/protest.html. Accessed April 2006.

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12 As reported by Chris Mondics. Glaxo's CEO: Insure Everyone. Philadelphia Inquirer April 18, 2006 available at http://www.philly.com/mld/philly/business/14364857.htm

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North Carolina MEDICAL JOURNAL

One of North Carolina's Largest Philanthropies Supports and Listens to HIV/AIDS Service Providers

Edgar G. Villanueva, MHA

One of the target populations served by the Kate B. Reynolds Charitable Trust (KBR) over the past decade has been low-income North Carolinians with HIV/AIDS. In the past five years, grants totaling over $2.4 million have been made to HIV/AIDS service organizations across the state. While grants have supported prevention efforts, access to primary care, mental health, and end-of-life services, the vast majority of the grants have been for the provision of case management services for HIV/AIDS clients. Case managers play a pivotal role in the health of individuals with HIV/AIDS. For example, case managers conduct comprehensive needs assessments, then develop and manage service plans with clients. They advocate for clients, make appropriate referrals, and link them to public benefits, medical care, mental health services, and substance abuse treatment. They often provide basic counseling and crisis intervention as well.

In January 2006, KBR convened 24 HIV/AIDS service providers, mostly case management agencies, to listen and learn first-hand of the challenges facing the agencies who daily serve this vulnerable population, many in rural, underserved counties. At this gathering, KBR garnered information from those who may be one of the most important links in providing comprehensive, continuous care to HIV/AIDS patients.

When asked what the significant healthcare needs in their communities were regarding HIV/AIDS, the greatest need identified was the lack of access to primary medical care and dental services for HIV/AIDS clients. Other significant needs described were housing and medications. When asked about some of the barriers their agencies faced in delivering HIV/AIDS services, four key issues were noted. The issues were lack of ongoing operating support, education for clients and the community, lack of transportation for clients, and the stigma associated with HIV/AIDS.

Next, KBR inquired about the methodologies (treatment or prevention) that the agencies considered to be most effective in providing HIV/AIDS services. Overall, education and awareness were considered to be the most effective in the prevention and treatment of the disease. Other methods were face-to-face interventions, prevention presentations by HIV+ clients, and outreach and testing. Many agencies commented that they saw the most successful outcomes from one-on-one interventions, especially when HIV+ individuals were involved. These individualized approaches are more effective than social marketing campaigns, particularly in smaller, more rural communities where stigma has prevented the broadcast of HIV/AIDS-related messages. KBR also learned that the agencies most often obtained information about best practices in disease prevention and treatment from the North Carolina HIV/STD Prevention and Care Branch. This is not surprising as the agencies rely on the state for their certification, training, and the majority of their funding. In those communities where Infectious Disease physicians are available, local service providers also relied on these physicians to keep their staff informed.

As KBR learned from the January session, many HIV/AIDS service providers are 'spread thin,' causing them to work in silos, unaware of what their sister agencies are doing. In addition, they often feel disconnected from the medical community. One solution proven to impact this issue is demonstrated through an innovative KBR grant to the Western North Carolina HIV/AIDS Consortium in Asheville for a case manager coordinator. This position served as a point of contact in a 17-county area for 18 case managers. The coordinator ensured that case managers in rural areas had equal access to information and services as those in Asheville.

Despite the efforts of the healthcare and philanthropic community, the number of HIV-infected persons continues to increase. As of July 2005, there were 18,900 individuals living with HIV/AIDS in North Carolina. Many counties with the highest number of cases are among the poorest and most rural. As the number of infected individuals continues to rise, the North Carolina healthcare community and its partners should not overlook the role of community-based case managers in providing and supporting continuous care. Opportunities for collaboration and partnership are ripe to influence health outcomes for this population. **NCMedJ**

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Running the Numbers

A Periodic Feature to Inform North Carolina Healthcare Professionals about Current Topics in Health Statistics

From the State Center for Health Statistics, NC Department of Health and Human Services
http://www.schs.state.nc.us/SCHS

Interpretation of Sexually Transmitted Disease Surveillance Data

By law, all cases of chlamydia, gonnorhea, syphilis, and HIV infection in North Carolina must be reported to the appropriate county health department. The information is then forwarded to the HIV/STD Prevention and Care Branch in the North Carolina Division of Public Health in Raleigh for compilation and aggregate reporting to the Centers for Disease Control and Prevention (CDC). The Branch publishes the data in the form of summary counts and rates. Correct interpretation of these published rates requires some knowledge of how the cases are detected and reported.

Chlamydia

The most prevalent reportable sexually transmitted disease (STD) in North Carolina is chlamydia. It is also the disease with the least reliable surveillance data. Cases of laboratory-confirmed chlamydia must be reported to the local health department within seven days. The surveillance problem lies in the fact that chlamydia is most often asymptomatic in both males and females. It is also a major cause of pelvic inflammatory disease (PID) and infertility in females. For this reason, there are a number of programs targeting asymptomatic young women for screening. There are virtually no comparable state programs for screening young men. Most male cases are detected and reported when infected females encourage their male partners to seek care. As a result, chlamydia case reports are highly biased towards screened populations, i.e. young women attending public clinics. In 2005 there were 31,183 cases reported in North Carolina, and more than 80 percent were female.

So how do we interpret the published data? Surveillance data are a very poor indicator of trends in chlamydia incidence. In fact, the growing number of case reports over the last five years is primarily due to the expansion of screening programs, an indication of positive public health activity. However, the surveillance data can provide some useful information. Recognizing that a great many chlamydia cases remain undetected and therefore unreported, the reported cases represent a lower boundary of the estimated prevalence of the disease in North Carolina.

Gonorrhea

Gonorrhea is the second most frequently reported STD in North Carolina, with 15,075 laboratory-confirmed cases reported in 2005. In contrast to chlamydia, nearly all gonorrhea cases among males are symptomatic and females are only slightly less likely to have symptoms. This means that many infected people will present for care and, if gonorrhea testing is ordered, their disease will be detected and reported. Additionally, many asymptomatic young women are screened for gonorrhea during chlamydia screening.

As a result, gonorrhea reporting is quite reliable and has no apparent gender bias (in 2005 50% of North Carolina cases were male and 50% were female). It is possible that public STD clinics may be more inclined than private healthcare providers to order gonorrhea tests (as opposed to presumptive treatment without testing). This tendency, and the female screening programs in public clinics, may lead to some reporting bias towards patients who attend public clinics, but this is difficult to assess. Gonorrhea reports have declined steadily for the last eight years and this is most likely due to a real decline in incidence of the disease.

Syphilis

All reactive syphilis tests must be reported to the local health department within 24 hours. Each individual reported will be investigated thoroughly to determine whether or not the person is infected at all and, if so, whether the infection is a new one or a failed treatment of a previous one. If the infection is new, the appropriate stage must be diagnosed as well. This investigation is conducted by local or regional health department personnel and can take days or weeks. Patients are interviewed to help determine their stage of infection and to identify sexual partners who have been exposed. These partners are then interviewed and tested for syphilis.

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The early stages of syphilis have very distinct symptoms which makes diagnosis errors unlikely. In the later, asymptomatic stages, interviews are needed to establish the time of the infection and therefore the current stage. In general, reporting of early syphilis (primary, secondary, and early latent) in North Carolina is likely to be quite accurate.

Syphilis is much less common than chlamydia or gonorrhea (only 489 cases of early syphilis were reported in 2005). It is also viewed by providers and public health officials as being a much more serious disease. These factors make it much more likely that suspected syphilis cases will be tested and reported. Good initial reporting and thorough contact tracing of related cases make syphilis surveillance data the most reliable and complete STD data available in North Carolina. A small number of cases will always be missed by surveillance, but trends in early syphilis incidence mirror the true incidence in the population more closely than is the case for any other STD. The rate of early syphilis in North Carolina declined by approximately 50% from 2001 to 2005, due in large part to comprehensive public health control efforts.

HIV and AIDS

AIDS, the syndrome resulting from HIV infection, has been reportable in North Carolina since 1984, while HIV infection itself has only been reportable since 1990. Physician diagnoses must be reported to the local health department, which then forwards them to the state. In addition, laboratories must report HIV-positive results directly to the state. As previously described for syphilis, North Carolina has thorough contact tracing and partner notification programs for all cases of HIV infection and AIDS. Many cases are detected when the partners of HIV-infected index cases are interviewed and tested.

Because HIV infection is largely asymptomatic for many years, early detection is very dependent upon whether or not infected people are screened for the disease. This can lead to many of the same problems described previously for chlamydia — the surveillance data reflect the population that receives screening. In the early years of the epidemic, such screening was closely targeted to groups known to be at very high risk of infection. e.g., men who have sex with men and injection drug users. In recent years, HIV testing has been more widespread and public health messages have stressed that "knowing one's HIV status is part of good sexual health." However, the CDC estimates that currently one-fourth to one-third of all people infected with HIV have not been tested and therefore have not been reported with HIV infection.

When an HIV-infected person meets certain criteria (lowered CD4 cell counts, acquisition of certain infectious diseases, etc.) they meet a case definition for AIDS.

Because AIDS is generally symptomatic, it is likely that AIDS reporting is more complete than HIV reporting. However, some providers may be unaware that a patient previously reported with HIV must be reported again when AIDS case status is met. Also, approximately 30% of new HIV infection reports are among people who have already met the case definition for AIDS.

Because the stage of AIDS occurs very late in the course of HIV infection, AIDS surveillance data are not useful in evaluating the current epidemic trends. These data are most useful in assessing the prevalence of AIDS cases and the need for resources for treatment. Surveillance data for HIV disease (the first report of HIV infection, regardless of stage) are a better indicator of which groups are currently at highest risk. In 2005, there were 1,806 new HIV disease cases reported in North Carolina.

Finally, it should be noted that changes in case detection methods will have an impact on how many STD cases are reported. In May of 2004 the State Laboratory of Public Health changed to a more sensitive test for chlamydia. This immediately caused a slight increase in case reports as more tests were found positive. Likewise, the HIV/STD Prevention and Care Branch instituted some new policies surrounding laboratory reporting of HIV in 2003. This caused a number of "old" HIV cases to be first reported in 2003. The surveillance data reflect this with a noticeable increase in reports for 2003, which leveled off in 2004.

To view copies of published reports from the HIV/STD Prevention and Care Branch, please see our webpage: http://www.epi.state.nc.us/epi/hiv/.

Contributed by Lynne A. Sampson, MPH, Epidemiologist
HIV/STD Prevention and Care Branch, North Carolina Division of Public Health

Hospital Quality and Patient Safety

Notable News from The North Carolina Center for Hospital Quality and Patient Safety

North Carolina Center
for
Hospital Quality and Patient Safety

Rapid Response Teams in North Carolina Hospitals

> *Mr. Smith, a 52 year old male underwent elective knee surgery. Post operatively on the hospital floor, he complains that he is uncomfortable and his respiratory rate has increased to 34 breaths per minute. His SpO2 dropped to 88 percent despite the 4-liters of nasal cannula O_2. The nurse pages the surgeon and twenty minutes later the surgeon calls back with an order to increase the morphine pump and increase the nasal cannula to 6-liters. A half-hour after the increased morphine and O_2 the nurse notes that Mr. Smith is more comfortable. His respiration had decreased to 26 breaths per minute, but his saturation dropped to 85 percent. The nurse pages the surgeon again and the surgeon verbally orders a CXR, ABG, ECG and a CBC and states that he will see the patient as soon as he finishes with his current patient. Forty-five minutes later the labs, CXR and the ECG were completed. Almost three hours after the symptoms were first noted, the surgeon and the code team enter the 52 year old man's room simultaneously. The man was resuscitated and spent the next 10 days recovering from an AMI in the ICU.*

Mr. Smith needed a rapid response team. The North Carolina Hospital Association, in partnership with the North Carolina Area Health Education Centers Program and The Carolinas Center for Medical Excellence (CCME), was one of nine Robert Wood Johnson Foundation grant recipients selected to establish hospital rapid response teams (RRTs). RRTs, also called medical emergency teams, bring critical care expertise to a non-critical care patient at the first signs of physiological instability. The aim of RRTs is to assist care providers to deliver the *right care* to the *right patient* at the *right time*.

In April 2006, 224 participants representing 58 North Carolina hospitals attended three regional RRT collaborative kick-off sessions. In addition to the kick-off learning sessions, the participants have an opportunity to participate in monthly telephone conference calls and receive individual coaching. Monthly on-line data collection assists the hospitals in trending their progress and evaluating their rapid response team processes. Additionally, the participants have access to a secure Web site that contains tools and resources for all the materials accumulated during the collaborative. The collaborative will be completed in March of 2007.

The data collected by the participating hospitals are: percent of codes outside the ICU; codes per 1,000 discharges; rapid response team utilization; and call data-level information, such as reasons for the calls, duration of the call, intervention, and outcome of the call. It is too early in the data collection phase for the hospitals to see the overall impact of their RRTs, but stories of lives saved are abundant and indicate that success is being realized.

Several different models of rapid response teams exist. Some teams consist of an ICU nurse; others have an ICU nurse and a respiratory therapist, and others consist of an ICU nurse, respiratory therapist and a physician. Most often the process that is set up in hospitals is to notify the patient's attending physician of the call as the rapid response team is being activated. This results in decreased delay to assessment and intervention of a deteriorating patient since the team is in the hospital, yet keeps the attending physician informed. It offers an important safety net to both the patient and the

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attending physician. This immediate assessment and intervention is not to question or take over the attending physician's role or responsibility, but to provide an important safeguard.

The case for RRTs is unmistakable. Buist[1] found that prompt assessment and intervention by personnel who are experienced in the evaluation and care of critically ill patients has been associated with a 50 percent reduction in non-ICU arrests. Early assessment and intervention has also been associated with a reduction in postoperative emergent ICU transfers (44%) and death (37%),[2] and reduction in arrest prior to ICU transfer (4% vs. 30%).[3]

In the vignette above, Mr. Smith's scenario of progression to cardiopulmonary arrest occurs to seven out of 1,000 hospitalized patients. One study found that mortality for these patients is 91 percent. Other studies indicate that these patients showed evidence of physiological instability for six to eight hours prior to a cardiopulmonary arrest.[4,5] RRTs will make failure to rescue scenarios, such as the one Mr. Smith experienced, a thing of the past in more than fifty hospitals in our state thanks to the newly launched statewide initiative to establish RRTs in North Carolina hospitals.

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Readers' Forum

To The Editor:

Attitude, Actions and Service at a "Public" Hospital

I am still "manning the clinics" at the University of North Carolina Hospital in Chapel Hill. When I started as a young physician forty-two years ago, there was a sign at the front of the hospital which read: "Built by and for the people of the State of North Carolina."

This service philosophy attracted me a place which has worked hard to educate, to be a leader in medical research, and to provide medical care to all the people of our state. During these years, the costs to accomplish those tasks have greatly increased, and the sources of money have changed. The proportion of the annual budget for education and patient care provided through the UNC Hospitals by the state legislature has dropped to near 10%. All other sources of financing for patient care (e.g., Medicare, Medicaid, private health insurance, etc.) are "managing" their payments for patient services while trying to keep their payments as small as possible, and, in the case of the private insurance companies, to show a profit to their shareholders. The fact that the executives for these companies are getting huge salaries and bonuses is well known and a constant reason to question the yearly announcements of benefit reductions, or increases in co-payments and deductibles associated with these plans and their enrollees.

Those responsible for the "management" of both public and private insurance companies have squeezed the UNC Health System (and all other providers of care), creating make-believe charges (such as $2 for an aspirin tablet) so that as much money as possible can be retrieved from firms that have negotiated a favorable "discount" for the patients they insure. This is fine, except that those without health insurance (which is over 40% at our institution) are billed for the full charges for their care and are asked to make full payment or negotiate a plan for such.

Administrative responsibility for all of this has fallen to our healthcare system "executives." Our chief executive, Dr. William L. Roper, has worked within the current (in my view, broken) system of healthcare payments to make sure that the budget balance for the institution is favorable. Oversight for the enterprise falls to a board of directors largely made up of people from the business world who have done much to support the UNC Hospitals and to keep their services and facilities excellent. The yearly accounting for this "non-profit" institution shows a substantial "profit" (or revenues in excess of expenses).

The dilemma of squeezing money to deliver care out of those who are sick, needy, uninsured, and outside any support network (such as undocumented immigrants, but including many native North Carolinians with low incomes as well) leads to policies which discourage delivery (and the seeking) of service. For instance, there are now telephone calls to remind patients in our hospitals and clinics which include the automatic message "please be prepared to pay any balance of your bill at the time of the visit," or "you will have to bring $250 or $500 to pay before the study/necessary procedure will be performed."

My impression is that such messages (or "attitudes" reflected in these messages) will often lead a patient without adequate healthcare insurance to forego needed medical care or services, and ultimately to a less-than-optimal health outcome. When this type of "caring" occurs at the same time as incentive bonuses are offered to the administrators who organize this "care" (which can be up to $100,000 per year for some), the "service" focus is lost. We need, as a society, to re-examine the whole system, starting with the UNC Health Care System enterprise, but including all elements of the public and private healthcare industry on which we all depend.

James A. Bryan, II, MD
Professor of Medicine and Social Medicine
UNC School of Medicine
Chapel Hill

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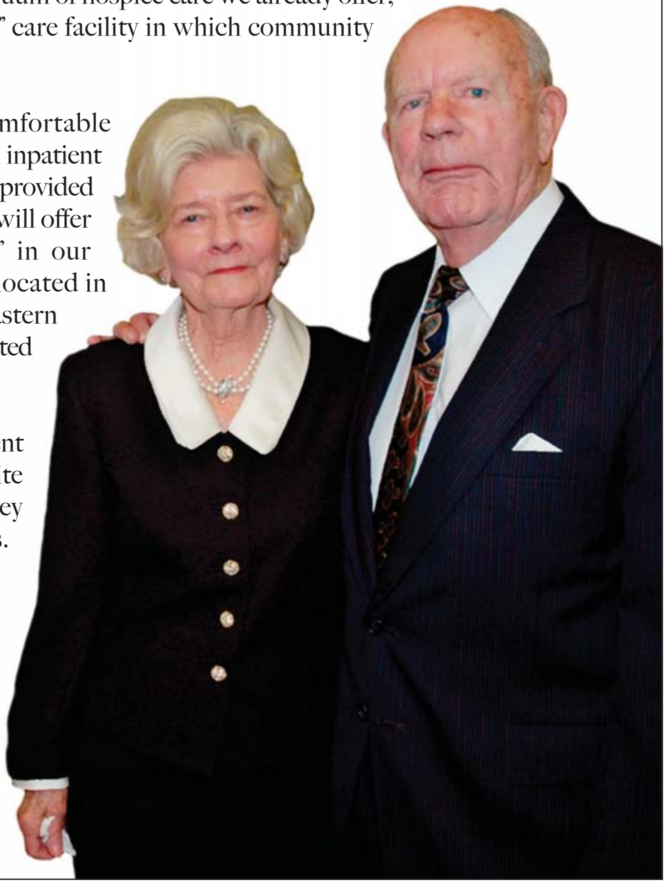
AND IT JUST GOT BIGGER.

SRMC has always believed in the idea of neighbors caring for neighbors. More than a full-service healthcare facility, SRMC is the hub of a comprehensive healthcare system in southeastern North Carolina that offers a wide array of services, such as the newly opened Southeastern Heart Center managed by Duke; five primary care clinics located throughout the county; the Gibson Cancer Center; comprehensive medical imaging services; long-term care; psychiatric care; Southeastern Lifestyle Center for Fitness and Rehabilitation; and home-care services that include Home Health, Home Medical Equipment, and Hospice. Our main focus is giving the members of our community the best healthcare they can receive—throughout their lifetimes.

But this time, we are proud to be on the receiving end of our neighbors' generosity. The generous donation through the SRMC Foundation of local couple Pete and Marguerite Lindsey of Lumberton is enabling SRMC to add, as a part of the continuum of hospice care we already offer, Southeastern Hospice House, an "End of Life" care facility in which community volunteers will play a large part.



While hospice care in the familiar and comfortable surroundings of home is often preferred, at times, inpatient hospice care is more appropriate, and care can be provided more effectively. Southeastern Hospice House will offer inpatient hospice care right here at "home" in our community. Slated to open in early 2007 and located in the former Carolina Manor building, Southeastern Hospice House will include a family lounge dedicated to the memory of the Lindseys' daughter.

SRMC feels honored to be chosen as the recipient of this gift. It's neighbors like Pete and Marguerite Lindsey that make this community special. They truly represent neighbors caring for neighbors.

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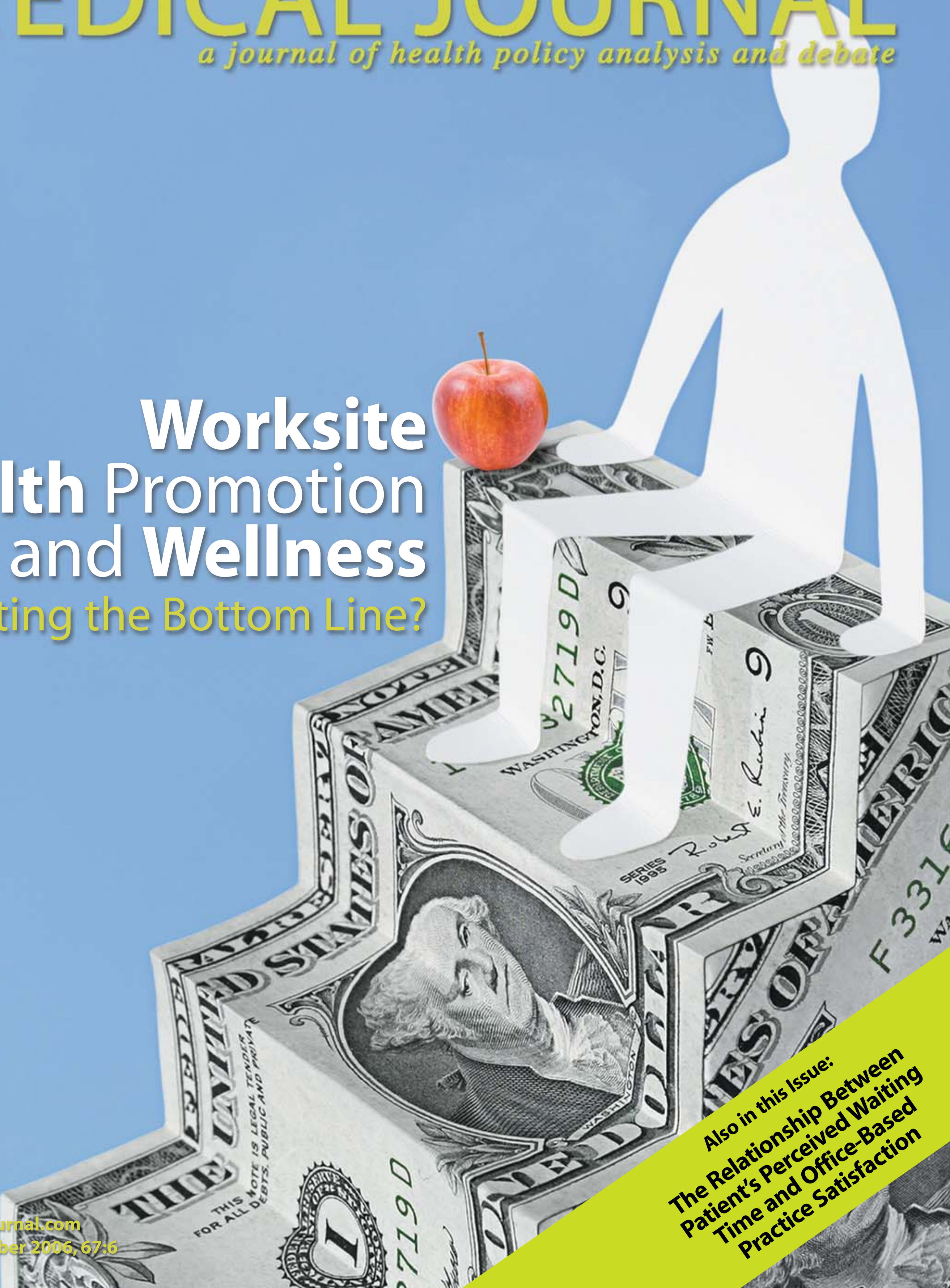

Worksite Health Promotion and Wellness

Affecting the Bottom Line?

Also in this Issue:

The Relationship Between Patient's Perceived Waiting Time and Office-Based Practice Satisfaction

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November/December 2006, 67:6

Surgery and science combine to unlock the secrets of diabetes

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Working together, Pitt County Memorial Hospital and Brody School of Medicine surgeons have been performing and studying gastric bypass surgery since 1978. To watch a live web cast of bariatric surgery at Pitt County Memorial Hospital or learn more about bariatric surgeons at the Brody School of Medicine and Southern Surgical Associates, visit www.bariatric.uhseast.com.

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Tarheel Footprints in Healthcare

Recognizing unusual and often unsung contributions of individual citizens who have made healthcare for North Carolinians more accessible and of higher quality

Sharon Nicholson Harrell, DDS, MPH
Director, Dental Care Centers, FirstHealth of the Carolinas, Pinehurst, NC

Sharon Nicholson Harrell, DDS, MPH

North Carolina is facing one of the most severe shortages of dentists and primary dental care of any state. Nationally, there are 5.7 dentists per 10,000 population. As of 2004, North Carolina had 4.2 dentists per 10,000. The ratio of dentists-to-population is quite different in metropolitan and rural areas of the state, where there were 4.8 dentists per 10,000 population in urban areas and only 3.1 dentists per 10,000 population in rural areas.

North Carolina's ratio of dentists-to-population is 27% lower than the national average. In fact, North Carolina ranks 47th among the states in terms of the dentist-to-population ratio. Moreover, the maldistribution in this state that has resulted in four eastern North Carolina counties not having a single dentist, three other counties having only a single dentist, and as many as 40 counties in North Carolina where there is no dentist willing to serve a Medicaid patient. This means that small, rural counties in our state are in a considerably more underserved situation than are our urban areas. Even in our metropolitan counties, obtaining services can be difficult if one is covered only by the Medicaid program or otherwise dependent on subsidized (or free) care through local public health departments, migrant or community health centers, or other "safety net" providers.

The good news is that there are dentists in this state, and a few major healthcare organizations, who have stepped up to the plate and taken on the huge task of finding a better way of organizing and providing needed primary dental care services for those most in need. One of those organizations is FirstHealth of the Carolinas, a not-for-profit integrated healthcare system headquartered in Pinehurst in Moore County, but serving a primary service area that includes five North Carolina counties. One of those dentists is Dr. Sharon Nicholson Harrell, who came to FirstHealth in 1998 to launch a dental care program serving those least able to obtain dental care in the counties served by FirstHealth. Through her efforts, three clinics have been opened under the sponsorship of FirstHealth (a full-time clinic in Southern Pines and part-time clinics in Troy and Raeford). These dental centers employ four dentists, 13 full-time staff, and several fill-in dentists and auxiliaries. These dental centers have served more than 13,000 children since they opened the first clinic in Southern Pines in 1998. Approximately 70% of children seen in the first year had either never seen a dentist or had not seen a dentist within the last year.

Dr. Harrell came to her position in Moore County after having served for seven years as Dental Director of the Cumberland County Health Department in Fayetteville, and before that for three years as a public health dentist in York, Pennsylvania. After graduation from the University of North Carolina (UNC) School of Dentistry, she was a fellow in general dentistry at the University of Maryland and then received a master's of public health degree at the UNC School of Public Health. When she was hired by FirstHealth, she was charged with the tasks of planning, designing, and opening three regional centers to provide comprehensive dental care to low-income children up to age 18, administering the centers, serving as an area dental public health consultant, and functioning as the liaison with private dentists in the local area and the state. In each of these arenas, Dr. Harrell has become widely recognized as highly effective, and her opinions and experience in the organization and provision of dental care to the most in-need populations of our state have been sought by many, both in North Carolina and nationally. FirstHealth's new dental care program for low-income children was funded by the Kate B. Reynolds Charitable Trust and The Duke Endowment.

Charles Frock, CEO of FirstHealth, had this to say about Dr. Harrell: "She has distinguished herself professionally in many ways. She has been nationally recognized for the way she mentors young dental health professionals. She is recognized throughout North Carolina for her public health approach to dental care for the underserved, and she is known by her patients and her colleagues as a completely caring, compassionate, and accessible caregiver."

Although meeting the primary dental health needs of underserved children through such special-purpose "safety net" programs as the one begun by FirstHealth of the Carolinas is not likely to meet the majority of unmet need for these services statewide, the 1,000 patient visits these clinics now offer each month, including 8,000 preventive dental sealants they provide yearly, and the 100 new patients they enroll each month are significant and grateful beneficiaries of a model program now being studied and replicated elsewhere. In Dr. Harrell's own words, "It's not only about filling cavities. It's about filling a big need in our community."

For her untiring efforts and considerable accomplishments in meeting the dental healthcare needs of so many children in our state, the Editors of the *North Carolina Medical Journal* are pleased to recognize Dr. Sharon Nicholson Harrell and FirstHealth of the Carolinas for these contributions to the health of the Tar Heel State.

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November/December 2007, Volume 67, Number 6 **Published by the North Carolina Institute of Medicine and The Duke Endowment**

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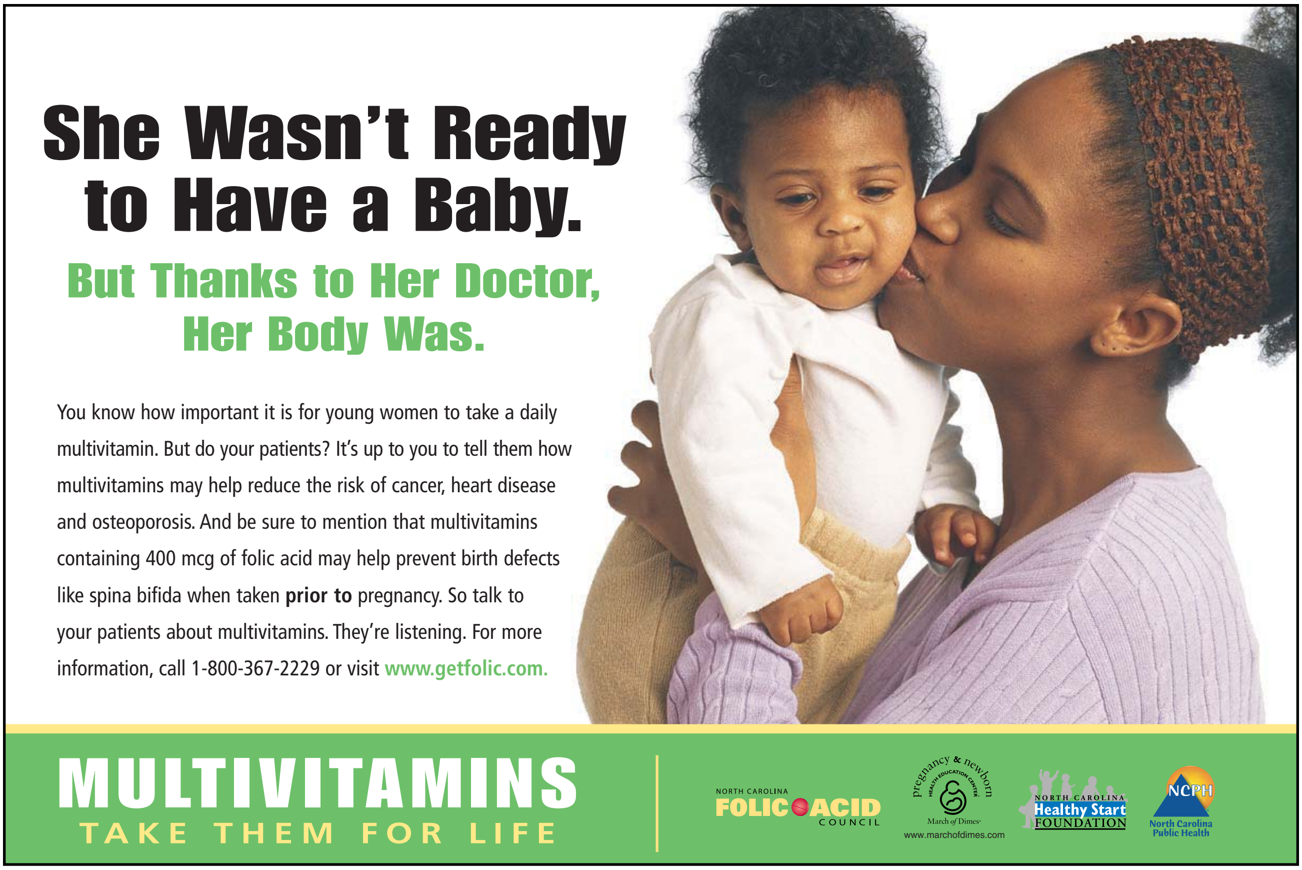

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ARTICLE

The Relationship between Patient's Perceived Waiting Time and Office-Based Practice Satisfaction

Fabian Camacho, MS; Roger Anderson, PhD; Anne Safrit, BS; Alison Snow Jones, PhD; and Peter Hoffmann, MD, MPhil

Abstract

Background: *The amount of waiting time a patient experiences in a primary care or specialty care outpatient setting may have an effect on patient satisfaction and may depend on other visit characteristics. We sought to investigate and quantify the association between waiting time and satisfaction outcomes in clinics belonging to the Wake Forest University Baptist Medical Center and assess how this relationship varies by time spent with the provider.*

Methods: *Cross-sectional survey data was collected at point of care from 18 primary and specialty care clinics at the Center. Overall satisfaction with provider care, the office ratings, and willingness to return were each rated on a 0-to-10-point scale. Multivariate and logistic regressions were performed to examine the relationship between waiting time and outcomes. Covariates included visit time spent with physician, patient care processes, visit convenience, and demographics.*

Results: *2,444 cases were analyzed. Waiting time significantly predicted provider ratings. When time spent with the physician was five minutes or less, provider ratings decreased by 0.3 rating points for each 10-minute increase in waiting time. When time spent with the physician was greater than five minutes, provider ratings decreased by 0.1 rating points for each 10-minute increase in waiting time. The association between waiting time and office satisfaction showed a similar pattern; increased waits also decreased willingness to return (odds decrease by 2% per minute).*

Limitations: *Results may be affected by unreliability of the measures used and from possible selection bias. There is also concern over missing confounders.*

Conclusions: *Our findings confirm that reduced waiting time may lead to increased patient satisfaction and greater willingness to return in primary and specialty care outpatient settings. Furthermore, increased waiting time combined with reduced time spent with the physician coincide with noticeable drops in patient satisfaction.*

Key words: *Patient satisfaction, waiting times, CAHPS*

Introduction

A source of dissatisfaction with healthcare, often noted by patients, is the amount of time they wait during an office or clinic visit. Several studies have documented the relationship between waiting for service and overall satisfaction, with longer waiting times being associated with decreased patient satisfaction. This relationship is not only localized to individual organizations or types of care, but is well documented in general situations involving waiting customers.[1,2]

The strength of the association between waiting time and overall patient satisfaction in healthcare settings varies across the literature. Much of this research has been conducted in emergency departments, where waiting time may be considerable and the level of patient discomfort may be high.[3-7] Results in this area may not apply to traditional primary and specialty care settings, since qualitative differences between situational emergency care and outpatient settings are substantial. Most studies conducted in primary care outpatient settings find a detectable relationship between waiting times and satisfaction,[8-13]

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Peter Hoffmann, MD, MPhil, is Medical Director of the Wake Forest University Physicians Group.

though results seem to be less uniform than in emergency care.

The literature on perceived quality of primary care indicates that key attributes of healthcare valued by patients are patient-centered, including time spent with the physician, willingness of the physician to listen to the patient, and other measures of patient empathy.[14-16] It is uncertain how waiting times combine with these attributes to affect patient satisfaction, even though understanding such combinations may translate to improvements in patient care. For instance, examining how perceived wait times and time spent with the physician combine to influence satisfaction may help preserve satisfaction levels when time and professional staff resources are tightly constrained, as is typically the case.

In this study, we sought to investigate the association between perceived waiting time and satisfaction in outpatient settings of a large North Carolina hospital after accounting for other factors. At the same time, we included an interaction effect of waiting time and time spent with the provider into our models in order to highlight how certain combinations may be associated with particularly low satisfaction levels. Perceived waiting time was conceptualized as a measure of a patient's time investment in accessing a specific set of healthcare services, which we call "willingness to wait." Patients who perceived themselves as having to wait long periods of time to see a healthcare provider on the day of their visit were hypothesized to have a larger investment in the visit.

Methods

Sample

This study was observational and cross-sectional across primary and specialty care clinic settings. Data were collected using a validated survey methodology,[17] in which a handheld computer was used throughout a clinic business day to collect information from a patient immediately after the patient's clinic visit. Convenience samples were collected from two primary and 16 specialty care clinics in the Wake Forest University Baptist Medical Center from May 2004 to September 2004, for an aggregated total of 2,535 patients distributed throughout 18 clinics. Only patients who were 16 years or older in age were selected into the sample.

Measurements

We assessed three distinct dimensions of patient satisfaction: an overall rating of the provider seen by the patient using the Consumer Assessment of Health Plans Study (CAHPS) global item[18] ranging from 0 (worst provider) to 10 (best provider); a global rating for office staff ranging from 0 (worst) to 10 (best); and 'willingness to return for medical care' rating dichotomized into willing to return versus not willing to return. These items were taken from a more comprehensive set of items that assessed satisfaction with quality of care provided by the physician, which were included in our standard survey. The three global measures were selected as dependent variables for this based on parsimony and ease of interpretation, consistent with scientific literature on this topic.[19]

Perceived waiting times at the office were captured by patient self-report after the physician-patient encounter, using an item consisting of six categories: 1-5 minutes waiting time in office, 6-15 minutes, 16-30 minutes, 31-45 minutes, and 46 minutes to 1 hour, and more than 1 hour. The shorter time intervals at the start were chosen in order to capture waiting time with more precision, since previous pilot data suggested approximately 70% of the patients waited less than 15 minutes. Waiting times in the exam room were captured in a similar manner.

Dansky[1] showed, out of several definitions of waiting time, that total time spent waiting in the office and exam room was the strongest predictor of satisfaction. For this analysis, we summed both waiting time variables to create a total waiting time composite. We interpolated the categories of waiting time by their midpoints (assuming an average wait of 1 hour and 15 minutes for the relatively few patients who waited more than 1 hour) and summed the midpoints to produce a continuous measure of time.

Potential predictors of patient satisfaction considered in this study are listed in Table 1. These include visit time spent with the healthcare provider, whether visit was to a primary or specialty care clinic, whether the patient was new to the office, self-reported

Table 1.
Population Characteristics[a] (N = 2,444)

	Descriptive Statistics
Mean waiting time in minutes[b]	20.97 (14.71)
Visit time with provider	
0-4 minutes	14.3%
5-10 minutes	85.7%
Visit was convenient	86.0%
White ethnicity	82.6%
Patient saw preferred provider	34.7%
Age in years[b]	45.9 (16.97)
Highest possible provider empathy score	41.3%
Patient stress reported	45.6%
First visit	22.1%
Visit was for routine check-up	50.5%
Patient had multiple appointments	18.3%
Male gender	34.7%
General practice clinic	7.5%
Office staff rating[b]	8.76 (2.26)
CAHPS provider rating[b]	9.37 (1.23)
Willing to return	83%

a Restricted to patients who had a total waiting time of 75 minutes or less.

b Means are shown with standard deviations in parenthesis.

convenience of visit, reason for visit, whether the patient had multiple appointments during the day, patient stress, gender, age groups, and ethnicity (white versus other minorities combined). Patient perceived stress was measured from a single item asking "Overall, how stressful was your visit today?" Responses were categorized into no patient stress reported versus at least some patient stress reported.

We also used a scale developed and validated for use on a computer platform in order to assess provider empathy.[17] This scale is based on the premise that quality of care can be conceptualized as the patient's perception of provider empathy, concern, friendliness, and compassion.[8] Consistent with previous work, the Cronbach Alpha of this scale in the study sample was 0.93. For analysis purposes, the scale was dichotomized into perfect scores and scores less than perfect.

Statistical Analysis

Multivariate regression and logistic regression models predicting the three satisfaction ratings were estimated using the Generalized Estimating Equations (GEE) method implemented in the SAS System v9 procedure, proc genmod.[20] In order to adjust for clustering, an exchangeable working correlation matrix was specified where the observations were clustered according to clinic. The default robust standard errors in proc genmod were used.

Since 20% of the observations had missing values, we treated missing data by conducting multiple imputations as described in Rubin (1991).[21] The MCMC method in the SAS system's multiple imputation[22] was used to derive imputed values for all the variables listed in Table 1. These same variables were included in the imputation model, as well as the interaction between waiting time and visit time. Three data sets with imputed values were used to conduct the analysis. Wherever possible all estimates and statistics were calculated using combined estimates of three multiply imputed data sets.[23]

Results

Only patients who waited for 75 minutes or less (N = 2,444) were selected for the analysis, as the waiting time variable for patients waiting more than 75 minutes was considered too unreliable, and only 3.6% patients were lost as a result.

From Table 1, mean total waiting time was estimated to be 21 minutes (Standard Deviation = 15), mean age was 46 years (SD = 17), 83% were white and 35% male. Mean office rating was 8.76 (SD = 2.27), mean CAHPS provider rating was 9.37 (SD = 1.23), and 83% of patients were willing to return for care.

Regression results are shown in Table 2. Model predictors explained approximately 23% of the variation for both the CAHPS provider rating and willingness to return, but only 7% of the variation for office rating. No multi-collinearity problems

Table 2.
Regression Results[a]

	CAHPS Provider rating (0 - Worst, 10 - Best) Regression Coefficients	**Office Staff Rating (0 - Worst, 10 - Best)** Regression Coefficients	**Willingness to Return** Odds Ratios
Intercept	8.76 (0.14)***	8.54 (0.23)***	
Waiting time in minutes	-0.03 (0.01)***	-0.03 (0.01)**	0.98 (0.98, 0.97)
More than 5 minutes spent with provider	0.13 (0.13)	-0.23 (0.25)	1.59 (2.39, 1.06)
Visit was convenient	0.41 (0.10)***	0.58 (0.13)***	2.12 (2.60, 1.73)
White ethnicity	-0.04 (0.06)	-0.20 (0.14)	0.92 (1.13, 0.75)
Patient saw preferred physician	0.04 (0.05)	-0.01 (0.10)	1.03 (1.23, 0.86)
Highest possible provider empathy score	0.63 (0.04)***	0.64 (0.08)***	3.81 (4.89, 2.97)
Age in years	0.01 (0.00)***	0.01 (0.00)	1.02 (1.02, 1.02)
Patient stress reported	-0.42 (0.05)***	-0.50 (0.12)***	0.46 (0.60, 0.36)
First visit	-0.23 (0.06)**	0.01 (0.10)	0.53 (0.66, 0.42)
Visit was for routine check-up	0.11 (0.04)**	0.06 (0.07)	1.27 (1.52, 1.06)
Patient had multiple appointments	0.01 (0.06)	0.00 (0.11)	1.07 (1.47, 0.78)
Male gender	-0.13 (0.05)*	0.09 (0.10)	1.00 (1.42, 0.71)
Generalist care clinic	-0.07 (0.04)	0.18 (0.15)	1.50 (2.05, 1.11)
Interaction of total time verses visit	0.02 (0.01)**	0.02 (0.01)***	
R-square estimate	0.24	0.07	0.23[b]

a Standard Errors are shown in parenthesis. 95% Confidence Intervals are shown next to odds ratios. Sample was restricted to patients who waited less than 75 minutes (97% of original sample). Coefficients and values are derived from multiple imputations with three replications. * implies p-value of significance test is < 0.05, ** is < 0.01, and *** is < 0.001.

b Adjusted R-square as described in Nagelkerke (1991).

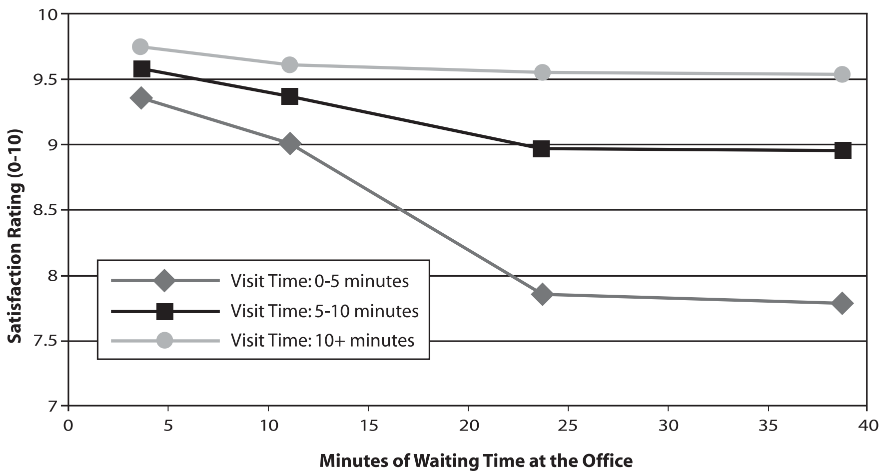
were detected in any of the three regressions, with the lowest tolerance detected at 0.85.

We found that physician satisfaction was lower than expected for patients who waited more than 20 minutes and who had short visit times of 0-5 minutes, as illustrated in Figure 1. The interaction term consisting of waiting time and visit time with physician tested for significance when added to the model (p-value < 0.01).

Satisfaction with the provider decreased by approximately -0.10 rating points per 10 minute increase in waiting when visit times were five minutes or more and -0.30 rating points when visit times were less than five minutes; office satisfaction declined by the same rates; and the odds of willingness to return decreased by 2% per minute.

In addition, satisfaction with the provider was associated with: convenience, quality of care rating, patient age, having a stressful visit, nature of visit, and gender. The findings were consistent by showing that a longer wait, a shorter visit time, a more stressful visit, and lower quality rating were independently associated with lower global satisfaction scores.

Figure 1.
Mean Provider Ratings by Waiting Time and Visit Time



Discussion

This study suggests that increased waiting time is an important source of patient dissatisfaction. For situations in which the time spent with the doctor exceeds five minutes, the regression equations suggest the difference in provider satisfaction may become clinically important after a 50-to-60-minute total wait, at which time the decrease in provider satisfaction exceeds the ½ the standard deviation of the CAHPS provider rating distribution. In addition, the findings suggest longer waits and shorter visits with the physician are, in synergy, associated with increased erosion of overall patient satisfaction (see Figure 1).

We conjecture that a patient's time investment or 'willingness to wait' for healthcare may itself be an indicator of patient satisfaction, analogous to measures of revealed preference for health outcomes, such as the standard-gamble or time trade-off methods.[24] It certainly conforms to methods employed by economists that use consumers' reactions to changes in price and income to learn about their valuation of purchased goods and services.[25] Economic theory predicts that patients will be willing to incur time and money costs that approximately equal their valuation of the benefit that they expect to receive from this expenditure of time and money.[26,27] In this framework, waiting time is an important component of time price, and willingness to wait should rise with patients' perceptions of increased quality of care. Patients' willingness to wait or their "willingness to pay" for care in time units will also depend on their wage rates and on the severity and chronic nature of their illness. Waiting time can also be conceptualized as eroding the value derived from a treatment.[28] In this sense, it can be viewed as the amount an individual would be willing to pay for a reduction in waiting time.

Willingness to wait for medical care could serve as a readily observable indicator for ranking clinics or patient visits by patients' satisfaction levels. However, this does not suggest that perspectives on the timeliness of care are unimportant. It is important to offer brief waiting times so that patients do not feel discomfort or perceive barriers to care, and to communicate respect for the patient. Our results, however, suggest that the threshold for what is satisfying is partially determined by the visit experience and suggest that patients weigh their inconvenience or resource investment against their gain to determine their willingness to return.[29-31] Future work is needed to examine the concept of "willingness to wait" more directly and to explore its value as a measure of patient satisfaction or quality of care.

There are several limitations to this study. The documented reliability of the CAHPS provider rating is fairly low, ranging as low as 0.19 for one subgroup.[32] However, despite this apparent instability, there is a consistent pattern of predictors, which in many cases correspond to the predictors observed for the other two markers of satisfaction, particularly willingness to return. This agrees with other findings in literature that have noticed an association between willingness to return and other measures of patient dissatisfaction.[9,33]

Our survey did not collect additional confounders, which may play a role in changing study results, such as general health status,[30] arriving early,[8] wage rates, travel time to clinic, or additional technical aspects of care, such as provider thoroughness. Of the omitted predictors, general health and wage rate may be strong predictors of the relationship between waiting time and satisfaction. If the reason for visit proxies health status, one might expect people in poor health to be willing to wait longer for care since they would most likely be seeing specialists. It is not clear that they would rate providers lower on quality. Results here suggest that patients who visit for a routine check-up rate their providers higher.

Despite these limitations, our findings confirm that timeliness is an important component of quality of care in this setting, and that clinically significant drops in satisfaction may be observed after a one hour wait. Although measures of patient empathy and, thusly, of interrelated factors, such as personal attention, communication, and interpersonal style may play a more important role in determining satisfaction, these results suggest that timeliness should not be ignored if patient satisfaction rates are to be maintained, especially if the provider cannot devote much time to his or her patients. **NCMedJ**

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POLICY FORUM

Worksite Health Promotion and Wellness

> *"...50% of chronic disease in the United States population results from preventable causes related to lifestyle choices, and half of all deaths can be attributed to a limited number of preventable behaviors. Health risks drive present and future costs for employers and employees."*

INTRODUCTION

Policy Forum:
Worksite Health Promotion and Wellness

Ever since the United States Department of Health and Human Services initiated the decennial publication of the *Healthy People* goals for the nation, which began under the Administration of President Carter, ways have been sought to advance the cause of national health improvement through initiatives that would couple a concern for health and health improvement with some of the everyday functional activities of the American people. For the health of children, the schools have been an important venue for a variety of health promotion program initiatives. For working-age adults, the workplace has figured as an important target of opportunity for addressing the fundamental health issues of our population, from disease screening to immunizations to chronic disease self-management to lifestyle modification and health risk factor reduction. With huge proportions of employees spending at least 40 hours per week in one or more occupational settings and consuming a third of their meals during their time at-work, program initiatives that focus on stimulating healthy lifestyle changes can not only improve the prospects of long-term health outcomes, but significantly impact the healthcare cost obligations of the employing organization as well.

In this issue of the *North Carolina Medical Journal*, we have chosen to focus our attention on the potential these types of initiatives may have for businesses and industries, the reasons why some companies have seen benefit in making such investments, why it may not be so easy to establish (or quantify) the "return on investment" (or ROI) that can provide the rationale for these investments, and the kinds of incentives necessary to assure adequate levels of employee participation in such programs when they are offered at the workplace.

We have invited a distinguished group of North Carolinians and national figures in the health promotion field to address these issues, and we are fortunate that so many accepted our invitation. Following an extensive Issue Brief on critical issues in this field by Dr. Joyce M. Young, the person responsible for health promotion and wellness activities in the United States for IBM Corporation, each author offers a particular set of observations on the way this movement in American business has developed. We are also pleased that Dr. Alexandra Farrow, a friend and colleague of many years who studies these issues in the United Kingdom and Western Europe offers her own view of how these same issues have been faced on the other side of the Atlantic.

North Carolina has a number of large, national (or international) corporations with the capacities to provide impressive and effective health promotion programs for their employees at the workplace. But, our state is characterized by having one of the largest proportions of small companies, many of which could never afford to offer such services to their employees. Many cannot even afford to offer healthcare insurance. Hence, a consideration of the value and potential of workplace-based health promotion efforts is a matter of seemingly less importance to North Carolina health policy deliberations than would be the case in other states. This is why our readers need to give serious attention to the commentaries in this issue of the Journal. In these pages, one can discover not only the argument in support of workplace-based health promotion programs, but options for small businesses to consider if they wish to leverage local community resources and programs in support of the health promotion interests and needs of their employees. The health of all North Carolinians is at stake.

A Personal Editorial Note:

With this issue, the 30th under our editorship, we conclude our stewardship of the *North Carolina Medical Journal* in its new format, a venture we began in January 2002. We want to express our deep appreciation to the hundreds of authors, reviewers, Editorial Board members, and our colleagues at the North Carolina Institute of Medicine and The Duke Endowment who have given us this opportunity to engage the leading policy makers, healthcare professionals, and the lay public in lively information exchange and debate on important matters for the health of North Carolinians and our nation as a whole. We welcome Dr. Thomas C. Ricketts III as the Journal's new Editor-in-Chief and wish him and his colleagues the very best as they continue this important work. Having a person of his national reputation and ability accept this responsibility is itself a testimonial to the quality of what this Journal has set out to achieve.

Gordon H. DeFriese, PhD
Editor-in-Chief

Kristie W. Thompson, MA
Managing Editor

Promoting Health at the Workplace:

Challenges of Prevention, Productivity, and Program Implementation

Joyce M. Young, MD, MPH

Over the period since the 1980s, American business and industry spokespersons have often expressed their frustration and dismay over the rapid escalation of the annual costs of medical care for their employees, dependents, and retirees. As these companies have been forced to re-examine their contributions to healthcare insurance, they have been prone to focus on the impact these expenditures have on their bottom-line and their competitive position domestically and internationally.

In this period, there is rising concern about the ability of businesses to manage healthcare investments, especially since, in comparison with other nations who spend less per capita on healthcare, life expectancy, days of disability, and overall health status put the United States at an unfavorable disadvantage. Business and industry leaders have been forced to look carefully at ways to stem the tide of annual increases in healthcare costs for their employees, dependents, and retirees. In addition to shifting some of the burden and responsibility for healthcare costs to employees through higher co-insurance, deductibles and other out-of-pocket expenses, American business and industry leaders are beginning to give attention to employee health-related lifestyle choices and behaviors. Choices and behaviors related to diet, exercise, tobacco and alcohol use, and stress management affect an individual's health risks and, in turn, their healthcare costs.

> *"Since 63% of the adult population is employed, workplaces provide an excellent opportunity to expose a large number of adults to health promotion programs."*

In an attempt to reduce their employees' health risks (and use of healthcare services), many American companies, particularly larger ones, have chosen to invest in health promotion and wellness programs. These programs may be in addition to conventional health and safety efforts, and some are based at the worksite, while others are offered through arrangements with local commercial health and fitness centers or non-profit organizations, such as local YMCAs. Companies making such investments have used a number of rationales, some having to do with their desire to respond to employee interest in health and fitness; others related to concerns for overall corporate productivity, job performance, and workplace environment, in addition to their concerns about the cost of healthcare and its impact on the corporate bottom line.

These programs sponsored (or arranged) by employers vary a great deal depending on the physical location of the employer's facilities, the characteristics of the employed workforce, and the availability of staff to lead such efforts.

In consideration of the issues related to worksite health promotion and wellness program investments, their cost and their impact on employee and community health, the editors of the *North Carolina Medical Journal* have decided to devote this installment of the Journal's Policy Forum to this topic. While there is considerable evidence of positive benefit accumulating from national examples of worksite health promotion initiatives, the extent of implementation and value of these programs here in North Carolina is not so well documented.

North Carolina has its own mix of large and small companies, but a sizeable proportion (42%) of the state's employed population works for companies with fewer than 100 employees; 30% work for companies with fewer than 25 employees, and 20%

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work for companies with fewer than 10 employees. North Carolina, compared to all other states, has the 14th highest proportion of employees working for firms with fewer than 25 employees.[1] For these smaller companies, where nearly half of all North Carolinians work, the capability of offering any kind of workplace-based health promotion options are limited. Yet, there are other options for small companies choosing to support their employees' personal choices to promote their own health and the health of their families.

In his commentary in this issue of the *North Carolina Medical Journal*, David Chenoweth of East Carolina University describes the interest and adoption of these health promotion programs in North Carolina businesses over recent decades.[2] As he points out, the content of these programs has been expanded from simple health risk appraisals and clinical health screenings to include a variety of worksite modifications, which include outdoor walking and jogging trails, lunch 'n learn tutorials on health promotion topics, health-focused newsletters, healthful vending machine options, and Web-based instructional programs.

In this Issue Brief, current patterns of investment in worksite health promotion and wellness programs in the United States are described, along with discussion of the rationale used by businesses for these investments and the return on investment that may be expected. The Issue Brief will also give attention to some of the issues surrounding the development of these programs and their potential for influencing the health of the workforce in those industries where these programs have developed.

The Workplace as a Focus of Health Promotion Programs

Historically, the workplace has been recognized as an excellent location for employee-directed health improvement interventions. Since 63% of the adult population is employed,[3] workplaces provide an excellent opportunity to expose a large number of adults to health promotion programs.[4] Just as schools are seen as an opportune venue for improving the health of our children, worksites offer many advantages as a health promotion venue. One advantage is the social nature of the work environment. Employees interact with each other frequently, have socially important relationships, and provide social support for each other, which suggests that co-workers have the potential to influence each other's health behavior. Existing communication channels between employers and employees also facilitate health messaging,[a] which through repetition has the potential to impact health behavior. Positive health messaging can even extend beyond the workplace to affect employee dependents.

Beyond the logistical advantages, the importance of the workplace as a health promotion venue has grown each year as double-digit increases in healthcare costs have required employers to devote much greater effort to the challenge of allocating and managing health-related resources. Providing health insurance is one of the largest components of employee benefit costs, averaging 10.5% of payroll.[5] Many employers regard health insurance as a benefit, focusing on these costs and ways to contain further increases. As a consequence, opportunities to maximize the value of these investments by ensuring the availability of services that include improving health as a key component have become a higher priority for American business and industry leaders. Including health improvement and risk reduction as a focus in the corporate healthcare strategy provides a means for employers (and employees) to optimize their healthcare spending.

In general, employees view access to and the provision of wellness programs and activities positively. They view it as an indication of their employer's commitment to their well-being and, thus, view the employer more favorably. The United States Department of Health and Human Services has announced the goal of having as many as 75% of *all worksites*, regardless of size, offering *comprehensive* health promotion program opportunities to their employees as part of the *Healthy People 2010* initiative.[4] As Jennifer Childress and Garry Lindsay point out in this issue of the *North Carolina Medical Journal*,[6] recent surveys of business and industry employers find that only 6.9% offer the program elements that experts would consider the five key elements of such "comprehensive" programs: viz., (1) health education, (2) links to related employee services, (3) supportive physical and social environments for health improvement, (4) integration of health promotion into the organization's culture, and (5) employee screenings with adequate treatment and follow-up. In other words, the national goals for worksite-based/sponsored health promotion are ambitious, despite significant progress in this direction among some of the nation's leading business organizations.

In this issue of the *North Carolina Medical Journal*, Michael O'Donnell, President of the *American Journal of Health Promotion*, provides a commentary[7] explaining the rationale for federal governmental incentives to encourage American businesses and industry to invest in workplace health promotion programs and describes proposed legislation introduced in the United States Congress by Senator Tom Harkin of Iowa.

Shifting the focus to regard healthcare (when it includes health promotion and wellness components) as an *investment* rather than merely a *cost*, necessitates identifying outcomes and specifying measurement goals for that investment. Reasonable expected outcomes in health improvement would include: increasing the use of health screenings and immunizations and reducing the health risks associated with tobacco use, physical inactivity, and stress. Adopting benefit strategies with targeted health outcomes are increasingly seen as yielding higher returns than strategies designed only to contain and control healthcare costs. The Towers Perrin 2007 Health Care Cost Survey documented that employers who made aggressive efforts to manage health program performance—including implementing health improvement features—succeeded in slowing the upward spiral

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[a] Health messaging includes newsletters, web sites, posters, and other communication vehicles devoted to educating and providing information on health related topics.

in their own program costs when compared to similar companies that did not make efforts to manage program performance.[8] Surveyed companies with lower cost trends offered a variety of health management programs, including those directed toward health improvement and disease management.

American Business-Sponsored Health Promotion Programs Offerings and Issues

As early as the 1970s, national interest in the potential of workplace-focused health promotion programs had emerged as a new emphasis in public health. Fielding and colleagues[9] authored the first industry survey reporting on the extent to which large companies had invested in these types of programs. This initial survey was followed by others,[10] and together these sequential surveys revealed a clear trend in the direction of more widespread investment in workplace health promotion programming. Whereas most companies responding to these surveys in the 1970s considered worksite programs that had a specific focus on worker *safety* as "health promotion;" by the 1990s, company respondents to these surveys included a much wider variety of options for employee consideration, and most options were directly related to the enhancement of health status, not merely addressing on-the-job issues of safety.

In this issue of the *North Carolina Medical Journal*, Laura Linnan and Ben Birken,[11] as well as Jennifer Childress and Garry Lindsay[6] offer extensive discussion of not only the trend toward a wider spectrum of employer offerings in the area of health promotion and wellness, but also give a picture of the range of companies, both large and medium-size, now opting for investment in this area.

The goal of workplace health improvement programs is to help employees maintain good health and prevent disease by adopting healthy lifestyles, lowering health threats, and increasing the use of proven clinical preventive medical services. The methods employ change strategies designed to help individuals incorporate beneficial health habits into their regular life routines. These include health education with self-care and consumerism, health risk assessments, and behavior change programs. Delivering these methods through a coordinated delivery infrastructure multiplies the impact of individual initiatives. Comprehensive integrated programs are needed to achieve greater impact. These are comprised of: workplace policies and provisions that advocate and support a healthy work culture; benefit design coverage for screening, clinical prevention, health provider counseling and medications that assist tobacco cessation and weight loss for higher classes of obesity; access to tools for medical information search and use, including medical treatment decision making and consumerism (commonly called "health decision support"); Health Risk Appraisals (see text box page 420); and effective behavior change methods and program evaluation that assesses the effects on employee health status, health cost, and productivity.

Even comprehensive wellness programs need to be integrated within an overall strategy for employee healthcare that addresses the other important aspects for optimal personal and business health management, and successful implementation poses a number of challenges. Many employees know from their own personal experience and failure that improving health behavior is not easy, especially when the time and energy needed to devote is already taken up by work, family, and other commitments. Employees may not fully understand how additional medical expense and reduced work output personally impacts them. These and other factors make it challenging for employers and program managers to achieve sufficient participation in wellness offerings. A pervasive problem is that many organizations' programs are not robust enough to achieve the desired outcomes. Often educational and awareness programs are good at raising awareness, but are ineffective in changing behavior or reducing risk. Workplace behavior change interventions are frequently offered as stand-alone initiatives that only reach a limited proportion of the work community and are too short in duration to affect lasting change. In addition, the lack of data access and integration prevents the feedback and monitoring needed for improvement and performance measurement.

While implementation is hard to do well (given it is not a simple prospect) doing nothing worsens risks, costs, and productivity losses. Employers choose from a mix of approaches using human resource personnel and employee wellness committees, health plan offerings, hiring outside vendors, or a combination of approaches. Education and awareness campaigns (employee- or plan-sponsored) are the most common and frequent interventions. Integrated, comprehensive programs are the most infrequent. Improving health is a process that requires time, and insufficient program duration hampers impact as much as ineffective interventions. Lacking vendor standards or certification, employers have to develop their own vendor selection criteria and methods to select which suppliers are the best fit for their work environments.

Rationale for Company Investment in Health Promotion Programs

It is frequently noted that 50% of chronic disease in the United States population results from preventable causes related to lifestyle choices, and half of all deaths can be attributed to a limited number of preventable behaviors.[12] Health risks drive present and future costs for employers and employees. Many companies do not recognize that the presence of common health risks among employees may account for 15-35% of their annual medical claims cost.[13] This is magnified by the fact that a large portion (approximately 80%) of health claims costs are generated by a small portion of the insured employee workforce (5% to 20%). The smaller segment draws the attention, but the larger segment (employees in "moderate-to-good" health) offers the better option for health promotion-driven cost savings. In this issue of the *North Carolina Medical Journal*, Dee Edington[14] of the University of Michigan argues for the support of workplace health promotion programs that can help this larger group *maintain* a lower level of health risks. Learning that greater healthcare savings could be made through incremental reductions in health risks among the larger group of an organization's more healthy employees can be a surprising finding for many companies. It is Edington's thesis, based on the data he and his colleagues

Health Risk Assessment or Health Hazard Appraisal

What does it mean to complete an "HRA?"

Workplace health promotion or wellness programs in most settings conventionally ask participants to complete a brief questionnaire that summarizes key individual characteristics and health information through which a statistical estimate of one's overall health risk status can be determined at the outset of program participation. These questionnaires (or surveys) are often referred to as "health risk assessments." Years ago, and still in some forms, they were referred to as "health hazard appraisals," but in either case they are most commonly referred to by the initials: HRA.

These instruments take a number of index informational items and from them calculate an assessment of one's life expectancy, based on "risk factors" and the profile they represent. Comparisons are often made to populations of persons of a similar age, with similar patterns of health risk status and behaviors, for whom mortality (and often morbidity) outcomes are known. The results then are summarized in terms of one's "achievable" age IF certain risk factors are modified through systematic behavioral and biomedical change (e.g., weight loss, increased physical activity, better nutrition, alcohol and tobacco use, etc.).

HRA instruments, and the methods by which results are calculated and communicated to those who complete them, vary a great deal. Some go through elaborate calculations based on population-specific epidemiological profiles of mortality risk associated with particular patterns of behavior and biomedical characteristics. Others offer simple summaries of key current risk factors (often displayed in colorful diagrams) followed by specific advice as to which of these are most amenable to modification through intentional efforts toward a more healthy lifestyle and personal health behaviors.

Most would agree that completion of an HRA alone will not likely result in a significant change in one's overall health risk profile. What most experts recommend is that all HRAs should be followed by specific risk-factor counseling and opportunities to participate in health promotion interventions (like nutrition counseling, organized physical activity, or smoking cessation programs) relevant to the significant modifiable risk factors identified through the completion of an HRA.

HRA results, when aggregated in a confidential manner across multiple members of a workplace population, and where HRA results are periodically available from the same respondents, can provide useful and powerful means of tracking the impact of workplace health promotion and wellness programs over time. For this reason, most experts in the field recommend that HRAs be the fundamental starting point in any workplace health promotion effort and that these measures serve as the primary measuring gauge of program impact and effectiveness.

have collected from many companies, that preventing this larger population of "healthy" employees at low-risk from moving to a higher level of health risk holds the key to long-run savings for any company sponsoring health promotion initiatives.

The same common risk factors that affect healthcare expenditures also negatively impact attendance, work output, disability, and job safety. Burton et al[15] found that 10 of 12 health risk factors were significantly associated with self-reported work limitations. Musich et al[16] found increased presenteeism (employees present for work, but unable to contribute at their usual level) associated with high stress, life dissatisfaction, back pain, and absenteeism were associated with overweight, poor perception of health, and chronic disease. In studying 2,200 employees in the northeast, Boles et al[17] found that participants with higher numbers of personal health risk factors reported greater productivity losses.

Recent research has demonstrated that employees are capable of reducing their health risk in the setting of employer-sponsored health improvement programs. Goetzel et al[18] reported that participants in Johnson & Johnson's *Pathways to Change* program achieved significant risk reduction in eight of 13 risk categories over an average of $2\,^{3}/_{4}$ years. Pelletier,[19] who has been reporting on this topic for decades, found that results from randomized clinical trials and quasi-experimental designs suggest that providing individualized risk reduction for high-risk employees within the context of comprehensive programming is the critical element of worksite interventions. Herman et al[20] demonstrated that combining a cash incentive with a physical activity intervention resulted in increased participation and significant levels of health risk reduction. Finally, Pelletier et al[21] reported that individuals who reduced one health risk factor improved their presenteeism by 9% and reduced absenteeism by 2%.

Expected Returns on Investment (ROI) in Worksite Health Promotion Programs

A cynical examination of employer investment trends in health promotion programming would expect that there could be no other motivation for such investments than corporate "bottom-line" returns. But, just how important (or critical) are these ROI considerations to these investments?

Research evidence substantiates the presence of risks among employees and the negative impact on health costs and productivity and the ability of health promotion interventions to reduce both employee risks and associated costs. However, a major reason why businesses have been slow to fully embrace risk reduction programs is the difficulty of quantifying their impact on the overall healthcare cost picture.

Determining the economic impact of wellness has been vexing for many years, primarily due to lack of data and systems to capture and measure information about the relationship between interventions and their impact on cost. It is more common for objective data on productivity to be unavailable than available. Since worksites are not laboratories, randomized trials assessing impact are rare. Likewise, health plans have not translated data into actionable information. Many organizations lack access to claims data and analytic methods for evaluation. In addition, businesses customize their wellness programs, drawing from a wide spectrum of approaches, which limits comparisons and benchmarking. An easy-to-implement, universally applicable approach for calculating potential and actual ROI is not readily available. Employers consistently express concerns about not being able to factor ROI into program evaluations and investment decisions.

However, changing trends and efforts to integrate data from multiple sources to conduct valid systematic analysis are surfacing through numerous publications and the work of organizations like the Integrated Benefits Institute (www.ibi.org) and the Institute for Health and Productivity Management (www.ihpm.org). Reductions in healthcare cost among wellness participants as compared to non-participants and ROI values are reported more frequently. A comprehensive review of current ROI literature determined that results for programs in operation an average of 2.5 years experienced an average annual cost reduction range of 2% to 4% of total healthcare claims for comprehensive health promotion disease prevention. The corresponding ROIs or cost-benefit ratios ranged from 1:1.5 to 1: 3.0.[22] Ozminkowski, Goetzel et al[23] used company data and information from published studies to estimate the amount of risk reduction needed to break even on that company's health promotion programs. They found that a 1.08% to 1.42% per year reduction in lifestyle-related health risk was needed to break even on the costs of the intervention program.

Drs. Goetzel and Ozminkowski have also written, in this issue of the *North Carolina Medical Journal*,[24] a commentary on why employers should (or should not) consider investing in worksite health promotion or wellness programs. In their analysis, Goetzel and Ozminkowski summarize the extant evidence that these programs can have a positive ROI, but acknowledge the difficulty some employers may have in realizing these returns and the factors that may affect these results.

Cost avoidance or reducing the upward trend and velocity of healthcare cost increases is one of the key interests of employers who invest in workplace wellness interventions. In this instance, if the increase in healthcare expenses is less than expected (i.e., reflects a reduced trend) because wellness-driven health improvement and/or risk reduction leads to reductions in health services utilization, then these investments are considered worthwhile. Identifying and quantifying the avoided cost requires a specific analysis that also accounts for the impact of other influences, such as plan design changes or risk pool ratings. Cost avoidance can be determined by comparing the health cost experience of wellness program participants to those of non-participants at the individual level. Achieving a measurable financial impact on the entire employee population can require a robust (i.e., 80% or greater) rate of employee participation in proven interventions shown to be effective—an achievement few organizations are able to realize.

Health promotion's impact on worker productivity is probably larger than it's impact on healthcare cost, amounting to, in some studies, values that are three times higher. Measuring changes in productivity, especially as office workers comprise larger segments of the employment landscape, relies on mechanisms to quantify lost work time or absence and work output, both requiring specific methods for capturing time and assessing productivity. Recording attendance is increasingly less meaningful for knowledge workers. Options to measure productivity include quantitative indicators, such as days worked or units produced; simulation in hypothetical situations (e.g., a typing test); and self-report through surveys or health risk assessment questions. The most frequently used and easiest to administer though, not the most accurate, is self-report. Both attendance and work output can be assessed through self-report. Methods can be as simple as incorporating two to five questions in the HRA or as comprehensive as the 25-item Work Limitations Questionnaire or the Health and Labor Questionnaire that measure as many as four dimensions. A convincing example of health promotion's effect on attendance can be seen in the $600,000 annual savings achieved during a five-year period from reductions in absenteeism in a manufacturing environment.[25] Larry Chapman's meta-evaluation of 56 high quality health promotion economic return studies[26] found an average 26% reduction in the use of sick leave among 44.6% of the studies. Reductions in the use of sick leave ranged from 11% to 68% in this analysis.

In this issue of the *North Carolina Medical Journal*,[27] Larry Chapman of WebMD Health Services, argues that as we raise the expectations of health outcomes of worksite wellness programs (e.g., significant amounts of body weight lost, increasing levels of physical activity, smoking cessation rates, etc.), we should expect to have to raise the incentives and rewards for program participants, including possible monetary rewards. Rewards have the potential to reduce corporate ROIs and require alignment with the Health Insurance Portability and Accountability Act (HIPAA) to avoid ethical and legal complications that could stem from employees' inabilities to engage in these activities at the level of reward eligibility.

The negative impact of employee absence is magnified by the changing nature of work. Work that relies on skills, company-specific knowledge, critical thinking, and innovation cannot easily be performed by substitutes. Given the interdependencies among the work teams present in many companies, the productivity of whole teams of employees may be diminished by the absence of an individual. Therefore the savings from health promotion's ability to reduce absenteeism (as trends indicate) has the potential to be greater than healthcare cost savings.

In this issue of the Journal, Alexandra Farrow of Brunel University in the United Kingdom[28] reviews the history of investment in workplace health and safety programs in that country as well as in Western Europe. Her commentary shows how efforts to stimulate and encourage workplace investment in health promotion in Britain and Europe have been integrated with overall national public health strategies for population health improvement. In this country, where private businesses and local public health agencies have worked in tandem, considerable benefit can be brought to employees who need and seek health promotion opportunities in the larger surrounding community when they are not available through their place of work.

Health Promotion Options for Small Employers

Given the fact that so many of North Carolina's employees work for firms having fewer than 100 employees, and at least a third of all of the state's workers are employed by firms with fewer than 25 employees, the prospects for extensive (and certainly not "comprehensive") worksite health promotion programs seem remote. Many firms with few employees do not offer healthcare insurance to their employees, so the risk to these small firms from employee illness and disability are direct risks to the productivity of the firm and not to the overall bottom-line cost of paying for the healthcare services their employees may need at the time of illness or injury. But, these productivity costs, plus the cost of recruitment and training of new employees, may still present sufficient economic incentive for investment. Moreover, many of these smaller firms have deep and lasting personal commitments to their employees, with whom both the company's productivity and the quality of relationships with business clients have been built over a long period of time. The desire to offer opportunities for employees to realize a more positive health status outlook and to maintain long-term capacity for work and life satisfaction is sufficient motivation for many small business owners to entertain the possibility of offering health promotion opportunities to employees.

In this issue of the *North Carolina Medical Journal*, Ben Birken and Laura Linnan[29] provide an extensive discussion of the prospects for small businesses offering health promotion programming for their employees. While the number of small businesses currently offering such opportunities is still small, there are ways in which these businesses may be encouraged to offer such opportunities to their employees. Both federal and state governments have considered tax incentives for small businesses offering wellness programs, but at present these have not been enacted except in a few states.

One of the most promising avenues for small businesses to consider, if they are interested in encouraging employee participation in health promotion initiatives, is to explore linkages with local YMCAs, hospitals, or other community organizations (such as schools) to make available local recreational resources and programs in which these small business employees may participate. Employers should take full advantage of local advocacy group initiatives that provide training at lower cost on ways to effect health along with creating employer networking opportunities. One such organization is NC Prevention Partners (www.NCPreventionPartners.org), which supplies a wealth of easy-to-use and accessible tools and support to businesses interested in initiating health promotion and wellness programs.

An incentive arrangement might include some time from normal work routines to engage in physical activities or health-related counseling (e.g., weight loss consultation) through these community-based programs. Moreover, screening programs can be arranged in cooperation with local public health agencies or hospitals and conducted on-site at the workplace. As Birken and Linnan point out, many of these initiatives work best if employees serve as the steering committee leading these efforts and have the responsibility for promoting employee participation in these programs once these arrangements have been worked out.[29]

It should be pointed out that many health promotion initiatives in the workplace can be offered at little or no cost. There is little employer cost to implementing policies for smoke-free workplaces, healthy choices in vending machines and cafeterias, and communications (e.g., signage) encouraging physical activity during the day, like stair use and walking opportunities. Government Web sites often contain templates for policies that can easily be implemented in businesses of any size. Benefit plans, including high deductible plans, should include low-cost health risk assessments (HRAs), preventive screening and counseling, and immunizations. Many states have set aside Tobacco Settlement funds for smoking cessation and prevention programs, and employees can be encouraged to take advantage of these where they are available. North Carolina's robust *Quit Now NC* program (www.quitnownc.org) that promotes and sponsors tobacco cessation interventions is highly accessible throughout the state.

Cautions and Prospective Pitfalls in Workplace Health Promotion Programs

Despite the promise and potential of health promotion initiatives based at the worksite, there are some words of caution. First, there are important confidentiality and privacy considerations that should be a part of any workplace-based health promotion initiative. Employees who voluntarily agree to the completion of a standardized health risk assessment (HRA) should have the confidence that his/her responses to such questions will be held in strict confidence and not shared with employers or supervisors unless explicitly agreed to by the responding employee. Questions about health practices and personal risk behaviors should not become a part of the employee's personal employment record. Data derived from the administration of an HRA within a company should be summarized in a general way for management only, and results should not be transmitted in a way that make it possible to identify individual employees with specific health risks. This can be particularly important in small companies with few employees where statistical summaries of data can make confidentiality problematic.

Second, participation in health promotion programs at the workplace should be entirely voluntary, and participation should not be tied in any way to wages or other incentives that effectively discriminate against those who choose not to participate. That said, it is still worthwhile to offer incentives, even monetary incentives, to employees to encourage their participation in programs to both maintain and enhance their overall health status.

One of the ways in which health promotion programs have taken the matter of employee participation into account is through the use of employee-interest surveys at the outset of program planning. As an example, the Running the Numbers section of this issue of the *North Carolina Medical Journal*[30] includes an account of the way in which the North Carolina Department of Health and Human Services conducted such a survey before beginning departmental participation in the State Employees Health Plan Health*Smart* program. Strong support was forthcoming from the chief executive of the Department, Secretary Carmen Hooker Odom. The employee-interest survey (with responses received from more than a third of all employees either on-line and in writing) revealed great interest in ways to increase daily physical activity and the establishment of tobacco-free workplaces. These responses made it possible to target program content to address employee priorities rather than to offer program elements based on the presumed employee interests and needs. Another commentary in this issue of the Journal, by George Stokes, Executive Administrator of the State Health Plan, and his colleagues[31] describes the way in which the six components of the Health*Smart* program (viz., health tracking, including an HRA; centrally designed health promotion interventions; targeted disease management; health coaching services available 24/7; high-risk case management; and worksite wellness) were developed in partnership with state and local health departments, how pilot demonstrations of the program were first implemented, and how employees themselves were involved in planning the initiative itself.

Fourth, health promotion and wellness initiatives undertaken by business organizations of any size will obviously face the inevitable question of staffing such efforts. Although volunteer leaders of these efforts can often be identified from within employee groups, having persons with expertise in relevant fields (e.g., nutrition, exercise and physical activity, stress management, etc.) and having personnel involved in offering such services who are not employee colleagues or members of corporate management can make initiatives more acceptable to a wider spectrum of employees. Just as there are concerns over the privacy and confidentiality of information provided via HRAs, so it is that many employees prefer to receive instruction and other types of health-specific services from persons whose professional roles seem distinct from those of other corporate staff. Moreover, the kind of program elements that are most likely to benefit participating employees and attract the interest of persons who should participate are those that have been carefully designed using the best available knowledge in the technical subfields of health promotion. In some cases, such skills can be acquired from outside the organization and arranged on a contractual or short-term basis. However, some companies may choose to hire their own health promotion staff and not share their time with other organizations. Bonnie Rogers, a nurse and specialist in the field of worksite health promotion, offers a detailed discussion of considerations for the staffing of worksite health promotion programs in this issue of the *North Carolina Medical Journal.*[32]

Summary

In the current complex employment landscape providing employer-sponsored benefits involves much more than offering financial protection when employee illness drives a need for costly medical treatment. The transitions in work from product/service production to knowledge generation, along with the transitions in the predominant health and disease conditions from acute illness to preventable chronic disease, require employers to recognize the need to manage their health investment more strategically. This includes the more recent requirement to maximize their investment by ensuring that provisions for maintaining and improving employee health status are incorporated into their health benefits approach. Meanwhile employee health improvement, a highly active but emerging field, is in the process of incorporating experience, research, and more effective methods that result in favorable and demonstrable employee health (and corporate cost-benefit) outcomes. **NCMedJ**

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COMMENTARY

Who Are the Intended Beneficiaries (Targets) of Employee Health Promotion and Wellness Programs?

Dee W. Edington, PhD

The medical journals and medical-related popular press are filling pages with the news about the increasing levels of obesity, diabetes, and other health-related behaviors, risks, and diseases. This development is not new, but has been on the increase for several years. In the early 1970s, some companies began providing health promotion and wellness programs, primarily to their executives and later extended the programs to other employees. The purpose of the programs was to improve the health of the employee, with the company also benefiting from that improved health through lower levels of healthcare costs and increased likelihood of the employee remaining at work. The programs were simplistic and focused on getting to the high-risk individuals, which were typically defined as employees who have the risks for cardiovascular disease. Second generation programs were more inclusive of other risks and behaviors, such as the use of safety belts, but still were primarily focused on metabolic diseases and high-risk individuals.

After 25 years of measuring and evaluating these programs, it has become clear that the current programs are meeting with success only at the margins. Few companies or locations can demonstrate less obesity, more physical activity, and less disease than the benchmarks of 20 years ago. In addition, the overall adoption of these programs was unexpectedly slow until the rapid rise healthcare costs came into focus.

In response to the marginal success of health promotion and wellness programs, it is clear that a different approach is necessary in order for organizations to effectively address the higher levels of obesity and diabetes, for example, and the growing burden of healthcare costs and decreasing productivity. The solution is to expand the economic outcome metrics; to include programming for worksite environmental factors; to include programs for all employees, regardless of risk levels; to expand the programs to families; to seek professional partners in these efforts; and to install measurement metrics that will provide internal feedback for program revisions. With these Next Generation Programs, the benefits derived from health promotion and wellness programs span the total employee population, their respective families, the sponsoring organization, and extend well into the community and eventually to the state.

The economic and personal value of a healthy and productive worksite and workforce is indisputable by most measures of success. Individual employees and their families define health outcomes of employee-targeted health promotion and wellness programs by their level of vitality, quality of life, and freedom from the pain and suffering associated with disease. Employers rely on measures of the energy level, productivity, and creativity of the employees and the moderated medical and pharmacy costs that can be associated with these programs. Communities and states measure health outcomes by the number and sustainability of healthy and productive companies within the community or state.

Although the value of these outcomes is widely shared, obtaining a healthy and productive worksite and workforce has eluded most companies and their employees. The reasons for this are obvious, given the “natural flow” of individual health risks, the “natural flow” of individual medical care costs, and the escalating high-stress worksite cultures that have developed in most modern companies. The natural flow of health risks within a population is toward high-risk, in the absence of programs targeted at maintaining the population at low-risk. The natural flow of medical costs follows the natural flow of risks. Increasing marketplace competition results in a more stressful worksite, unless attention is being paid to the workplace environment.

Companies such as the SAS Institute and IBM, located in the Research Triangle, have been leaders in beginning to design total solution and total population programs for their employees and employees’ families. Dow Chemical and Pitney Bowes are also companies beginning to expand the breath and depth of health promotion and wellness programs into a more comprehensive health management solution for the full population. Most cities and states in this country now have healthcare coalitions, wellness councils, and local examples of companies who began with the early programs, but are now looking for more effective solutions.

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At the urging of General Motors, we began to model the best of the 22 major companies in our corporate consortium and to learn from other companies to design the Next Generation of Health Management Programs on a total population level, since it was clear that focusing only on the small percent of high-risk individuals has not been successful in changing the clinical and economic outcome measures. In addition, other companies such as Matria, a population health enhancement company, is rolling out its Next Generation Program as are some of the national health plans including Anthem, Aetna, and CIGNA. These Next Generation programs are expected to be available in the spring of 2007.

Next Generation Health Management Programs

It is now clear that *something* was missing from the early (1975-2005) worksite health promotion program strategies and that *something* is really *two* things: (1) paying attention to everyone in the population and (2) paying attention to the worksite culture and environment itself. If employees are the beneficiaries, then all employees need to be given access to programs addressing health promotion objectives and to the incentives that drive participation, and eventually full engagement, in the process. In our thinking about the Next Generation of Health Management Programs, there are seven components that are critical if the employees (and other beneficiaries) are to fully benefit from these initiatives.

1. Corporate leadership must set the vision for health management throughout the company.
2. All environmental policies and procedures must be aligned with the goal of a healthy and productive worksite and enlistment of critical partners in the effort.
3. Health Risk Appraisals should be available to all employees (and spouses/significant others).
4. All individuals should be risk-status stratified and offered access to health promotion interventions and resources appropriate to their needs (risk categories) and interests.
5. Population-based health promotion programs should be available to all employees.
6. Appropriate incentives for program participation should be available to all employees.
7. Measurement, evaluation, and decision support should be conducted to drive program decisions.

The first hallmark of a successful program is the clear and observable vision of the organization's senior leadership. In addition to announcing the vision, leadership must share the vision with everyone in the organization. The next step is to ensure that the organization's policies and procedures are aligned with the goal of a healthy and productive worksite. This includes such things as smoking policies, stairwell access, vending machines, cafeterias, job design, flexible working hours, and benefit design. Critical partners in this effort require the enlistment of the health plan, benefit consultants, primary care physicians, health enhancement companies, and pharmaceutical companies.

Health Risk Appraisals (HRAs) are a core technology for health and wellness programs and need to be completed by everyone in the organization. The critical choice of an HRA depends upon the program's overall objective. Some HRAs are focused on health education, others focus on longevity, but our bias is on a more comprehensive approach, which includes vitality or quality of life, medical and pharmacy utilization, disability absences, and presenteeism. The customized individual profiles obtained from HRA completion focus on vitality and risk and behavioral factors leading to quality of life and possible disease. The organizational reports summarize (in aggregate form) the individual health risk profiles and then the data are combined (or modeled) with outcome data to create a scorecard of the health-status of the population.

Once a person completes an HRA, they then need to contact a coach, advisor, or advocate to discuss their risk/health status profile and to create goals to maintain or improve their current health status. This is a very critical step and one that could continue indefinitely. The fifth step is to provide wellness programs to the total population. "Know-your-numbers," "no weight gain," and a "1,000-step pedometer" are examples of programs or interventions that can serve this function well.

Crown Equipment Corporation

Crown Equipment Corporation, located in New Bremen, Ohio, manufacturers battery powered material handling equipment. Crown is the first company to adopt the components of the Next Generation Health Management Program to move toward a Champion Company.

After successfully rolling out its HRA and wellness screening initiatives with over 90% participation in 2004 to all Crown locations, Crown decided to adopt the full set of health management components while planning for 2007. The president and senior management set the vision to become a Champion Company. The Medical Director, Benefits Manager, and the Program Manager were given the task of implementation to 5,500 employees throughout the company's several locations.

Benefit design is the driver of the program. Participation begins with an impressive benefit credit for employees and spouses to engage in the program, including the HRA, wellness screenings, and health coaching. The company engages outside vendors to assist with its programs for 2007. The health advising initiative is particularly innovative and designed to maintain 90% or higher participation to reach total engagement of the employees and spouses in understanding personal health accountability. Participation with the health advisor is driven by a significant cash award for employees and spouses. Resources are made available to any employee or spouse who wants to further engage in any program designed to help them maintain or improve their health risks and lifestyle behaviors.

The company also has an innovative healthier vending program, including offering a healthy drink and healthy snack during break.

For more information, contact Karen O'Flaherty at 419-629-6330 or healthwise@crown.com.

Incentives and measurement are the sixth and seventh steps in the Next Generation Program. We now know that the success of a program requires 80% to 95% participation and engagement of the total population, regardless of risk level. Anything less than that falls short of meeting the objectives of a healthy and productive worksite and a healthy and productive workforce.

One of our major learnings over the 30 years we have been studying the health management of populations is that paying attention to healthy (or low-risk) employees is the secret to creating and maintaining a healthy and productive workforce: that is, *keep the low-risk people low-risk*. The second secret is to *first create winners* in the population. For example, initiatives like "know your numbers" and "no weight gain" programs give employees the opportunity for realizing early accomplishment and serve to motivate further attention to personal health risk issues as interventional opportunities are made available. Most programs go immediately for reductions in blood pressure, cholesterol, and body weight; and most individuals end up right back where they started within one or two years.

Benefits to Employees

Most people immediately think of the employee as the first and foremost beneficiary of these programs, and most programs over the past three decades were focused on the high-risk employees (perceived beneficiaries) in particular, while the low-risk employees were ignored. While a few of the high-risk employees and their families were helped as a result of this strategy, the overwhelming evidence is that high-risk employees (and employed workforce health in general) are no better off by nearly any measure of success than we were 30 years ago.

Three strategies have emerged within the Next Generation Programs. The first strategy is to continue to work with the high-risk individuals, but on a *whole person* and *self-leader* approach, rather than a lifestyle risk or disease management approach. The reason for this is that previous risk reduction strategies focused on single risk factor reduction and tended to ignore other risks that might have influenced the person (e.g., weight loss while ignoring smoking or job satisfaction). In addition, the teaching opportunity is such that each individual could be taught to value their own risk-status and serve as their own leader in maintaining positive risk and behaviors and modifying the rest. The second strategy is to work with all the employees regardless of risk level with the same type of intervention strategy. This strategy is somewhat counter-intuitive, and the goal is to convince the participant to value remaining at a relatively low-risk level. The third strategy flows from the environmental component where the organization creates a working environment and benefits that are aligned with a healthy and productive worksite and healthy and productive individuals.

Benefits to Employers

Employers most often sponsor these programs hoping to improve overall productivity and decrease medical and pharmacy spending. However, there is an even greater benefit to employers: survival and prosperity. It is clear that as the world moves toward a global economy and world-wide competition, any company committed to maintaining a competitive position will need to develop and maintain a healthy and productive worksite and workforce.

Also, given the emerging demographics of the American workforce, the value of older workers will increase exponentially. Companies will find that facilitating good health status offsets the medical costs of older workers and the increased company knowledge and relationship possessed by the older workers can be retained by the company. In this era of the "knowledge worker," older workers are likely to be the reservoirs of much of the important knowledge needed in the future.

The Next Generation Programs were designed in part to engage the maximum number of employees. Previous strategies have suffered from low participation rates (somewhere around 30%) and the obvious avoidance of the programs by the high-risk individuals who felt targeted and stigmatized by the focus on the high-risk interventions. The Next Generation approach attempts to engage all employees—making everyone feel included—and participation rates are now approaching 90% or higher in companies adopting this philosophy and approach.

Employers recognize that they cannot accomplish their goals without help from partners. Health plans, benefit consultants, primary care physicians, health enhancement companies, and pharmaceutical companies all have a major role to play in order for all the benefits to be derived from comprehensive health management programs. Even the most conservative estimates of these programs' economic benefits in relation to medical and pharmacy costs put the benefit at the break-even point, while the most common return is estimated at 3.0. When absentee days, disability days, and worker's compensation costs are added to the calculations, the estimated returns are even greater.

Benefits to Communities and States

Communities and states should encourage employers to sponsor these programs with the intention of improving the overall working environment, an overall decrease in the cost of disease care, and an improvement in productivity, which drives increased revenue for the overall economy and, thus, increased tax revenue. Healthy residents lead to lower medical utilization and higher productivity. When worksites and their workforces are characterized in this way, fewer companies will look for relocation options, and more companies will look to relocate to the state and community where these conditions exist.

Summary

There is nearly no downside to clinically and economically effective health management programs since each stakeholder is a beneficiary: the family, the employee, the employer, the community, and the state. These programs drive both the cost and the revenue sides of the economic equation. **NCMedJ**

COMMENTARY

What's Holding You Back:

Why Should (or Shouldn't) Employers Invest in Health Promotion Programs for Their Workers?

Ron Z. Goetzel, PhD; and Ronald J. Ozminkowski, PhD

A question we are often asked is: How can I convince my senior management that investing in the health and well-being of workers will save money and produce a positive return on investment (ROI)? If leadership of the organization has already made up its mind that health promotion programs are a waste of time and money, then it is next to impossible to convince them otherwise. If, on the other hand, leaders have not yet made up their minds, and importantly, if they have not been exposed to the body of evidence suggesting that worksite programs have the potential to improve workers' health and lower company expenses, then there is hope.

Below, we offer the main arguments in favor of increased employer investment in health promotion. We emphasize the economic rationale for such investment, rather than arguing that it is the "right thing to do" and a socially responsible way of treating one's workers. We contend that health promotion programs not only improve worker health and well-being, but also produce bottom line effects.

> *"...health promotion programs not only improve worker health and well-being, but also produce bottom line effects."*

Reasons to Invest In Worksite Health Promotion Programs

Some support for our view can be found in the book, *Corporate Responsibility and Financial Performance: The Paradox of Social Cost,*[1] written by two accounting professors, Pava and Krausz. They analyzed the financial performance of 53 companies identified as "socially responsible," and compared them to a control sample of firms matched by industry and size. Among the activities considered reflective of social responsibility were health promotion programs, which the authors described as "viable and legitimate" institutional mechanisms to alleviate an important social problem—poor health habits among workers. The authors concluded that, across almost every one of the financial outcome measures examined, "socially responsible firms … perform no worse and, perhaps, … better than non-socially responsible firms."

But, should employers pay additional money for health promotion programs? We believe the answer is "yes." The rationale for such investment can be summarized as a series of hypotheses, stated as follows. (1) Many of the diseases and disorders from which employees suffer are preventable. (2) Modifiable health risk factors are precursors to a large number of these diseases and disorders. (3) Many modifiable health risks are associated with increased healthcare costs and reduced worker productivity, within a relatively short-time window. (4) Modifiable health risks can be improved through workplace-sponsored health promotion and disease prevention programs. (5) Improvements in the health risk profile of a population can lead to reductions in healthcare costs and absenteeism and improve worker productivity. (6) Well-designed and well-implemented worksite health promotion and disease

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prevention programs can save companies money.

Below, we note some of the salient studies addressing the previous hypotheses.

Many Diseases and Disorders Are Preventable, Yet Costly

A large body of medical and epidemiological evidence shows the links between common, modifiable, behavioral risk factors and chronic disease.[2] Preventable illnesses make up approximately 70% of the total burden of disease and their associated costs.[3] Half of all deaths in the United States are caused by behavioral risk factors and behavior patterns that are modifiable.[4,5] In particular, the United States has been witnessing alarming increases in obesity, diabetes, and related disorders for many years.[6] These diseases strain the resources of the healthcare system, as individuals who experience them generate significantly higher healthcare costs.[7] Employers pay over one third of the total national annual medical bill for these and other conditions.[8]

Modifiable Health Risks Increase Employer Costs

Analyses by Anderson et al[9] show that 10 modifiable health risk factors account for approximately 25% of all healthcare expenditures for employers. Moreover, employees with seven risk factors (tobacco use, hypertension, hypercholesterolemia, overweight/obesity, high blood glucose, high stress, and lack of physical activity) cost employers 228% more than those lacking those risk factors.[10] Workers with these risk factors are more likely to be high-cost employees in terms of absenteeism, disability, and reduced productivity.[11] Synthesizing the health promotion literature spanning 15 years, Aldana concluded that there is consistent evidence that a relationship exists between obesity, stress, and multiple risk factors, and subsequent healthcare expenditures and worker absenteeism.[12]

Workplaces Offer an Ideal Setting for Health Promotion

Most people agree that the workplace presents an ideal setting for introducing and maintaining health promotion programs. Individuals generally spend over half of their waking hours at work. The workplace contains a concentrated group of people, usually situated in a small number of geographic sites, who share a common purpose and common culture. Communication and information exchange with workers are relatively straightforward. Individual goals and organizational goals, including those related to increasing profitability, generally are aligned with one another. Social support is available when behavior change efforts are attempted. Organizational norms can help guide certain behaviors and discourage others. Financial or other incentives can be introduced to encourage participation in programs. Measurement of program impact is often practical using available administrative data collection and analysis systems.

Worksite Health Promotion Can Positively Influence Employees' Health Risks

Given the previous information, is there evidence that worksite programs can change habits of worker populations? It appears the answer is "yes." Heaney and Goetzel examined 47 peer-reviewed studies, over a 20-year period, focused on the impact of multi-component worksite health promotion programs on employee health and productivity outcomes.[13] The authors concluded that there was "indicative to acceptable" evidence supporting the effectiveness of multi-component worksite health promotion programs in achieving long-term behavior change and risk reduction among workers. The most effective programs offered individualized risk-reduction counseling, coaching; and self-management training to the highest risk employees within the context of a healthy company culture and supportive work environment.[13] The reviewers concluded that a more comprehensive approach to worksite health promotion across multiple risk factors was preferred to one that is single-risk factor-focused where only a small selected group of employees benefit.

Worksite Health Promotion Can Achieve a Positive Return on Investment

So, if worksite programs can change health habits, can they also save money and even pay for themselves? Several literature reviews that weigh the evidence from experimental and quasi-experimental research studies suggest that programs grounded in behavior change theory and that utilize tailored communications and individualized counseling for high-risk individuals achieve cost savings and produce a positive return on investment.[14-16] The ROI research is grounded in evaluations of employer-sponsored health promotion programs. Studies often cited with the strongest research designs and large numbers of subjects included those performed at Johnson & Johnson,[17,18] Citibank,[19] Dupont,[20] the Bank of America,[21,22] Tenneco,[23] Duke University,[24] the California Public Retirees System,[25] Procter and Gamble,[26] and Chevron Corporation.[27] Even accounting for certain inconsistencies in design and results, most of these worksite programs produced positive cost outcomes.

In the most recent review summarizing results from 42 qualifying financial impact studies conducted over the past two decades, Chapman concluded that worksite programs achieve a 25-30% reduction in medical and absenteeism costs in an average period of about 3.6 years.[28] In a widely cited example of a rigorous ROI analysis, Citibank reported a savings of $8.9 million in medical expenditures from their health promotion program as compared to their $1.9 million investment on the program, thus achieving an ROI of 4.56 to 1.0.[19]

Conclusion

In this commentary, we put forth the main arguments in favor of employer investment in health promotion programs for their workers. There are also legitimate and powerful reasons why some employers have been reticent to spend money on health promotion. Generally, these have to do with philosophical reasons that reflect a desire to avoid the potential for perceived intrusions into the private lives of employees, despite the fact that an economic business case in support of these appears incontrovertible.

As for small businesses that cannot afford to conduct and/or evaluate their own programs, we recommend that they press federal agencies to support collective health promotion purchaser consortia. These consortia would define common health and business objectives, achieve consensus on health promotion program designs, issue a request for proposal to vendors and health plans that can offer desirable programs, and put in place specific guarantees regarding the performance of these programs. Importantly, purchaser consortia should include a requirement for vendors to support rigorous, independent evaluations of the health and economic outcomes from their programs, with reasonable definitions of success and a timetable for reporting results. Making the result of such evaluations public will enhance the credibility of the vendor's programs and contribute to the ability of the human resources manager to make a successful business case. **NCMedJ**

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COMMENTARY

Employee Participation in Workplace Health Promotion and Wellness Programs:

How Important Are Incentives, and Which Work Best?

Larry Chapman, MPH

Health promotion and wellness efforts for working populations are receiving significant attention. American employers, faced with unacceptable rates of increase in employee health plan costs are moving to introduce more expansive and better designed wellness programs for their employees.[1] During the past decade, dozens of well-designed studies have documented the health improvements and economic return outcomes from a wide variety of worksite settings.[2]

Also emerging as a *sine quo non* for the field is the equation… participation/engagement = risk reduction = economic return.[3] Generating high levels of participation and engagement is essential to the success of all prevention programs. In the early days of the field, it was thought that by vigorously promoting program activities, offering them during work time, and building cultural awareness and acceptability was all one needed to do to produce high levels of program participation. However, program managers have learned differently. Once the "newness" and curiosity of a wellness/health promotion program has worn off, employee participation will almost always drop significantly. This has led to the almost universal use of incentives for program participation.

> *"The relative effectiveness, or overall participation levels, …is directly related to the dollar value of the rewards."*

Beginning with simple program participation incentives, employers are usually moving through three basic incentive phases. The first phase is usually marked by token incentives, typically limited to inexpensive trinkets (under $10 in cost), such as water bottles, t-shirts, sun visors, or pens. Employees receive these trinkets for participating in programs. For example, they may receive a t-shirt for completing a health risk assessment, attending at an educational workshop, using of an E-Health Web site, or participating in a biometric screening event. The second phase usually capitalizes on moderately priced gift merchandise, such as emergency road kits, flashlights, gift coupons, lamps, and other merchandise in the $20 to $50 cost range. When employees participate in the second phase, they typically accumulate points, which are then redeemed for merchandise. The third phase usually involves significantly larger dollar values and in more easily redeemable forms, such as cash, debit cards, or reductions in health plan payroll deductions. The magnitude of incentives in this third phase is often in the $300 to $1,200 per-employee per-year range, and it usually involves meeting several wellness "criteria," including program participation and wellness achievements, such as maintaining a healthy body weight, healthy cholesterol fractions, and controlled blood pressure. The relative effectiveness, or overall participation levels, of these three phases is directly related to the dollar value of the rewards. The higher the average dollar reward the greater the participation levels. In phases two and three, employers often use lottery or raffle approaches for reward distribution, but this type of approach, where uncertainty is added to reward attainment, rarely equals the participation levels associated with known and surer receipt of rewards.

As we raise the bar of expectations for wellness achievements to include more demanding and difficult achievements, such as losing significant amounts of body weight, increasing physical activity levels, overcoming tobacco use habits, and others, it is clear that the magnitude of the reward has to be raised as well. This also tends to create a concern that, as the reward size gets larger; it is going to be more difficult to maintain a positive level of economic return or return on investment (ROI). Many employers are therefore beginning to realize that they can add

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the projected incentive cost and the wellness program costs to their health plan premium and through premium contributions can have employees share this cost. Employees who don't cooperate then end up paying a larger proportion of the combined premium cost than those who participate or engage in wellness programs and activities. This approach is considered to be a "play or pay" based program strategy and can make all wellness-related costs a zero sum budget expenditure for employers. Some employers have actually generated revenue with this approach.

This third phase of wellness incentives is generally built around a set of voluntary wellness criteria, such as those listed below. Due to the great flexibility inherent in the design of wellness criteria, it is likely that these types of criteria will be tested and refined over time and will help to create a dynamic tension around engaging in wellness behaviors.

For example, in a phase three approach to wellness incentives, if the individual meets any eight out of the following 10 wellness criteria, they may qualify for a $600 reduction in their health plan premium contribution for the year.[4]

- Non-tobacco user or participation in a smoking cessation program.
- Body Mass Index (BMI) less than 30 or participation in a weight management program or wellness coaching.
- Overall Wellness Score from an HRA of 85 or greater.
- Physical activity more than four times per week.
- Completion of 30-minute Webinar on wellness and consumer health.
- Current on preventive screening (form completed by their doctor).
- Agree to wear a seat belt 100% of the time they are in a motor vehicle.
- They have a Primary Care Practitioner (PCP).
- Use of medical self-care in the past three months.
- No more than three sick leave days in last 12 months.

Under the new final regulations for the non-discrimination provisions of the Health Insurance Portability and Accountability Act (HIPAA), this approach is allowable as long as the financial reward does not exceed 20% of the total health plan cost and the approach meets the other four reasonable provisions called for in the final regulations.[5]

In conclusion, incentives are absolutely essential to participation and engagement in wellness and prevention activities for virtually all populations and are likely to become a standard feature of health plans that are serious about managing the health of their members. Additionally, many employers are now demanding increasingly effective approaches to long-term health cost stabilization through health management and health improvement. **NCMedJ**

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COMMENTARY

Small Businesses, Worksite Wellness, and Public Health:

A Time for Action

Laura A. Linnan, ScD, CHES; and Benjamin E. Birken, MS

The United States Small Business Administration (SBA) defines a "small" business as an independent business employing 500 or fewer employees. The SBA estimates that there are approximately 25.8 million "small" businesses in the United States, and they employ roughly 50% of the working population.[1] Small businesses tend to offer less health insurance for employees.[2] While 98% of businesses with 200 or more employees offered health benefits, only 59% of firms with less than 200 workers offered health benefits to employees.[3] A lack of health insurance severely limits access to health and medical care for employees and places them in a precarious financial position if an injury or illness befalls the employee or a member of his/her family. National worksite survey results indicate that health insurance or managed care providers are the leading source of health risk appraisals, health screenings, lifestyle behavior change programs, and disease management programs offered by employers of all sizes.[4] As a result, when a small business does not offer health insurance, employees have less access to health promotion programming of all types. However, even among small businesses that offer employee health insurance, the evidence is clear that at nearly every level of employee size, smaller worksites are less likely to offer all types of health promotion programs, offer fewer environmental programs or supports, and report fewer health-oriented policies.[4] Moreover, these patterns have persisted over the past 30 years![4-7] Given growing evidence that worksite-based health promotion programs lead to improvements in employee health, morale, productivity, while helping employers address the rising cost of healthcare. It is a matter of public health concern that small businesses and the 50% of United States workers employed by them do not enjoy these important benefits. This paper will offer some plausible explanations for why small businesses offer fewer health promotion and safety programs, why this problem has persisted over time, suggest a multi-level intervention strategy for increasing the number of small businesses who offer health and safety programs for their employees, and offer a few final research-related next steps.

> *"When business survival is the focus, any other costs, including those linked to employee health, may be seen as prohibitive."*

Why Do Small Businesses Offer Fewer Health Promotion and Safety Programs?

First, we acknowledge that understanding why some small businesses offer health promotion and safety programs (and others do not) is an important question that is worthy of additional research. There may be different reasons for different types of businesses (e.g., service, retail, manufacturing), different "size" businesses (e.g., under 15 employees vs. over 250 employees), businesses in different regions of the country, and/or businesses with different longevity (e.g., start-up, over five years, etc.). While more information would be desirable, here we offer several plausible reasons why small businesses are less likely to offer employee health and safety programs. One likely reason is the additional cost of offering these programs. Small business owners take a serious personal and financial risk to open a new business. More small businesses fail than succeed. Start-up costs for any business are

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substantial. Owners must learn how to hire and retain employees and to run a successful business. When business survival is the focus, any other costs, including those linked to employee health, may be seen as prohibitive. In addition to direct costs, a small business may be less likely to offer health and safety programming because indirect costs (e.g., time and resources) for anything other than the business enterprise are typically in short supply. Competing demands to meet production or service goals, to operate efficiently, and/or to grow the business, are constantly being juggled with human capital needs and resources in the small business environment. Thus, employee health promotion may be low on the list of priorities for small business owners.

A third possible reason why small businesses offer fewer health promotion programs is a lack of personnel dedicated to employee health and safety. National survey results indicate that worksites with a dedicated staff person for health and safety are 10 times more likely to offer a comprehensive worksite wellness program than are worksites without dedicated staff.[4] Small businesses have fewer staff members, and these staff tend to have multiple responsibilities. Thus, few small businesses employ individuals who are able to dedicate any time/effort to worksite health and safety. Interestingly, as small businesses grow in employee size, some of the barriers to offering health and safety programs may diminish. Wilson[8] conducted a nationally representative survey of small businesses and learned that employers with 50-99 employees were different than even smaller employers (i.e., those with less than 50 employees) on nearly all categories. While access to safety programming was about the same in these two categories of employers, the slightly larger worksites were more likely to offer employee health insurance, had more formalized health-related policies and practices, and offered more health promotion programming than companies with less than 50 employees. They also found that the slightly larger employers were more likely to have dedicated staff for health promotion, occupational health and safety, and employee assistance programs.[8] Having a dedicated staff person is a necessary, but not sufficient, condition for success. It is important to have dedicated and knowledgeable and/or experienced staff to successfully plan, implement, and evaluate worksite health promotion programs.

One final reason why small businesses are less likely to offer worksite health promotion and safety programs is linked to the small business culture and leadership tendencies of their owners. Here, some fundamental research has been undertaken. Eakin[9] conducted an important study on the social culture of work in small businesses and the role of manager beliefs and attitudes in framing the meaning and experience of work in those environments. She interviewed 53 small business owners and found that the prevailing way of "managing" health and safety issues was to "leave it up to the workers." Owners discounted health hazards overall and emphasized the perspective that if they tried to address employee health behaviors, they were viewed as paternalistic and/or meddling. Linnan and colleagues[10] corroborated these findings with survey results from more than 1,000 managers in 23 small-to-medium size manufacturing worksites where they found that, while managers strongly believed that safety issues are the responsibility of employers to address, they rated far lower the matter of employer responsibility for supporting employee lifestyle health and/or behavioral issues.[10] It follows that, because most United States small businesses have less than 15 employees, issues of privacy and confidentiality, which are essential to ensuring employee program participation in health promotion programs, can be compromised. As a result, some small business owners may choose not to offer any programs at all, so as to avoid the perception that they are prying into the private lives of their employees.

Despite the many reasons why small business owners are less likely to offer health and safety programs, small businesses have assets and strengths that will serve to help facilitate the adoption of these programs. Specifically, small businesses have fewer organizational layers than larger companies to consider in the decision-making process, so that if an owner wants to adopt a new program or create a new policy, it is typically not a cumbersome decision and approval process. In larger companies, these decisions involve multiple people and additional time. In addition, with fewer employees, it is easier to solicit opinions or assess health needs from the entire workforce at a small business. In larger companies with remote locations, these efforts are complicated, and some employees may be left out. Third, the influence of the leader may be more direct and, thus, stronger in small businesses. As a result, if the leader is supportive of health promotion efforts, employees may be more highly motivated to get involved in worksite-sponsored health promotion, given the stronger and more direct interpersonal relationship between managers and employees in small businesses. Small business owners also know that the health of every employee is important; and employees may be family members (or viewed as "part of

"...if the leader is supportive of health promotion efforts, employees may be more highly motivated to get involved in worksite-sponsored health promotion, given the stronger and more direct interpersonal relationship between managers and employees in small businesses."

the family"), which provides additional motivation to treat employee health as a priority issue.

Recognizing both the challenges and potential strengths of working with small businesses to address health promotion is an important first step toward addressing this public health imperative. One of the *Healthy People 2010* national objectives states that "75% of employers (of all sizes) should offer a comprehensive worksite health promotion program," which is defined as including: (1) *Health education programs* (e.g., skill development and lifestyle behavior change along with information dissemination and awareness building); (2) *Supportive social/physical environments*; (e.g., an organization's expectations regarding healthy behaviors and implementation of policies that promote health and reduce risk of disease); (3) *Integration* (e.g., of the worksite program into the organization's structure); (4) *Linkage* (e.g., to related programs like employee assistance programs (EAPs) and programs to help employees balance work and family); and (5) *Worksite screening programs* (e.g., linked to medical care to ensure follow-up and appropriate treatment). While the majority of employers offer one or more of the five key elements of a comprehensive program,[4] it is clear that small businesses offer far fewer of all programs and are unlikely to reach the 2010 national health objective. In the remainder of this commentary, we share some strategies for how to successfully increase the likelihood that small businesses offer worksite health and safety programs for their employees.

Strategies for Success—Increasing Adoption and Implementation of Health and Safety Programs among Small Business Owners

There are multiple reasons why small businesses may not be offering these programs, so a successful strategy for increasing adoption and implementation of health promotion programs among small businesses should involve multiple levels of intervention, consistent with ecological approaches.[11] Here we present a brief review of some promising strategies at three levels of the social ecologic framework (policy, community, organization) and conclude with a call for additional research.

Policy-Level Changes

Public policy at the federal, state, and local levels could be enacted to support small business owners who want to implement employee health promotion efforts. For example, legislation extending tax credits to small businesses that offer selected health promotion programs was sponsored by Senator Tom Harkin (D-IA) in the Healthy Lifestyle and Prevention America Act (S. 1074). This type of legislation was proposed at the state level in Rhode Island as well.[12] In addition to tax credit strategies, public policy changes that would offer some type of universal healthcare coverage at reduced rates to small businesses would be helpful. As noted previously, because managed care or other health plans are the primary source of employer-sponsored health promotion programs, offering health plan coverage that includes a basic health promotion package would be desirable. These public policy changes—whether at the national or state level—have the potential for making an immediate and significant impact on small business adoption and implementation of health promotion programs for employees.

Community-Level Changes

If not a part of a franchise or a larger corporate affiliation, small businesses can be isolated organizational structures without much power or leverage in a given community. Recommended community-level changes to help stimulate small businesses to adopt and implement health promotion programs is all about identifying and creating leverage points for change through partnerships. Promising community-level interventions include encouraging partnerships to address health promotion initiatives with regional Small Business Administration offices, local Chambers of Commerce, local Business Councils, and national or local Business Groups on Health. These organizations typically exist to support businesses, and if health promotion "packages" or training sessions or workshops could be developed with a small business focus, it might stimulate owners to adopt more health promotion programming. In addition, these partnerships create leverage opportunities where members could be called upon to advocate for policy changes at the national, state, or local levels. In Rhode Island, the state health department helped to organize a statewide worksite wellness council that included business leaders of all sizes, health department officials, insurers/health plans, consultants, and researchers.[12] In North Carolina, most local communities have a Healthy Carolinians Task Force that could embrace and sponsor worksite wellness initiatives. University-based partnerships can bring student skills and help; opportunities for student projects or practicum experiences; and expertise in planning, marketing, or evaluating programs. These community-level partnerships and activities could be a powerful force for change.

Organizational-Level Interventions

Here, we refer to interventions that might be initiated within the small business itself to support the adoption and implementation of employee health promotion programs. Barbeau et al[13] reported that there were no significant differences between small manufacturing sites that did/did not agree to participate in a cancer prevention research trial. Happily, there is growing research evidence that small businesses are interested in and can successfully adopt these programs and that employees who participate can improve their health. For example, Sorenson and colleagues[14] found that small businesses randomized to receive a social-contextual intervention, which included employee participation through wellness committees, and a multi-level intervention addressing employee and manager health and work conditions, were significantly more likely than control worksites to improve multivitamin use and physical activity among employee participants.

The types of strategies that an interested small business can use to develop a successful health promotion program include many of the same approaches that other businesses (of all sizes) should consider. Specifically, first it is important to mobilize all available internal and external information and resources that might be related to health promotion (e.g., marketing, facilities, nurses, benefits, etc.). Small businesses should create a small team, task force, or wellness committee including employees who are interested in helping focus attention on employee health. This small group can provide the staffing and leadership needed to get a project underway. Second, if there is a labor union or employer-sponsored healthcare plan already present, resources/expertise available through these sources might offer possible staffing, resources, intervention materials, or expert help. Third, it would be useful to conduct an assessment to determine the top five healthcare claims costs, the top five health needs/interests of managers and employees, the behavioral risk profile of the workforce (e.g., via a Health Risk Appraisal), and the important expectations that managers and employees have for this program. Make sure the most current literature from worksite-based research studies is carefully and critically reviewed. Fourth, develop a working plan that takes into account the assessment results and current evidence about what works, as well as realistic objectives for success. It is essential to obtain approval and encouragement for implementation from top management and the wellness committee or task force established at the worksite. A systematic and tailored communications plan and a festive kick-off event can help to get the program underway. Fifth, it is important to include as program components a menu of evidence-based health promotion program offerings that take into account different learning preferences, convenience, cost, time to participate, and any privacy/confidentiality concerns that might exist among employees.

The program, once implemented, should take steps to stay visible among both employees and managers. The program should include multi-level interventions that address work conditions, as well as the physical and social environment. Ongoing visibility can be aided by E-mail messaging, events, contests, print, video, online sources, classes, support groups, and other relevant methods. In order to identify evidence-based programs for possible program inclusion, one can review the most recent published worksite-based literature, the Community Guide to Preventive Services published by the Centers for Disease Control and Prevention (www.thecommunityguide.org/worksite/), CancerControl Planet (http://cancercontrolplanet.cancer.gov/), the Centers for Disease Control and Prevention-sponsored Healthier Worksite Initiative (www.cdc.gov/nccdphp/dnpa/hwi/index.htm), and other compendia of information about effective programs and policy interventions. Specific resources (handbooks) that include examples of small business success stories can be found at the Wellness Councils of America (WELCOA) (www.welcoa.org) or Partnership for Prevention (2001) (www.prevent.org/) Web sites. Finally, successful worksite health promotion initiatives include specific plans to evaluate the health outcomes at the worksite and employee levels, as well as the process of delivering these programs, so that employees and managers can talk about their experiences and the results of these endeavors. It is important to find ways to periodically share the results with employees, the wellness committee members, and with managers. Similarly, it is important to work toward securing a budget (however small to begin with) and some portion of dedicated staff support for employee health promotion activities. Over time, individual training for health promotion program staff will build internal expertise. Successful programs will pursue all partnership opportunities in the larger community, and within their own company environment, so as to leverage small resources and expertise into successful outcomes.

Research to Benefit Practice

Ongoing research is needed to determine how to create structural, political, and economic incentives, as well as strategies for how best to motivate small business owners to adopt these programs, and then to help owners be successful once they embark on these efforts. Research is needed to decipher what the underlying and persistent barriers are to offering these programs and to determine how best to overcome identified barriers in the highly diverse and complex small business community. Divine[15] recently found that small business owners deciding to offer employee health promotion programs were less motivated by financial arguments (e.g., the programs will address a business need or rising healthcare cost), but were more persuaded by evidence that the wellness programs actually work to improve employee health. Qualitative research is critically important to uncovering the root causes of why this problem has persisted for more than three decades. How to best "tailor" a menu of health promotion offerings to the small business environment continues to be a worthy research question. Because partnerships are central to overcoming some of the barriers to offering these programs in small businesses, future research on which partnerships are most effective, how to best characterize these partnerships, and how these partnerships can grow and be sustained over time seem to be critically important scientific pursuits. The role played by managed care organizations and other healthcare provider organizations needs further investigation. Research on the policy level that uncovers examples of legislation or incentives that work to increase small business adoption is clearly needed as well.

> *"Because nearly 50% of American workers are employed in small businesses, we need to address this problem as a public health imperative."*

For the past 30 years, while worksite health promotion programs have proliferated, and many employees and companies have benefited from these programs, small businesses and their employees have lagged behind and, in fact, have made very few strides toward offering health promotion programs for their employees. Because nearly 50% of American workers are employed in small businesses, we need to address this problem as a public health imperative. We have offered some of the plausible reasons why small businesses have not offered health promotion programs, noted some of the challenges and opportunities, have identified some potential strategies for success, as well as research needs. As we move further into the 21st century, we must take up this challenge so that all workers can benefit equally from successful worksite health promotion efforts, regardless of whether they are employed in a corner convenience store with five employees or a Fortune 500 corporation. This public health challenge is one that we can begin to address with strong partnership models, a multi-level intervention strategy, and the political will to focus attention on this issue now. **NCMedJ**

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COMMENTARY

Implementation Challenges in Worksite Health Promotion Programs

Benjamin E. Birken, MS, and Laura A. Linnan, ScD, CHES

Effective worksite health promotion programs address challenges that occur during planning, development, implementation, and evaluation efforts.[1] In this commentary, we focus on implementation challenges faced by employers—issues that must be addressed after an organization has made a commitment to offering a worksite health promotion program. Of course, initial support from top management must be secured. But evidence suggests that management support alone does not guarantee program success.[2,3]

A nationally representative sample of employers responded to the 2004 National Worksite Health Promotion Survey and reported that the most common barriers or challenges to health promotion program success were: lack of interest among employees (63.5%); lack of staff resources (50.1%); lack of funding (48.2%); lack of participation among high-risk employees (48.0%); and lack of management support (37.0%).[4] No significant differences in barriers were reported based on industry type or worksite size except that worksites with 750+ employees were significantly more likely to report lack of participation by high risk employees as a barrier.[4] We review each of these potential implementation challenges and argue that engaging employees and managers in identifying and addressing them early in the planning process allows an organization to develop the necessary strategies to overcome them.

First, some employers clearly believe that employees are not interested in worksite health promotion programs. This tends to occur when employee participation in programs is low. It is important to both understand and clarify some of the potential underlying "causes" of low levels of employee interest and participation.[5] For example, insufficient or ineffective communication about health promotion programs could result in low levels of participation simply because employees were not aware of programs being offered. Another potential "cause" of low perceived employee interest is that employees might not participate at all (or in lower numbers) if they have to pay to join a program, or if the program is offered at inconvenient times or locations, or when child care and other issues may limit participation. Employees exposed to stressful and/or otherwise hazardous work conditions might not participate because they are skeptical of worksite health promotion programs and/or angry if these programs are being prioritized ahead of addressing work conditions.[6] Additionally, if employees believe that employers are intruding on their privacy or trying to "control" their health, they may not participate.[7] Thus, low employee participation may be caused by several of these factors and may lead to a perception among employers that employees are not "interested" in health promotion programs.

> *"...we encourage employers to consider funding worksite health promotion programs as an investment in "human capital" that will lead to bottom line advantages for the organization."*

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Improving Employee Participation

Strategic program planning efforts can help organizations overcome problems with low participation and low perceived employee interest. First, we encourage employers to mobilize an employee wellness committee—a group of employees that represent key work teams and departments in an organization—who can be involved in planning, promoting, and developing health promotion programs at work.[8] If unions are present, be sure to work with local representatives to understand their priorities and incorporate those into the planning process. Second, develop a comprehensive marketing plan that gets the word out about program offerings through channels that reach all employees. Third, consider offering incentives to increase employee participation. For example, 25.9% of respondents to the 2004 National Worksite Health Promotion Survey reported using incentives for this purpose.[4] Such incentives, if properly designed and communicated clearly to employees, have been shown to enhance participation in worksite health promotion programs.[9] Fourth, be sure to offer high-quality health promotion programs and use a variety of educational methods (self-help, group classes, Internet options, etc.) that appeal to different employee interests and learning styles. These programs should be free, or low-cost, and convenient for employees to participate, including offering options for shift workers and employees who travel or work offsite to participate. If programs are to be held during regular daytime hours, management should be lobbied to either allow employees to participate during work time or to institute a policy of shared employee/work time or flex time. Fifth, finding program "champions" (members of the wellness committee, managers, or members of the general employee population) who both participate and enthusiastically support programs will help increase employee participation as well. Finally, addressing work conditions that are oppressive, stressful, or hazardous to employees will influence participation among employees.[10] Evidence suggests that employees who have a voice in addressing the pace or conditions of work will be more engaged in worksite wellness efforts while maintaining productivity.[11,12] If implemented early in the planning process, all of these strategies can help overcome potential problems with employee interest and/or low participation.

Addressing participation among "high-risk" employees is an implementation challenge recognized by new as well as experienced program staff. Evidence suggests that moving high-risk employees to a lower-risk category will have a positive impact on employers' healthcare costs.[13,14] However, Edington and colleagues have demonstrated that maintaining the health of low-risk employees over time is also important for ensuring long-term control of healthcare costs.[15] While evidence suggests that high-risk employees might face different barriers to participating in health promotion programs than low-risk employees,[16] more research is needed to uncover best practices (e.g., tailored approaches, engaging peer educators, or offering online options that maintain privacy) for increasing program participation among all employees, including those at all levels of risk. For example, Grosch et al[17] surveyed a representative sample of workers from the National Health Interview Survey data and found that, when access to programs was equal for all workers, traditionally "high-risk" employees (e.g., blue-collar workers and blacks) were more likely to report they participated in worksite health promotion programs than were other workers. Emmons et al[18] conducted a qualitative study to ascertain barriers to participation among working women with different health risk factor levels. Research results like these have direct application for improving strategies for success on increasing participation over time.

Overcoming a Lack of Staff Resources

Lack of staff resources was another commonly reported barrier to offering health promotion programs as reported in the 2004 National Worksite Health Promotion Survey.[4] Among large employers, staff resources might be hard to identify or they might be "discovered" through a well-planned needs assessment. Among smaller employers, resources of all types, including staff resources, may be problematic for any programs that are not directly linked to the business operation. Importantly, evidence suggests having a staff person who has dedicated responsibilities for health promotion has been shown to be the single biggest independent predictor of having a comprehensive worksite health promotion program.[4] Existing staff may be both willing and interested in helping to organize health promotion efforts at work. Through continuing education workshops or externally-sponsored training programs, an employer can address this potential implementation challenge. For example, employee wellness committees can assist a designated staff person with program planning and implementation efforts. In fact, the North Carolina State Division of Public Health has worked with the State Health Plan to develop and deliver a training workshop for state employees and teachers who want to start an employee wellness program. (More information is available at http://statehealthplan.state.nc.us/worksite-wellness.html.)

Finding Funds

Lack of funding is the third most commonly cited barrier to offering worksite health promotion programs. This problem often goes hand-in-hand with a lack of staff resources. While all employers face this challenge to some extent, many potential funding and/or sources of support exist and can be tapped for assistance. Specifically, health plans are the leading source of health risk appraisals, health screenings, lifestyle behavior change programs, and disease management programs offered by employers responding to the National Worksite Health Promotion Survey.[4] Local hospitals, voluntary health organizations, health departments, business groups on health, chambers of commerce, and other groups may provide direct assistance to employers who offer worksite wellness programs. The Centers for Disease Control and Prevention sponsored Healthier Worksite Initiative Web site (www.cdc.gov/nccdphp/dnpa/hwi/index.htm) lists resources as well as funding opportunities for worksite health promotion. However, we encourage employers to consider funding worksite health promotion programs as an investment in "human capital" that will lead to bottom line advantages for the organization. Positive changes in employee health behaviors, healthcare claims costs, productivity, turnover, and absenteeism are possible, so program staff should be sure to include related measures in a comprehensive evaluation plan when considering the total return-on-investment perspective.

Cultivate Management Support at All Levels

One final implementation challenge universally acknowledged by employers is a lack of management support. Moreover, evidence suggests that different levels of management (e.g., line supervisors, middle managers, and top managers) report different barriers to program implementation that warrant serious consideration.[3] For example, in one study of over 1,000 managers from 23 manufacturing worksites, senior managers (vs. line supervisors) were significantly less likely to believe space or cost were barriers and were less likely than middle managers or line supervisors to believe production conflicts were a barrier to offering health promotion programs.[3] Management support should be cultivated early in the planning process, and throughout implementation.

Several strategies for ensuring management support are worth consideration. First, management representation should be included on the employee wellness committee as a visible sign that management is committed to its success and to keep management informed of the progress of the program. Second, key managers should be interviewed to ascertain their expectations for worksite health promotion programs. Third, ongoing communications with managers should take place to ensure visibility and to share success stories. Communications should include data that address managerial needs and expectations whenever possible. Finally, national (see Table 1), industry-specific or local data should be used whenever possible as benchmarks for success. Regular reports to management on progress toward achieving those goals are desirable.

Table 1.
Healthy People 2010 Worksite Setting Objectives[19]

Objective	Target
Increase the proportion of worksites that offer a comprehensive employee health promotion program to their employees.	75%
Increase the proportion of employees who participate in employer-sponsored health promotion activities.	75%

Conclusion

An employer who decides to offer a worksite health promotion program faces a number of important implementation challenges, and the underlying causes of these challenges are varied and complex. An effective planning effort can, however, address employer concerns while engaging employees in the process of planning, developing, implementing, and evaluating worksite health promotion programs that are most likely to be successfully adopted, achieve desired employee health outcomes, and sustained over time. **NCMedJ**

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Worksite Health Promotion:
Skills and Functions of Professional Staff

Bonnie Rogers, DrPH, COHN-S, LNCC, FAAN

Health promotion and wellness programs are designed to facilitate behavioral change and maintenance, emphasizing optimal health. General agreement exists that interaction among individual, social, and environmental factors influence behavioral choices that may result in detriments to health and/or increased health risk. Alteration or modification of these risk-based lifestyle choices and non-supportive environments are needed so that optimal health outcomes can be achieved. This can best be accomplished through a series of combined strategies that often involve programs, such as risk assessment and management, smoking cessation, weight management, fitness, stress management, and selected screening or targeted disease management programs, such as high blood pressure and cancer control.

Qualified and capable staff are essential to develop, implement, and evaluate worksite health promotion programs. McCauley and McCunney point out that selecting staff may be as easy as turning over programming to existing staff that have skills in health promotion program development, or it could be as difficult as hiring new staff or selecting qualified vendors, or both. However, it is important not to assume prospective staff capability based on credentials and referrals. Assessing prospective staff capability to lead such initiatives should include considerations of substantive knowledge and worksite-based health promotion experience, as well as effective interpersonal, writing, presentation, and management skills.[1] If an itinerant health promotion leader is necessary due to the configuration of business structure and location, then the ability to adapt programs to local worksite circumstances would be essential.

> *"...health promotion staff or specialists need to have not only skills and knowledge in targeted areas, but also the ability to communicate with diverse populations, including being able to deal with issues of language, culture and literacy barriers."*

Adult Learning: Constructing Knowledge

In any worksite health promotion program, staff will need to be intimately familiar with principles of adult learning. The classic work of Malcolm Knowles,[2] former professor at North Carolina State University, differentiates between adult and child patterns of learning and emphasizes the importance of teaching adults based on a framework of andragogy (teaching of adults), rather than pedagogy (teaching children). Knowles discusses that children have often been taught in traditional lecture-learner formats, although educators are finding more success and student interest when the actual principles of what is being taught are applied through hands-on experiences, field trips, and group work. Knowles points out that adults, because of their greater independence and more extensive backgrounds, bring more to the learning experience, and health promotion staff should serve as facilitators and enhancers of the teaching-learning process. Knowles' principles of adult education focus on four areas: independent learning, usefulness of past experience, readiness to learn, and problem-oriented learning.

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Independent learning emphasizes the importance of respecting the independence of workers and including them as active, self-directed participants, rather than passive recipients. This can be done by finding out what they already know about a topic, what they need to know to do the job better and safer, or what more they would like to learn.

Previous experience utilizes the wealth of life's experiences on which to base new learning. For example, an employee may have a relative who has had a heart attack and may be able to share related information about the rehabilitation process. This also presents an opportunity to assess employee baseline knowledge and to focus on areas of special concern.

Readiness to learn involves recognizing when an employee or employees are ready to engage in new learning events or when a teachable moment presents itself.[3] For example, a woman who becomes pregnant may be more interested in learning about workplace hazards or the effects of related lifestyle hazards, such as smoking, and an employee recently diagnosed with high blood pressure may be more interested in learning about dietary control strategies. Preventive information on topics such as AIDS or diabetes may not have a direct impact unless the employee knows someone affected.

Problem-oriented learning relates to helping employees address a problem area related to changing behavior of personal concern. For example, employees who have had difficulty in quitting smoking will probably consider it a health problem and, thus, be more amenable to a smoking cessation clinic or an educational program. In addition, Loos[4] asserts that adult learners:

- do not regard instruction as a means of reinforcing learning,
- utilize instruction to construct knowledge, and
- learn best what they "discover" for themselves.

Therefore, instructing adults must be an active process wherein the learner constructs knowledge rather than only acquires it, and it involves a process of supporting this construction rather than one of only communicating knowledge.

Communicating, Assessing, Planning, Conducting, and Evaluating

For many years, executives, management, and white- and pink-collar workers were the primary targets for health promotion programs.[1] Today the literature is replete with information about programs designed for special populations. For example, back care and musculoskeletal disorder care and preventive programs have been offered for petroleum workers,[5] healthcare workers,[6] municipal workers,[7] school personnel,[8] and police officers.[9] Hypertension, diabetes management, and stress reduction programs are being increasingly offered to employees from ethnically diverse populations.[10] What this means is that health promotion staff or specialists need to have not only skills and knowledge in targeted areas, but also the ability to communicate with diverse populations, including being able to deal with issues of language, culture, and literacy barriers.[3]

Health promotion programs may do one or more of the following: address an awareness level, focus on lifestyle or behavioral change programs, or encompass environments that encourage healthy lifestyles. Because the concepts of health promotion and wellness are multidimensional in nature, programs can and should encompass social, occupational, spiritual, physical, intellectual, or emotional dimensions.

Health promotion specialists should use a systematic approach to develop, plan, and implement successful health promotion programs.[11] The corporate culture needs to be assessed to determine if health promotion is valued within the organization and what the commitment of management is to health promotion. Assessing employee involvement is also critical for success. What programs would they like to have offered and when? In addition, examining existing healthcare data is critical to justify the need for programs. This information can be used to convince management to establish specific programs like prenatal education, breast self-examination and mammography, and nutrition/exercise programs. Health promotion planners should establish a wellness committee with employee representation that can assist with program planning and contribute to program success. Goals and objectives can be established along with a budget and an evaluation plan. After the program is completed, it must be evaluated. An evaluation of the program serves many important functions, including assessment of the achievement of objectives, identification of the strengths and weaknesses of the program, and analysis of its outcomes.

Specific functions of the health promotion specialist include, but are not limited to, the following activities:

- Assesses and targets health promotion program needs for the workforce.
- Develops and monitors the goals and strategies for the health promotion program.
- Develops and implements primary, secondary, and tertiary prevention programs.
- Provides programs and special events, such as health fairs and health education seminars, which increase awareness of health issues and choices, and help modify health risk behaviors.
- Collaborates with management to provide a healthy work environment.
- Selects and monitors vendor contracts.
- Conducts ongoing evaluation of the specific activities, as well as the overall health promotion program, and integrates cost-containment and cost-effectiveness aspects.
- Plans and directs the evaluation process.

Depending on the type of industry, health promotion planners will need to consider shiftwork, telecommuting, and remote locations. The latter two areas will require skills in distance education. In addition, the health promotion staff will need to be familiar with motivational readiness and concepts related to change.[12,13] For example, Prochaskas's model describes the five stages of change—precontemplation, contemplation, preparation, action, and maintenance. This model attempts to explain five stages through which individuals engage in behavioral change. The health promotion specialist can use this model to identify the stage of change where the employee is and utilize appropriate strategies to help workers move through these change stages, which will include dealing with relapse prevention.[3]

In conclusion, health promotion staff must have knowledge and skills that have breadth and depth. Knowing the worker population and industry needs and being able to communicate with diverse populations using principles of adult learning are essential to have successful and effective outcomes in achieving optimal health. **NCMedJ**

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COMMENTARY

Creating a Culture of Wellness in Workplaces

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The North Carolina State Health Plan (SHP), a self-funded plan established by the North Carolina General Assembly, provides healthcare coverage for more than 615,000 active public sector employees, retirees, and dependents. Employee members of the SHP work in 225 organizations in approximately 3,000 worksites throughout the state. Seventy percent of the health plan's medical and pharmacy costs are attributed to preventable chronic diseases related to poor nutrition/obesity, physical inactivity, tobacco use, and stress. In 2003, more than 164,000 SHP members were treated for one or more chronic diseases, an increase of 37% from 2000.[a] In response to these findings, the SHP launched NC Health*Smart*, a healthy living initiative for all eligible members in 2005.[1] The initiative includes six components: health tracking, including a health risk assessment; centrally designed health promotion interventions; targeted disease management; health coaching services available 24/7; high-risk case management; and worksite wellness programs.[b,2]

NC Health*Smart* delivers integrated services directly to the member via the Web, mail, telephone, worksite, and the healthcare community. These wrap-around services are designed to empower the members to play an active role in the management of their health.

Wellness programs in the workplace have great potential to impact employees' long-term lifestyle choices because the average employee spends 50 hours-a-week at work and eats one third of his/her meals at work.[3] Long-term results of wellness programs include improved health outcomes, reduced absenteeism, improved employee morale and retention, and reduced healthcare costs.[4,5,6]

Successful worksite wellness programs are characterized by:[6]

- Individualized behavior change information (self-care information, health risk assessments, behavioral counseling);
- Social supports (wellness challenges, classes, support groups);
- Senior-level management buy-in (financial incentives, department-wide policy changes, communication, long-term commitment); and
- Environmental supports (workplace fitness centers, on-site health services, smoke-free worksites, healthy meal and snack options).

> *"Wellness programs in the workplace have great potential to impact employees' long-term lifestyle choices because the average employee spends 50 hours-a-week at work and eats one third of his/her meals at work."*

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[a] Members eligible for North Carolina Health*Smart* services are members whose primary health insurance is through the North Carolina State Health Plan and who are not on COBRA.

[b] North Carolina Health*Smart* was developed in collaboration with the State Teacher and Employee Wellness Advisory Committee (STEWAC), North Carolina Institute of Medicine, the University of North Carolina School of Public Health, North Carolina Department of Health and Human Services, and the North Carolina State Health Plan Board of Directors.

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Based on this evidence, the SHP, in partnership with the Division of Public Health (DPH) in the North Carolina Department of Health and Human Services (NC DHHS), has developed the NC Health*Smart* Worksite Wellness Toolkit for use by worksite wellness committees in all North Carolina state government entities. Employers can use the Toolkit to build customized wellness programs. Currently, more than 160 committees from 93 eligible state organizations[c] have been trained to use the Toolkit. The State Health Plan is also funding a worksite wellness team at the DPH to offer new resources and technical assistance to support committee sustainability at these worksites. New services will include a Web site, seminars, a newsletter, and a consultation program. In 2007, the Toolkit and training initiative will be modified for public schools (approximately 175,000 SHP members). This work will integrate with the North Carolina Healthy Schools initiative and occur in partnership with the North Carolina Department of Public Instruction, Local Educational Agencies, and the Division of Public Health.

Pilot Worksite Wellness Program

In 2004, the SHP commissioned and jointly funded a wellness initiative with a single state agency, NC DHHS, as a prototype for leadership development, policy change, and building wellness infrastructure for all North Carolina state government employers. NC DHHS was chosen as the pilot because of leadership support for worksite wellness and its large size (18,700 employees in 22 agencies and 16 hospital and residential school facilities across North Carolina) The initiative aims to:

- Reduce the major chronic disease risk factors among NC DHHS employees, thereby reducing chronic diseases and containing rising healthcare costs.
- Demonstrate the effectiveness of a wellness program model that includes a full-time, department-level director.
- Establish wellness committees to create and sustain work environments that promote and support employee health and wellness.
- Change policies and work environments to help employees become more active, make healthier food choices, avoid tobacco, and manage stress.

Implementation of the Pilot

NC DHHS launched the Wellness Initiative in September 2005. In the first 12 months, the groundwork for a sustainable, department-wide wellness program has been created. It involves leadership at all levels of the organization and formally incorporates feedback from employees and agency wellness committees. NC DHHS developed a three-year strategic implementation and evaluation plan with measurable objectives to guide the initiative. Baseline and follow-up surveys were conducted to assess agency policy and environmental support for wellness, employee interest and participation levels, and management support. An online reporting system was created for committees to submit brief monthly reports of their wellness activities and program outcomes.

Prior to the launch of the Wellness Initiative, each division, office, and facility designated a Wellness Representative. The NC DHHS Wellness Director helped the 38 representatives establish wellness committees and develop tailored agency wellness plans. The Wellness Representatives also serve as members of a new Department-level Wellness Council to advise the Secretary on worksite wellness policy issues. All representatives received training on the Worksite Wellness Toolkit in the fall of 2005. The Wellness Director provides continued technical assistance, which includes on-site visits to help wellness committees implement programs geared to the needs and interests of their employees. Raffle incentives and exercise equipment grants were offered to committees to promote wellness activities and to increase employee participation. Wellness committees are also encouraged to integrate other NC Health*Smart* services, such as health coaching and the health risk assessment, into their program strategies.

NC DHHS determined that approving *department-wide policies* that support employee wellness and creating a *supportive work environment* were the most efficient and cost-effective ways to engage employees in health risk reduction activities. NC DHHS Secretary Carmen Hooker Odom addressed the first policy issue by raising awareness of an existing Department Wellness Policy that allowed employees, with manager approval, to use flex-time schedules to participate in wellness activities. The Secretary continues to consider policy and environmental changes as needs are identified.

> *"I firmly believe that we, the leading public health organization in the state, must fully support our own employees' efforts to live a healthy life," says Secretary Hooker Odom. "I am committed to working with managers and employees to create a 'culture of wellness' within the Department. I encourage other state agency leaders to embrace worksite wellness and to take advantage of what we have learned."*

Policy Recommendations

The NC DHHS Wellness Council made policy recommendations for the Department using employee and agency survey results, evidence-based wellness interventions, and council members' perceptions of department-level barriers. The recommendations are to:

- Increase employee access to on-site exercise opportunities.
- Provide incentives and increase management support for employee participation in wellness activities.

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[c] State agencies, universities, and community colleges are eligible for trainings in 2006-2007. A modified curriculum will be rolled out to public schools in the next two years.

- Ensure that all employees have access to designated break areas away from their workstations.
- Require training for supervisors on conflict resolution and stress reduction.
- Improve access to healthier meals and snacks in the workplace.
- Support policies that make workplaces tobacco free and provide on-site cessation programs.
- Establish procedures for addressing employees' concerns about air quality and ergonomic work areas.

Secretary Hooker Odom responded to the recommendations by providing key support for the implementation of department-wide formal and informal policy changes. Opportunities to increase physical activity helped drive several changes. State hospitals and resident school facilities with existing fitness areas were asked to allow employees use of the areas. For example, the Dorothea Dix Hospital Campus in Raleigh will reopen a gym facility (infrequently used by hospital patients) to employees, giving them access seven days-a-week. Improved exercise, shower, and locker facilities and scheduled wellness activities are planned for the site. Agencies were also encouraged to designate space for fitness areas. Fourteen sites received a commercial grade treadmill or exercise bike from a grant program offered by NC DHHS. To increase healthy foods at work, the State Services for the Blind vending contracts were modified to require vendors to include 15%, or at least five, healthier vending choices. Work is also underway to provide designated break areas and to offer incentives to support employee participation in health promotion programs.

Year One Outcomes and Participation

During the first 12 months of the Wellness Initiative, NC DHHS wellness committees reported implementing a total of 243 wellness activities and reported 49 changes to policies and environments that increased support for employees to become more physically active, eat healthier foods, avoid tobacco, or manage stress. Worksites with healthier vending options doubled (10 to 20), and the number of worksites providing information on healthy food choices increased from 10 to 41. More worksites have written policies supporting physical activity during the workday, and the number of indoor fitness areas increased from 14 to 22 worksites. More sites disseminated tobacco health risk information (from five to 33) and offered cessation programs (from three to 14). Stress management programs and materials offered in 14 worksites a year ago are now available in 36 worksites. Even without formal incentives, NC DHHS has achieved the highest rate of health risk assessment completion of any state department.

Preliminary data from a November 2006 employee survey (4,788 respondents) found that 62% of employees had participated in at least one workplace wellness activity in the past year. Employees reported exercising more often (51%), citing work-based walking programs (50%) as the most popular activity. They indicated that they were eating more fruits and vegetables (49%), and were closer to a healthy weight (27%). With regard to tobacco use, 106 employees stopped tobacco use completely, and 149 reduced their amount of tobacco use. Employees indicated that they had received health information from their worksite wellness committees (45%), attended health fairs (35%), and received a flu shot at work (46%). The main reason employees reported that they did not participate in wellness activities was a lack of time (36%).

Wellness committees receive survey results to guide their wellness program plans for the coming year. Use of the survey information appears to have played a critical role in achieving high levels of participation. For example, both the baseline survey in 2005 and the second employee survey in 2006 indicate that an indoor place to exercise at work was the primary wellness priority for the greatest number of employees. The Wellness Initiative responded to employee needs by addressing policies that prevent or limit access to existing fitness areas and providing fitness equipment to agencies.

Further evaluation of the NC DHHS Wellness Initiative will include analysis of aggregate employee health risk assessment data. It is anticipated that this information will further confirm changes in a majority of employees' health behaviors. Finally, a comparison of health claims data before and after implementation of the Wellness Initiative will assess the impact of this model of worksite wellness on improving employee health and containing healthcare costs.

The NC DHHS Wellness Initiative will not be completed for at least another year, yet mid-study data suggest that it is already positively impacting individual and environmental behaviors. Modifying lifestyle habits is difficult, and it is critical to use every point of entry to support individuals in taking a more active role in their health. A comprehensive worksite wellness program can increase employee satisfaction and productivity and improve employee health by reinforcing health messages from providers, care management services, and health education campaigns. The State Health Plan will build on the impressive NC DHHS preliminary results by using this experience and other resources to benefit all state government, university, community college, and public school employers and their employee populations. **NCMedJ**

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COMMENTARY

National Indications of Increasing Investment in Workplace Health Promotion Programs by Large- and Medium-Size Companies

Jennifer M. Childress, MS, CHES; and Garry M. Lindsay, MPH, CHES

Worksite health promotion programming has received growing interest over the past 20 years. In 1985, the Office of Disease Prevention and Health Promotion (of the United States Department of Health and Human Services) launched its first survey of national worksite health promotion practices. Subsequent to that, there have been three follow-up surveys, the most recent findings published in 1999. The 1999 survey reported that 90% of worksites were offering at least one type of health promotion activity to their employees. The results from the 2004 National Worksite Health Promotion Survey,[1] currently in the publication process, compares health promotion programming among worksites between 1999 and 2004, and more fully assesses the degree to which worksites are meeting the *Healthy People 2010* goal of having 75% of all worksites, regardless of size, offering comprehensive programming to employees. The 2004 National Worksite Health Promotion Survey, sponsored by Partnership for Prevention, Watson Wyatt Worldwide, and the Office of Disease Prevention and Health Promotion surveyed a nationally representative sample of over 1,500 worksites and found that employers offered a wide range of health promotion activities to their workers. However, only 6.9% of the responding worksites offered all five key elements that define a "comprehensive" worksite health promotion program: (1) health education, (2) links to related employee services, (3) supportive physical and social environments for health improvement, (4) integration of health promotion into the organization's culture, and (5) employee screenings with adequate treatment and follow up. Controlling for worksite size, indutstry type, staffing, and experience, worksites from agricultural or financial sectors and those with a dedicated staff person were significantly more likely to offer a comprehensive program.[2]

Along the continuum of worksite health promotion program elements, the level of sophistication usually correlates with the amount of resources invested. Despite the fact that the growth, and in some cases the very sustainability of business, is linked to employee health, many employers do not view worksite health promotion as being a core component of their business strategy. Yet, the issue surrounding the cost of health is at the forefront of business leaders' minds. Over the past four consecutive years, CEOs responding to the Business Roundtable's *CEO Economic Outlook Survey* have cited healthcare costs as their greatest cost pressure.[3]

> *"...research has documented that high-risk employees are also high-cost employees with higher medical and pharmacy expenses."*

Leveraging the workplace to improve health is good for employees and good for business. It's not just the direct costs of healthcare that companies have to take into consideration. The indirect costs of poor health (e.g., absenteeism, disability, presenteeism) can be two to three times higher than direct medical costs (see Figure 1).[4,5,6,7] Productivity losses related to personal and family health problems cost United States employers $1,685 per employee per year, or $225.8 billion annually.[8]

A study conducted at The Dow Chemical Company helped illustrate the total economic impact of employee health, including indirect costs. The analysis illustrated a staggering $750 million economic impact from employee health status by determining

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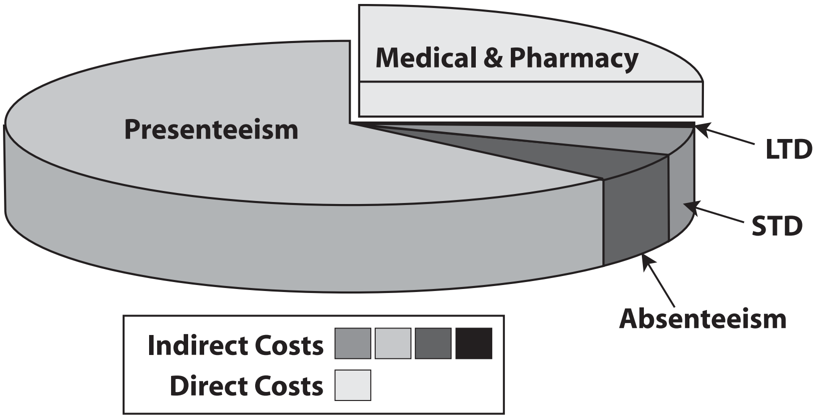
that the indirect cost associated with "presenteeism" far exceeded the costs of absenteeism and medical treatment combined. Spurred into action by these findings, Dow established a comprehensive health strategy with the goals of improving health, reducing health risks, managing costs, and improving health-related productivity (presenteeism).[9]

Figure 1.
Relative Contribution of Direct and Indirect Costs Within a Large Financial Services Corporation



Source: Edington DW, Burton WN. Health and productivity. McCunney, RJ: *A Practical Approach to Occupational and Environmental Medicine*. Philadelphia: Lippincott Williams & Wilkings. 3rd ed. 2003:140-152.

Table 1.
Worksite Wellness Program Awards

2006 C. Everett Koop National Health Awards Winners

- USAA – Take Care of Your Health Program
- Honorable mention: Roche, Inc., and Washoe County School District

(http://healthproject.stanford.edu/koop/2006winnerindex.htm)

2006 Innovation in Prevention Award Winners

Large employer (greater than 500 employees)

- Perdue Farms – Perdue Health Improvement Program – Large Employer
- Washoe County School District – Washoe County School Distric Wellness Program

Small employer (500 or less employees)

- Hudson River Healthcare – Step Up for Wellness

(http://www.hhs.gov/news/press/2006pres/20061026.html)

2006 Wellness Councils of America (WELCOA) Well Workplace Winners (Platinum)

- The Beacon Mutual Insurance Company
- Syngenta
- Motorola, Inc.
- Nebraska Methodist College
- The Principal Financial Group
- International Business Machines
- Lincoln Plating
- The Nebraska Medical Center
- Merril Lynch
- Monongalia Health System

(http://www.welcoa.org)

The Dow Chemical Company's "comprehensive health strategy" includes worksite health promotion integrated with other health-related initiatives. In recent years, many large companies have taken a similar approach by aligning previously separate functions, such as benefit design, occupational and environmental health, occupational and non-occupational disability management, Employee Assistance Programs (EAPs), work-family programs, together with worksite health promotion initiatives and incentives, to address overall employee health and productivity. Large employers are targeting the needs of employees and designing services that will drive the actions of both employees and the health plan/provider. Collectively these combined efforts are often referred to as employee health management, Pioneer Hi-Bred International, Inc. provides another example of an integrated preventive health and wellness program as part of a business strategy supporting the health and well-being of employees, their families, and retirees through maximum engagement and capability. The program aim is to attract and retain a world-class workforce, assure quality, efficient, sustainable, and affordable healthcare, with a safety goal of zero occupational injuries and illnesses. Health plans and programs are designed to encourage prevention, disease management, and the efficient use of the healthcare system and planning for future healthcare needs. Pioneer's program is integrated with the EAP, and life management with search, referral, and counseling services including childcare, eldercare, financial and legal assistance.[10]

Employee health management includes: linking employee health efforts with the company mission, data management, benefit design, supportive environment, programming, and evaluation integrated within a cost-effective business strategy. For more information on these components, and how they apply to organizations, please refer to the Health Management Initiative Assessment in *Leading by Example: Improving the Bottom Line Through a High Performance, Less Costly Worksforce—CEOs on the Business Case for Worksite Health Promotion.*[11] There is strong evidence supporting the cost-effectiveness of investing in employee health management including worksite health promotion. Healthy employees are more productive and consume fewer corporate resources in the form of benefit payments for medical care, short- and long-term disability, and workers' compensation.

- A review of 73 published studies of worksite health promotion programs shows an average $3.50-to-$1 savings-to-cost ratios in reduced absenteeism and healthcare cost.[12]
- A meta-review of 56 published studies of worksite health promotion programs shows:[13]
  - Average 27% reduction in sick leave absenteeism,
  - Average 26% reduction in healthcare costs,
  - Average 32% reduction in workers' compensation and disability management claims costs, and
  - Average $5.81-to-$1 savings-to-cost ratio.

Potential savings from average risk reduction is $153 per person per year, compared to a savings of $350 from risk avoidance (e.g., prevention).[14,15]

Forward-thinking organizations understand the link between the health of their organizations and their employees, and many have been recognized nationally for their efforts by receiving the C. Everett Koop National Health Awards (see Table 1) the Wellness Councils of America Well Workplace Awards (see Table 1), and/or the Innovation in Prevention Award from the Secretary of Health and Human Services (see Table 1). Two elements that are critical to program success, senior leadership support and establishing a supportive environment,[16] are among the criteria upon which candidates are evaluated. In 2004, Partnership for Prevention launched the *Leading by Example* CEO-to-CEO initiative to encourage communication at the senior-most levels regarding investment in employee health management strategies. The first publication released in 2005 featured 19 CEOs, including three state governors. Partnership has recently partnered with the US Chamber of Commerce on a new edition of the publication, which will feature 15 Chamber member companies. In addition to completing a Health Management Initiative Assessment, a tool to assess, in comprehensive terms, areas in which the programs are excelling and areas for improvement, the *Leading by Example* CEOs (see Table 2) have committed to:

- Assuring that senior management is committed to health promotion as an important investment in their human capital.
- Aligning health and productivity strategies with their business' goals.
- Educating all levels of management regarding the link between employee health and productivity, and total economic value.

The aim of the *Leading by Example* initiative is to increase senior executive awareness and involvement in employee health management strategies by transforming the paradigm in which employers view employee health as an investment to be maximized, rather than as a cost to be minimized.

So where does this leave us? Rising healthcare costs are driving changes in how traditional worksite health promotion programs are structured and positioned within large organizations. In past years, worksite health promotion primarily included activity-based programs focused on individuals to improve unhealthy lifestyle choices—lack of exercise, smoking, being overweight, and so forth. More recently, research has documented that high-risk employees are also high-cost employees with higher

Table 2.
Current Leading by Example Participating CEOs and Organizations

Leading by Example: CEOs on the Business Case for Worksite Health Promotion*	***Leading by Example: Leading Practices for Employee Health Management****
George DeVries, American Specialty Health	Harold Jackson, Buffalo Supply, Inc.
H. Edward Hanway, CIGNA Corporation	James W. Owens, Caterpillar
Delos M. Cosgrove, Cleveland Clinic Health System	Neal Patterson, Cerner Corporation
Rick Wagoner, General Motors	Jack Donahue, DonahueFavret Contractors, Inc.
Duncan Highsmith, Highsmith Inc.	Robert W. Lane, Deere & Company
William C. Weldon, Johnson & Johnson	John C. Erickson, Erickson Retirement Communities
Dean Oestreich, Pioneer Hi-Bred International, Inc.	Marc LeBaron, Lincoln Plating
Michael Critelli, Pitney Bowes	Daniel Ustian, Navistar International Corporation
Gov. Ruth Ann Minner, State of Delaware	Jeffrey B. Kindler, Pfizer Inc.
Andrew N. Liveris, The Dow Chemical Company	Jeff Sterba, PNM Resources, Inc.
Dick Davidson, Union Pacific Corporation	Surya N. Mohapatra, Quest Diagnostics Incorporated
Mary Sue Coleman, University of Michigan	Andrew N. Liveris, The Dow Chemical Company
Thomas J. Donohue, US Chamber of Commerce	Lee Scott, Wal-Mart Stores, Inc.
John P. McConnell, Worthington Industries, Inc.	Danny Wegman, Wegmans Food Markets
Anne M. Mulcahy, Xerox Corporation	

* Parnership for Prevention ** Partnership for Prevention and the US Chamber of Commerce
For more information on the Leading by Example initiative, visit www.prevent.org/LBE.

medical and pharmacy expenses. Research has also demonstrated that low-risk maintenance (keeping healthy employees low risk) is a necessary strategy for productivity and cost containment. Rather than reducing health benefits or shifting costs to employees, forward thinking organizations are now focusing on improving the health of their overall workforce populations through integrated health management strategies, including worksite health promotion with the support of committed leadership. The amount of evidence suporting the business case for investing in employee health management, along with the identification and recognition of leading practice programs to serve as models, demonstrates growth and investment in the field of worksite health promotion and employee health management. We need to continue to analyze and promote innovative and effective programs in order to further increase the investment in workplace health promotion. **NCMedJ**

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COMMENTARY

Workplace Health Promotion:
A North Carolina Assessment of Progress

David H. Chenoweth, PhD, FAWHP

Although a couple of worksite health promotion (WHP) initiatives in the United States can be traced as far back as the late 1890s, many of America's most notable programs were conceived in the 1960s, 1970s, and 1980s. North Carolina's earliest WHP programs were conceived shortly thereafter, with most taking shape in larger cities. The rationale for such programs initially focused on promoting employees' health and boosting their morale and productivity; yet, as employers' medical care costs spurred to double-digit levels in the 1980s and 1990s, a growing percentage of WHP adopters added cost containment to their list of desired outcomes. The original WHP programs consisted primarily of a health risk appraisal questionnaire, clinical health screenings, and educational seminars, with a few sporting on-site fitness and/or recreation centers. Nowadays, it's common to see worksites sporting outdoor walking trails, weekly lunch 'n learns, health newsletters, healthy food vending options, smoke-free workstations, financial incentives, e-mail-delivered daily health tips, and internet-based personal health programs.

> *"...health insurance doesn't really do anything for our company's productivity—healthy employees do."*

It stands to reason that since most adults work for a living and that employers pick up the lion's share of the state's healthcare tab, worksites arguably provide a natural venue to promote the overall health and welfare of employees. Nonetheless, many worksites have been slow to act on this opportunity while others have enthusiastically adopted WHP. Why such a dichotomy? First and foremost, I believe the philosophy of senior management greatly influences the presence or absence of WHP. Although I've seen a handful of WHP programs evolve from a bottom-up [employee-driven] perspective, the vast majority of successful WHP efforts are driven from the top, originating from senior management's belief that employees are an organization's greatest asset. Moreover, I've discovered that successful WHP programs are usually (1) operated by competent professionals, (2) tied, to some extent, to employees' health risk profiles as well as their interests, (3) enhanced with "carrots" (e.g., financial incentives), (4) positioned as a key business strategy, and (5) subjected to regular evaluations.

Fortunately, numerous employers throughout North Carolina have taken advantage of our state's temperate climate by developing outdoor recreational facilities and walking trails for employees to use. Continued growth in our state's evolving high-tech industries, which are typically comprised of more educated and health-conscious employees, also spurs more WHP initiatives for companies to achieve greater health and productivity outcomes. Flexible work hours have also made it easier for employers to offer on-site WHP programs since employees can use this "down time" to pursue on-site wellness opportunities. Also, as more employers are becoming aware of the strong correlation between health status, on-the-job productivity, and healthcare utilization patterns, we're seeing traditional WHP efforts expand into more far-reaching and progressive health and productivity management (HPM) initiatives. I'm also impressed with the growing number and quality of organizations (commercial, educational, healthcare, and governmental) throughout our state that are assisting employers of all sizes in their quest to establish successful WHP initiatives.

Rising Healthcare Costs to Employer Are a Primary Driver

Obviously, rising costs to provide employee healthcare benefits is one of the most pervasive forces behind the growth of WHP, as risk managers grow more frustrated with managed care and other short-term bandages to this long-term problem. Yet, numerous worksites have found out that WHP, like any other

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cost-containment strategy, must be positioned within an *integrated health management initiative* to really pay off. Thus, I expect more worksites to engage return-on-investment (ROI) metrics—ranging from break-even analysis to benefit-cost analysis—in their quest to measure the financial impact of these initiatives.

Barriers to Worksite Health Promotion Programs

On the flip side, numerous factors impede the growth of WHP programs in North Carolina. The high cost of doing business in today's costly economy keeps many companies on the sidelines. Business' unrealistic demand for a quick return doesn't bode well for WHP. Sadly, some decision-makers haven't realized that WHP is a human capital investment that yields proportionately greater results over time. Add to this list of barriers, the typical worksite culture that does little, if anything, to respect or support a person's right to practice health promotion.

Certainly, downsizing prevents many business owners from adopting any long-term human resource strategy (such as WHP), especially when they have high turn-over rates and view their workforce as "temporary." Another barrier to WHP is that most worksites spend virtually all of their healthcare budgets on purchasing traditional "defensive-minded" healthcare coverage for their employees; thus, leaving nothing to invest in more progressive health plan options (e.g., "good health rebate" and healthcare expense accounts) that motivate healthy lifestyles in addition to breeding more consumer-driven decisions among employees and covered dependents. No wonder an enlightened business owner recently stated, "health insurance doesn't really do anything for our company's productivity—*healthy employees do.*"

What does the future hold for WHP in North Carolina? Will the growth of WHP in the next 30 years reflect that of the past three decades? In these challenging economic times, how can North Carolina really be competitive in today's global economy without healthy and productive workers? From Murphy to Manteo, much of that challenge can be met head-on if today's business leaders steer their worksites with WHP and other human capital investments that will indelibly foster a healthier and more prosperous 21st Century. **NCMedJ**

Worksite Health Promotion Return on Investment

Many North Carolina employers have realized a positive return on investment (ROI) from their WHP efforts. ROI dividends have been reported by companies from the mountains to the coast. For example, WHP efforts have cut risk factors in 40% of diabetic-prone employees and shaved workers' compensation costs at Replacement, Inc.; enabled GlaxoSmithKline to earn honors as one of Working Mothers Magazine's list of "100 Best Companies to Work For" for 14 consecutive years; earned Capitol Broadcasting Company the state's first Be Active Workplace designation; yielded healthcare cost reductions at Blue Ridge Paper and Asheboro Elastics; reduced emergency room visits and held healthcare costs flat for the past two years at Syngenta Crop Protection; boosted productivity and work-life quality outcomes at SAS Institute; and enhanced employee recruitment and retention at Cisco Systems. Even smaller firms like Charlotte-based Robert Mason Company and Rivers & Associates in Greenville attribute much of their healthcare cost containment and productivity gains to WHP programs.

COMMENTARY

The Rationale for Federal Policy to Stimulate Workplace Health Promotion Programs

Michael P. O'Donnell, MBA, MPH, PhD

Health and Financial Impact of Lifestyle

Repeated analyses conclude that at least 40% of premature deaths in the United States are caused by lifestyle factors including tobacco use, sedentary lifestyle, poor nutrition, and overweight.[1] Furthermore, these lifestyle factors are responsible for at least 25% of medical costs[2] and possibly as much as 50%. This is occurring at a time when medical care costs are crippling United States employers, with an estimated $7,910 per employee in 2006.[3] These costs make it difficult for many employers to remain profitable. Being competitive in a global marketplace is more difficult for United States companies because per capita medical costs in the United States are double those of all but five other nations and because employee medical costs are highly subsidized by the governments in most other nations.[4]

Evolution of Workplace Health Promotion Programs

Employers started developing workplace health promotion programs in detectable numbers in the 1970s. Most of these programs were clustered in "high-tech" growth areas like the Silicon Valley in California and the greater New York City area and many of them were built around fitness centers. The primary motivation among employers was to attract and retain the most talented workers. Employers realized that spending several hundred dollars per employee per year to building a beautiful fitness center was a more effective recruiting tool than adding four or five dollars to an employee's weekly paycheck. Although it took several decades to produce a robust literature to confirm it, employers soon began to realize that employees with good health habits had lower medical costs and were more productive.[5] A systematic review of the literature on the financial impact of workplace health promotion confirmed this.[6] In fact, Aldana found that 88% of 32 studies showed that programs reduced medical costs, and 100% of 18 studies showed programs reduced absenteeism. He also found a mean return on investment (ROI) of $3.93 for medical cost savings and $5.07 for absenteeism savings.

In the 1980s, public health professionals realized that workplaces might be excellent environments in which to address chronic health conditions, especially heart disease, which had links to smoking, nutrition, sedentary lifestyle, overweight, and stress. Workplaces showed great promise for these programs because employees typically spend more than a third of their waking hours in the workplace, most employees remain in the same company for the year or two it takes to make a successful behavior change, and many are part of cohesive social groups at work that can provide ongoing support. Furthermore, workplace environments can be altered to provide access to healthy food and safe places to be physically active, as well as protection from second-hand smoke. Equally important, employers have financial incentives to support these programs. By the mid-1990s, almost 400 studies had been published on the health impact of workplace health promotion programs. A systematic review of this literature showed that well-designed programs produced short-term health improvements, but that very few programs examined long-term changes.[7]

> *"By 2001, 76% of United States workplaces were smoke free. By any standard, this is a remarkable achievement."*

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The prevalence of workplace health promotion programs has increased significantly during the past few decades.[8]

In summary, workplaces provide an excellent environment to address employee health; hundreds of well-designed programs have shown that programs do improve health, especially in the short term; and dozens of studies have shown that programs reduce medical costs and absenteeism at least enough to pay for covering the cost of the program, possibly producing savings in excess of program costs.

Limitations of Workplace Health Promotion Programs

Despite this positive picture, workplace health promotion is not without problems. The biggest problem is that at least half of working people in the United States do not have access to health promotion programs because they work in small companies or for those employers who have employees deployed in small numbers in multiple sites. Of the 4.9 million firms in the United States, only 936 (0.01%) have 10,000 or more employees, 8,674 (0.18%) have 1,000 or more employees, and 17,246 (0.35%) have 500 or more. Conversely, 99.65% of firms have less than 500 employees, and 97.9% have less than 100 employees. These firms employ 51% and 36% of the working population, respectively.[9] It is difficult for small employers to offer health promotion programs because they typically do not have a central human resources function to develop programs, and they often cannot afford to hire a full-time health promotion staff. Furthermore, their health insurance premiums are typically "community rated," which means their premiums are set by the medical utilization experience of their community. Large employers are "experience rated," which means premiums are based on the company's own medical utilization. The bottom line is that small employers who are successful in reducing medical care costs by improving the health of their employees will still pay the same medical premiums to their insurance company. This eliminates an important financial incentive to develop a health promotion program in these small companies.

Furthermore, most health promotion programs are not comprehensive. Most focus on enhancing awareness of health risks by offering health fairs, conducting health screenings, offering health risk appraisals, and providing information on the importance of a healthy lifestyle. Most employers do not offer programs that convey and enhance the personal skills employees need to make and maintain lasting behavior changes. Few employers make the effort required to create supportive environments, including providing nutritious foods in cafeterias and vending machines, offering access to safe and interesting places to exercise or be physically active, and fostering cultural workplace norms that value healthy lifestyle. The exception is smoking policies. By 2001, 76% of United States workplaces were smoke free.[10] By any standard, this is a remarkable achievement.

Emerging Federal Policy to Support Workplace Health Promotion Programs

In recognition of the success of past workplace health promotion programs, the medical care cost crises facing United States employers, the accelerating obesity epidemic, and the shortcomings of current workplace health promotion programs, Senator Tom Harkin of Iowa has authored legislation called the Healthy Workforce Act. It was introduced on May 18, 2005 as Title II, Subtitle A of the HeLP America (Healthy Lifestyle and Prevention) Act, (S.1074) and will be introduced as a free standing bill in early 2007. The main provisions of the bill are below. Note: This legislation was in revision at press time. Check www.Thomas.gov for final provisions.

- **Employer Tax Credits**
  - Provides employers a 50% tax credit for workplace health promotion programs, up to $200/employee/year, and 50% subsidy for tax exempt employers.
  - To qualify for the tax credit, programs must be offered to all employees who work at least 25 hours per week and be certified by the United States Department of Health and Human Services.
  - Programs for employers with 200 or more employees must have four basic components: programs to enhance awareness, programs to engage employees, programs to facilitate behavior change, and efforts to create supportive workplace environments. Employers with fewer than 200 employees must have three of these four major components.
  - *This tax credit is projected to provide a $734 million annual tax credit to employers, stimulate investments of $3 billion per year in workplace health promotion programs, and increase corporate and individual tax receipts in excess of its cost, making it revenue-neutral to the federal government.*

- **Directs CDC to Do the Following**
  - Contract with experts to provide employers with technical assistance on program evaluation.
  - Conduct a national study on employer health policies and programs.
  - Include questions on workplace health promotion in the Behavioral Risk Factor Surveillance System.
  - Award demonstration grants to test the effect of new workplace interventions and models.

- **Campaign to Educate Employers**
  - Directs CDC to develop a campaign to educate employers on the financial benefits of workplace health promotion programs, in conjunction with workplace health promotion organizations.
  - *This campaign is projected to cost $40,000,000 per year and is critical to stimulating employer investments in health promotion and thus, the increased tax revenues projected to result from the tax credit.*

An unpublished economic analysis of this legislation[11] concluded it is likely to be revenue-neutral or revenue-positive to the federal government. This means it will stimulate more tax receipts to the federal government than it costs in tax credits and subsidies. The bill is projected to stimulate investments of $3 billion in workplace health promotion programs through a combination of promotional campaigns, technical assistance, and employer tax credits or subsidies. The promotional campaigns and technical assistance are projected to have an annual cost of $59 million. The tax credit is projected to have a value of $734 million to employers, but it will be earned only when employers invest in programs, and received the year after the investment is made. Assuming an ROI of 1:1 in medical care cost containment, the economic stimulus from this program is projected to stimulate $985 million in increased federal income taxes, $409 million in FICA taxes, and $183 million in state income tax receipts, and these will be paid in the year prior to the tax credit. The bill will produce net gains to the federal government. With the exception of the $59 million stimulus, receipts to the federal government will be in the same line item as the tax credit and received prior to the tax credit. The savings to the federal government are caused by the increased economic stimulus of investments by employers and not dependent upon significant medical care cost reductions produced by the new health promotion programs. To break even, the health promotion programs must produce an ROI of 0.2 (20 cents on the dollar).

Conclusion

Workplace health promotion programs show great promise in reducing chronic disease prevalence and containing medical costs. Emerging federal legislation has the potential to improve the effectiveness of existing programs and make new programs available to employees in small companies. **NCMedJ**

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COMMENTARY

Workplace-Focused Health Promotion Programs in the United Kingdom and Ireland

Alexandra Farrow, PhD

Workplace health promotion is a fusion of two distinct themes, and in the United Kingdom, one theme has origins in United Kingdom legislation [Health and Safety at Work Act (HSWA), 1974] that promoted safe and healthy working environments. This theme puts the onus on the employer for the organization of the physical and psychosocial work domain. The other theme is related to the behavior, attitude, and lifestyle of the worker and is entrenched in personal responsibility for individual health. In an ideal world, promotion should unify these two concepts. Workplace health promotion is integral to ordinary work practice, the working environment, and the organization[1] and is envisaged as shared between communities, employees, managers, and their environments.[2] The European Union and the Luxembourg Declaration on Workplace Health Promotion[3] further defined workplace health promotion as the combined efforts to improve the health and well being of people at work. Both the healthy workplace environment and individual lifestyle changes are necessary to achieve health promotion goals, and these should go hand-in-hand. In reality, however, individual behavioral change is too often the focus, rather than the organizational aspects of the worker's environment.[4,5]

In the United Kingdom, health promotion activities in the 1980-1990s included smoking, alcohol, and drug education; weight control; exercise; stress management; and screening. New initiatives have been focused on obesity and fitness, exemplified by the recent statement that many young men are not fit enough for recruitment into the British Armed Forces. The former Health Education Authority (HEA)[6] prioritized development and support for health promotion in the workplace. The 1990s saw the emergence of the cost-benefit culture with the development of evaluation and assessment of effectiveness. The HEA report of 1993[7] found the aims of health promotion were not necessarily incorporated within workplace culture. A subsequent publication established that workplace health initiatives were largely motivated by compliance with legislative requirements, rather than the need to promote positive health.[8]

> *"Health promotion initiatives are driven by the belief that economic advantages will be gained from a reduction in absenteeism and accidents and improvement in employee morale. Workers who are motivated and healthy are essential for competitiveness and capacity to innovate."*

Influencing Factors for Health Promotion Initiatives

Health promotion initiatives are driven by the belief that economic advantages will be gained from a reduction in absenteeism[9] and accidents and improvement in employee morale. Workers who are motivated and healthy are essential for competitiveness and capacity to innovate. Another driver is the

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increased compensation culture that has had a positive impact on health promotion in that the employer has responded to the risk of litigation by encouraging healthy work environments, specifically seen with respect to passive smoking. However, it is estimated that in the United Kingdom, two million people suffer from ill health caused by work-related conditions, and 35 million days are lost annually.[10,11]

The changing patterns of work include increased part-time work, contracting out, privatization, loss of manufacturing, an increase in the service industry and the number of smaller companies, working from home, and self-employment. All of these have a negative impact on workplace health promotion, making any such initiative difficult to sustain. While there are only a few thousand occupational health doctors and nurses in the United Kingdom, these health professionals seem to overemphasize health problems with reference to worker lifestyle habits and behaviors and to focus on management and personnel requirements, rather than exposures in the workplace, prevention, and rehabilitation.[12]

Even when open to all, engagement in health promotion is limited, with those most likely to participate being healthy, white-collar, salaried staff with relatively high levels of education.[13-15] Barriers to uptake also include the fear that involvement is not confidential. Low participation rates are the limiting factor for any potential public health impact of worksite-based interventions. Therefore evaluation of programs on employee health outcomes, employee families/dependents, and on communities may be difficult.[16]

Provision of workplace fitness programs within health promotion schemes may fail to reduce absenteeism or to improve the health of the workforce. This may be due to the same user characteristics that also fail in public sector leisure activities.[17] United Kingdom employers, unlike those in the United States, rarely contribute to private insurance schemes and, therefore, have less incentive to become involved in health promotion. Nevertheless, large organizations with good workforce retention have much to gain by a holistic approach to health promotion programs. Targets for healthier work environments and lifestyle changes could influence better health over an employees' working life. The infrastructure of large organizations should also facilitate monitoring of take-up and measurement of improvement in health outcomes over time. The National Health Service, the largest employer in Europe, has historically provided long-term employment for a multi-professional workforce, but it has no well-developed strategy for health promotion.

Characteristics

The size of an organization probably has the biggest influence on health promotion activities. Due to economic changes, more people are employed in small- and medium-sized enterprises where there is often no workplace access to occupational health support.[18] Despite campaigns, such as "Good Health is Good Business,"[19] many employers remain unaware of long-term risks for workplace health and the need to take a proactive approach to prevention. The European Network for Workplace Health Promotion (ENWHP) observed that targeting large organizations with suitable infrastructure was more likely to be successful. A 1992 Health Education Authority survey of 1,344 workplaces found that larger workplaces addressed heart health, weight control, exercise, and fitness, with 40% undertaking at least one health promotion-related activity in the previous year. Health promotion increased with workplace size and good infrastructure; the size of an organization is therefore a key determinant.

Trade union representation, occupational health services, and workplace health promotion are concentrated in the larger United Kingdom public sector organizations.[7,14,20] The role of trade unions has mainly influenced the reduction of hazards at work, better working conditions, job conditions, working hours, wages, and job contracts. In 1989 the Labor Research Department study of 500 trade union representatives found common workplace health promotion activities were first aid medical treatment, inspection of hazards, and pre-employment medical screening. Activities that union representatives wanted were stress management, breast screening, and screening for hypertension. Smoking-related health promotion activity was found in 41% where a union was present versus 28% where a union was absent. Workplaces with no health promotion activity were small or medium sized, in the private sector, British owned, and mainly in distribution and catering businesses.

An international feasibility study has demonstrated the importance of partnerships between trade unions, health promoters, and related professionals in efforts to promote employee health. This is of particular importance in view of rapid globalization and the potential for worker health and safety to be overlooked.[21] Trade unions are involved in workplace health promotion partnerships and networks that include a broad range of industry, Chambers of Commerce, National Health Service (NHS), Health and Safety Executive (HSE), local government, education, legal, and independent consultants.

While small organizations may have fewer health promotion activities, a recent survey, commissioned by the Federation of Small Businesses (FSB), reported that the average number of days small businesses lost to absence per employee was 1.8 days (compared to the average of 8.4 days for businesses of all sizes). Employees of small businesses are therefore around six times less likely to take sick days compared to public-sector workers.[22] The national health and safety chairman of the FSB suggests that government should offer incentives to small businesses to provide access to occupational healthcare and health promotion initiatives. Smaller firms should be required to pay less in employers' liability insurance in return for good workplace health and safety initiatives.

Influence of Occupational Health on Health Promotion

The Health and Safety Commission published two reports: *Revitalising Health and Safety Program*[23] and *Securing Health Together*,[24] These presented a long-term occupational health strategy for England, Scotland, and Wales that by 2010, aimed to reduce ill health caused by work activity and accidents, the number of working days lost from work-related injury and ill health by 30% and the incidence rate of fatal and major injury accidents by 10%. The Health and Safety Executive commissioned survey,[25] found that only one-in-seven workers in the United Kingdom had comprehensive occupational health support. The *Securing Health Together* strategy required base-line information on current provision of occupational health, and this was provided by Pilkington et al[26] in a survey of 4,930 organizations. Over half of the companies reported taking steps to improve the general health of employees. The most frequently provided services were health promotion campaigns and information on healthy lifestyles. Least popular services were private healthcare schemes, access to leisure facilities, and well-person health checks. Where occupational health support was defined to include hazard identification, risk management, and provision of information, then approximately 44% of participating companies fulfilled this definition, equivalent to 15% of all United Kingdom companies after adjustment for company size and sector. A more rigorous definition of occupational health included the three parameters above, (i.e., hazard identification, risk management, and provision of information) plus modifying work activities, occupational health training, measuring workplace hazards, and monitoring trends in health. This definition resulted in an additional 3% of companies fulfilling the wider definition of occupational health support. Again more large companies met the criteria than small companies. Occupational health was found to take second place within health and safety, with no distinct identity and often no budget allocation. Formal evaluation of costs and benefits of occupational health support was limited and most likely in larger companies. Commitment to do more to acquire occupational health support was limited by available resources, particularly for smaller companies across all regions and sectors. There was a recognized lack of knowledge about how to deal with health issues, particularly in micro and small companies. Health and Safety representatives and managers were central to increasing awareness of occupational health issues within smaller companies.

Workplace Health Promotion at a European Level

The Health Promotion Unit is represented on the European Network for Workplace Health Promotion (ENWHP) as an informal network of national occupational health and safety institutes, public health, health promotion, and statutory social insurance institutions. It aims through the joint efforts of all its members and partners to contribute to improving workplace health and well-being and reducing the impact of work-related ill health on the European workforce. The Network was formally established in 1996, and since this time, it has been at the leading edge of developments in European workplace health promotion. Over the past three years, the ENWHP has been working on the development of national forums for workplace health promotion, in line with the new health strategy of the European Union, and linking these infrastructures on a European level. Encouraging this, the fourth European Conference on Promoting Workplace Health was held in Dublin in June 2006. The conference was held in the context of the Irish European Union presidency.

National Strategies within the United Kingdom

There are different approaches to health promotion in the four countries of the United Kingdom: England, Wales, Scotland, and Northern Ireland. Within all four home countries, Scotland has been well ahead with a coordinated approach to improving the health of the working population through a developed network, *Scotland Health at Work*.

Health promotion policy in **England** was shared between the Department of Health (DoH) and the Health Education Authority (HEA). The latter's terms of reference were limited, and there was constant disagreement about the extent to which HEA could operate independently. This was illustrated in relation to smoking, where the HEA took a line that was not in agreement with the more voluntary approach favored by Government. The HEA was subsequently split in two, with a research-based arm, the Health Development Agency (HDA), and a more overtly health-promoting arm, Health Promotion England. In 2001, the health-promoting arm was 'absorbed' into the DoH and in 2005, the research arm was incorporated into the National Institute of Health and Clinical Excellence. Legislation on smoking in workplaces and public places is to be introduced in 2007, months and years after other countries within the United Kingdom. The London Workplace Health Network includes members from London Boroughs, the National Health Service (NHS), the Health and Safety Executive, the Office of Deputy Prime Minister and consultancies. The London Regeneration Network focuses on 390 voluntary organizations throughout London, particularly companies with fewer than five employees and encourages them to engage in workplace health promotion.

In **Wales**, a strategy document for *Health at Work*, was published in 1996.[27] New initiatives included the appointment of a National Workplace Health Promotion Coordinator, the examination of the needs of small-to-medium enterprises, and the continued implementation of cardiovascular strategies in the workplace. This strategy built on the significant work developed by Heartbeat Wales in the mid-1980s. Each of these initiatives is expected to promote the development of workplace health promotion. At the same time a formal network of workplaces, stakeholders, and assessors involving an accreditation scheme for organizations that promote health at work has been set up. The Wales Counselling at Work Network has focussed on psychological issues at work while Heartbeat Wales made a major contribution with programs for cardiac health improvement. At the local Board level, workplace coordinators have been appointed with responsibility for the development of workplace health promotion plans and the initiation of pilot projects.

Scotland has been well ahead with a coordinated approach to improving the health of the working population through a developed network, *Scotland Health at Work*. Many organizations in Scotland have addressed health promotion in the workplace by developing and implementing health policies, such as those for smoking, alcohol, and food, forming health circles to identify and to take action on workplace health issues, promoting physical activity through membership of sports facilities, providing bicycle racks, encouraging employees to walk during lunch time, providing access to appropriate screening initiatives, and registering with the *Scotland Health at Work* award scheme. Another aspect is the formation of networks for the different geographical areas. The focus of these groups is to create mechanisms to help small and medium-sized enterprises address worksite and employee health promotion goals.

Northern Ireland, despite having an economy dominated by small businesses, has a well-established workplace health promotion program led by the Health Promotion Agency, known as the *Work Well Program*. Anticipated benefits include reduction in illness-related absenteeism, fewer working days lost, and, therefore, a long-term decline in the sickness rate; increased motivation among staff, and improvements in the working atmosphere in the company, leading to more flexibility, better communications, and readiness to cooperate; a measurable increase in the quality of products and services, more innovation and creativity, and a rise in productivity and improvement of the public image of the company. The *Work Well: Healthy Workplace Guide* is the focal point of the Work Well initiative and the starting point for all businesses interested in adopting a healthy workplace strategy. It is aimed at employers, health and safety workers, human resources staff, occupational health staff, and anyone else working in the field of workplace health.

Workplace health policy in the **Republic of Ireland** is distinctive from that in Northern Ireland, but there are now increasing numbers of cross-border initiatives. The structure emphasizes concepts of self-regulation and monitoring, rather than policing.[28] The *Happy Heart at Work* (HHAW) program, sponsored by the Irish Heart Foundation,[29] and in existence since 1992, is a national program designed to suit the Irish context. It aimed to promote a healthy lifestyle through specific modular materials. Evaluation of this program was commissioned with a survey of 785 registered sites. An initial level of interest in the HHAW program was expressed by 40%. Active organizations were less likely to be Irish owned and more likely to operate in shifts or to have an occupational physician among the staff. The program was purported to improve employees' lifestyle habits and morale and the company's public image. The drawbacks were its relatively low profile, even in actively participating organizations, and the fact that it was not seen to be independently sustainable without intensive and ongoing support.[30] Manufacturing organizations employing more than 200 workers were most likely to take part in HHAW. The Irish Department of Health and Children reported low levels of awareness for health promotion programs among workers with the main obstacle being lack of management commitment.[31]

Recent National Guidance

The English public health strategy was published in 2004.[32] Actions that employers and government can take to promote work and health were addressed, but focused on the NHS as the employer, rather than the English workforce as a whole. Specific sums were allocated to implement the strategy in relation to smoking, exercise, nutrition, sexual health, alcohol, and mental health, but these were largely diverted to cover overspending in other areas. In November 2005, the progress of the program was addressed. The Health and Safety Commission considered whether the Health and Safety at Work Act of 1974 should be amended in response to a changing world of work, and in particular, to ensure the same protection is provided to all workers regardless of their employment status.

In 2006, the Department of Health requested the National Institute for Health and Clinical Excellence to develop public health intervention guidance on workplace health promotion with reference to smoking and what works in motivating and changing employees' health behavior. The guidance will provide recommendations for good practice based on the best available evidence of effectiveness, including cost-effectiveness.

In conclusion, the situation in the United Kingdom is mixed, but the message that appears with respect to workplace health promotion is that it is up and running in large companies, rather than in smaller ones, and in international companies, rather than home companies, and is more likely to flourish where occupational health professionals are present and where there is good management commitment. **NCMedJ**

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North Carolina
MEDICAL JOURNAL

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Without the voluntary assistance and carefully executed reviews of a number of anonymous reviewers, no journal can offer the kind of peer-review for submitted manuscripts that can assure its readers the highest quality of published articles. We are fortunate in having the service of a number of individuals who have given generously of their time and expertise in service to the *North Carolina Medical Journal* this past year, and we are pleased to have this annual opportunity to acknowledge their efforts.

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Hospital Quality and Patient Safety

Notable News from The North Carolina Center for Hospital Quality and Patient Safety

North Carolina Center *for* Hospital Quality and Patient Safety

Hospital Quality Performance Report

The first North Carolina hospital report card has been developed by the North Carolina Center for Hospital Quality and Patient Safety and will be available on a public Web site. This transparent, hospital-specific on-line resource for hospital quality was designed to provide understandable information to patients so they can learn more about inpatient treatment for common causes of hospitalization and can participate in decisions that will impact their health. Furthermore, studies have shown that comparative hospital quality reports intensify hospital quality improvement projects, improve organizational culture toward quality and patient safety, and positively influence hospital operations by placing higher priority on quality performance.[1,2,3] Therefore, in addition to providing standardized and reliable quality information to consumers, the report's objective is to provide performance benchmarks that will assist and stimulate hospitals in continuously improving their quality of care.

The Quality Center initiated the NC Performance Reporting Workgroup to review inpatient clinical measures and to develop recommendations for measurement inclusion and report design. The Workgroup is a multidisciplinary team consisting of physicians, nurses, and executives representing hospitals, health systems, insurance industry, the Carolinas Center for Medical Excellence (CCME), NC Medical Society, and NC Department of Health and Human Services. The principles set by the group were to include measures that were actionable, standardized, well-defined, available, and would not add burden to hospital data collection efforts. In September 2006, the Workgroup's recommendations for the NC Hospital Quality Performance Report were approved by the Quality Center's Board and endorsed by the NC Hospital Association Board of Trustees.

The NC Hospital Quality Performance Report, to be available at www.nchospitalquality.org in January 2007, will display 21 process measure scores currently collected and publicly reported by the Centers for Medicare & Medicaid Services (CMS) (see Table1). The reporting of these measures is voluntary for hospitals; however, they are linked to Medicare payment via the Reporting Hospital Quality Data for the Annual Payment Update initiative. These evidence-based, process-of-care measures are treatment recommendations proven to give the best results to most adults with a diagnosis of heart attack, heart failure, pneumonia, or those admitted for surgery. The scores for each individual measure reflect how often recommended treatment was given for an eligible patient—which only includes patients whose history and condition indicate the treatment is appropriate. The Web site will include descriptions of all the measures, and there will be clear links to other Web sites that offer detailed information about each health condition, the recommended treatments, and the measurement methodology.

The NC Hospital Quality Performance Report will display the scores of the 21 measures and graphically display an overall condition score. The overall condition score is a composite score calculated by dividing the sum of numerators by the sum of denominators from a condition's measures. Benchmarks in the report will include the state mean, state 90th percentile and the national mean per measure. For example, the North Carolina mean was equal to or greater than the national mean on 19 of 21 measures during second quarter 2005 through first quarter 2006. The report will also link consumers to the NC Quality Center Web site and other healthcare improvement organizations to inform patients and providers of the national and statewide quality improvement initiatives currently in place in many North Carolina hospitals.

The NC Quality Center has partnered with CCME to provide enhancements in Summer 2007 to the Web site, such as (1) reporting data more current than available through Hospital Compare, (2) providing hospital- and state-level trend graphs, and (3) including four "optimal care" composite scores per condition. The optimal care measures, also known as "appropriateness of care" measures, use the "all or none" methodology to determine

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Table 1.
CMS Process Measures by Condition

Condition	Measure	NC Mean*
Heart Attack	ACE Inhibitor or ARB for Left Ventricular Systolic Dysfunction	78%
	Aspirin at Arrival	93%
	Aspirin at Discharge	89%
	Beta Blocker at Arrival	88%
	Beta Blocker at Discharge	89%
	PCI Within 120 Minutes Of Arrival	66%
	Smoking Cessation Advice/Counseling	85%
	Thrombolytic Medication Within 30 Minutes Of Arrival	31%
Heart Failure	ACE Inhibitor or ARB for Left Ventricular Systolic Dysfunction	81%
	Assessment of Left Ventricular Function (LVF)	86%
	Discharge Instructions	63%
	Smoking Cessation Advice/Counseling	86%
Pneumonia	Assessed and Given Pneumococcal Vaccination	70%
	Initial Antibiotic(s) within 4 Hours After Arrival	79%
	Oxygenation Assessment	100%
	Assessed and Given Influenza Vaccination	72%
	Smoking Cessation Advice/Counseling	82%
	Most Appropriate Initial Antibiotic(s)	81%
	Blood Culture Prior to First Antibiotic	90%
Surgery	Preventative Antibiotic(s) One Hour Before Incision	81%
	Antibiotic(s) are Stopped Within 24 hours After Surgery	75%

* Discharges 4/05-3/06. Data downloaded from www.hospitalcompare.dhhs.gov.

if a patient received all of the recommended treatment for which they were eligible.[4] This methodology supports the notion that achieving a desired clinical outcome requires the completion of a full set of tasks and results in more stringent scoring, thus raising the bar for performance and increasing the ability to improve outcomes.[5] Furthermore, the optimal care measures put an emphasis on system-wide improvements in areas such as communication and cooperation and they offer more sensitive scales for assessing improvement.

More measures will be added to the NC Hospital Quality Performance Report. These will include measures that will most likely be aligned with the Hospital Quality Alliance's reporting requirements and have National Quality Forum endorsement. For example, future measures may include patient perceptions (i.e., data from the Hospital Consumer Assessment of Healthcare Providers and Systems survey), 30-day mortality rates for heart attack and heart failure, and expanded information on surgical care that include steps taken to prevent venous thromboembolism and surgical site infections.

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Running the Numbers

A Periodic Feature to Inform North Carolina Healthcare Professionals
about Current Topics in Health Statistics

From the State Center for Health Statistics, NC Department of Health and Human Services
http://www.schs.state.nc.us/SCHS

Worksite Wellness Interest Survey of NC DHHS Employees

Background: Employers increasingly recognize the benefits of investing in workplace wellness programs to control medical plan costs and reduce absenteeism among their employees. Wellness programs have also been shown to increase productivity and improve employee morale and retention. Wellness programs can bring as much as a four-fold return on each dollar invested in wellness benefits.[1] Long-term evaluation of the impact of a corporate wellness program showed a substantial reduction in medical costs for employees with most benefits occurring after three to four years.[2]

Since 2000, the North Carolina State Health Plan has seen a large decline in the number of healthy state employees and school personnel younger than age 65. Healthy members of the NC State Health Plan are defined as those without medical claims for chronic diseases, acute illness or injury, or catastrophic illness or injury in the current year. Among approximately 408,000 Plan members, healthy members decreased from 64% in 2000 to 58% in 2003. By 2008, if present trends continue, only 51% of state employees will be healthy. Every 1% decline in the number of healthy members results in an additional cost of $68 million in healthcare costs. This decline in healthy employees is largely attributable to an increase in the prevalence of chronic disease conditions. Approximately 70 cents of every healthcare dollar was spent to treat members with one or more chronic diseases. In 2003, the average cost for a member without a chronic disease or major illness or injury was $800. Members with a chronic disease averaged more than nine times that amount ($7,400) per year in healthcare costs.[3]

Two thirds of chronic diseases can be attributed to three major lifestyle risk factors.[4] Low levels of physical activity, poor diet, and exposure to tobacco increase an individual's risk of developing a chronic disease and make the management of existing chronic conditions more difficult. Support in the workplace can greatly influence and sustain employees in changing their health behaviors. The NC Department of Health and Human Services (NC DHHS), with support from the NC State Health Plan, established the DHHS Wellness Initiative in 2004 in an effort to contain rising employee healthcare costs by reducing the major chronic disease risk factors among NC DHHS employees. The initiative focused on establishing wellness committees in each agency and facility within NC DHHS. The goal was to promote and support employee health and wellness primarily through changes to workplace policies and environments that increase opportunities for physical activity, improve access to healthier foods, reduce tobacco use, and help employees manage stress. This initiative is one component of the larger multi-faceted NC Health*Smart* healthy living initiative launched in 2005 by the NC State Health Plan to provide resources and support to keep healthy members healthy and better manage the care of members with chronic diseases.

Survey Description: Baseline information was collected via two surveys to assist NC DHHS agency committees in developing effective wellness plans and to guide a new 38-member NC DHHS Wellness Council in developing wellness policy recommendations for the Department. In September of 2005, wellness contacts in each NC DHHS agency and facility completed a survey of existing support for wellness at NC DHHS worksites. This article reports findings of a second survey launched in October of 2005 to assess the wellness interests of the 18,768 employees in the Department. The employee survey was a 14-item, Web-based questionnaire with primarily multiple choice answer options. Several questions provided employees opportunities for open-ended responses. Respondents were required to identify their agency or facility on the survey.

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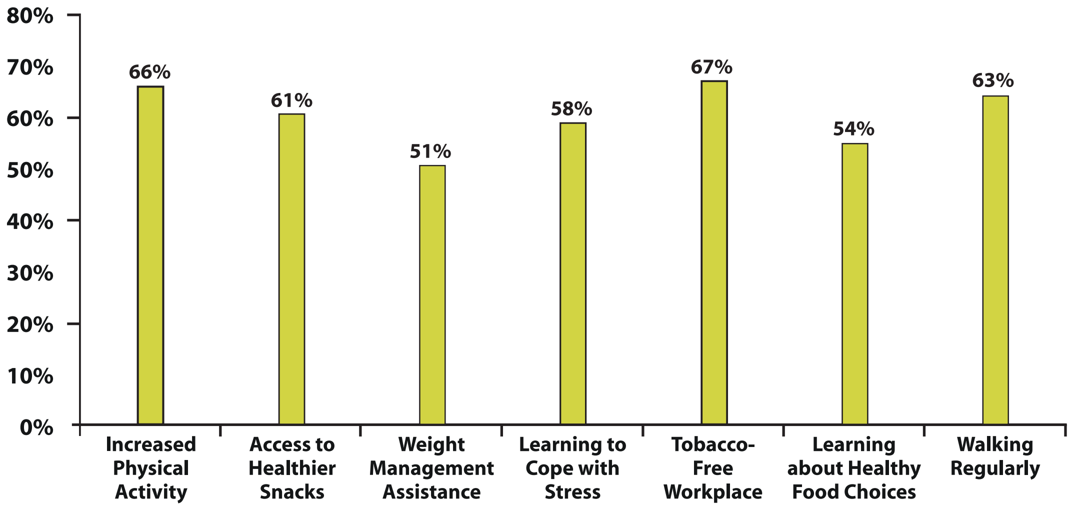
Survey Deployment: The Employee Wellness Interest survey was deployed through an online survey to approximately 10,000 employees with NC DHHS E-mail addresses. Each E-mail address could respond only once to the survey. Hard copies of the survey were provided to wellness contacts at the state facilities to reach their 8,000+ employees without a work E-mail address. The facility wellness contacts distributed the surveys, then collected and mailed them to the Wellness Director in Raleigh. The survey was deployed October 24, 2005 and closed January 9, 2006. E-mail messages were sent to remind employees to complete the on-line survey.

Response: A total of 5,821 employees (31%) responded to the survey. This included 4,256 E-mail responses (43% response rate) and 1,565 hard copy responses (20% response rate) from facility employees.

Analysis: On-line survey responses and scanned hard copy survey data were combined. Responses to open-ended questions were categorized using qualitative data analysis software. No significant differences were observed between the responses to on-line and hard copy surveys.

Results: More than 60% of respondents identified the following as major areas of wellness interest: opportunities in the workplace for increased physical activity and walking, access to healthier snacks, and working in a tobacco-free workplace (see Figure 1). Other workplace wellness interests identified by at least half of survey respondents included weight management, learning to cope with stress, and learning about healthy food choices.

Figure 1.
NC DHHS Employee Wellness Interest Survey Results: Major Areas of Wellness Interest Identified



Results of multiple choice questions shown in Figure 1 were confirmed by open-ended responses to a survey question asking for the single change in the workplace that would have the greatest impact on the employee's health and wellness. The most frequent response was a place to exercise at work. The second and third most frequent responses to that question were reduced work-related stress and improved access to healthier food options at work. Other frequent responses related to issues that were not provided as multiple choice options on the survey. These included employee health concerns regarding air quality, environmental health (mold, dust, lighting, and cleanliness), and ergonomic issues.

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The survey attempted to assess factors affecting employee participation in wellness activities. Time to participate at work was most frequently identified by NC DHHS employees as the single most critical factor affecting their participation in wellness activities at work. Other major factors affecting participation included incentives for participation and authorization to use flex-time to participate. A majority of respondents (53%) identified the lunch break as the preferred time to participate in wellness activities and 30 minutes was the length of time most frequently preferred for wellness activities.

Each agency and facility wellness committee received a summary of their own employee survey responses. The results provided valuable information needed by the committees to develop agency wellness plans geared to the specific interests and needs of employees at their workplace. Information from a summary of all survey responses was used by the NC DHHS Wellness Council to develop broader policy and environmental change recommendations for the Department to improve support for employee wellness programs. A follow up survey to assess employee participation in wellness activities and future wellness interests was disseminated to NC DHHS employees in October of 2006.

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Contributed by Suzanna A. Young, RD, MPH; Marcus Plescia, MD, MPH; Bertha Gorham, PhD
Chronic Disease and Injury Section, North Carolina Division of Public Health

Readers' Forum

To The Editor:

It is incredible that we should be addressing the problems of overweight and obesity and be concerned that they are now of epidemic proportion. The July/August issue of the Journal has done a major service in bringing to the attention of all concerned just how pervasive the problem is. As noted by many of the authors, a "cure" for this epidemic will not be easy. Yet, one must be obtained. The impact of each overweight person on the healthcare system, both in terms of their own health and the cost in dollars needed to provide their care, cannot be ignored.

Thank you for providing this most timely issue. And thank you, too for honoring one of North Carolina's most effective and passionate leaders in the fight to provide better health, better resources, and better information for the care of our children. Tom Vitaglione is truly a gift to us all.

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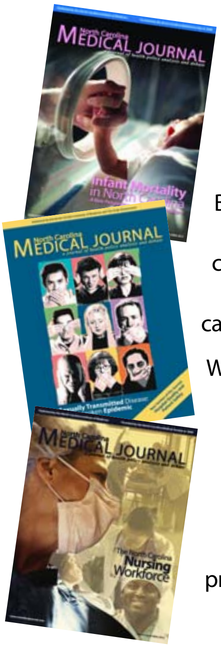

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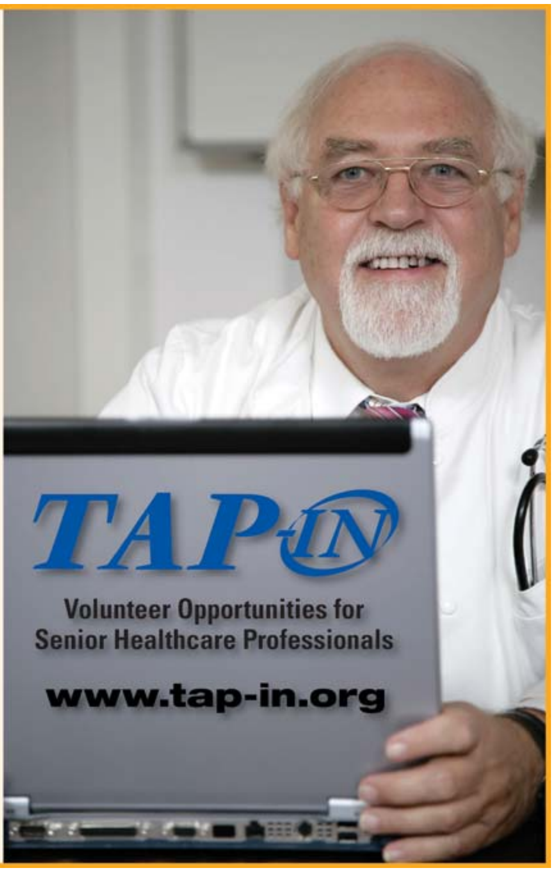

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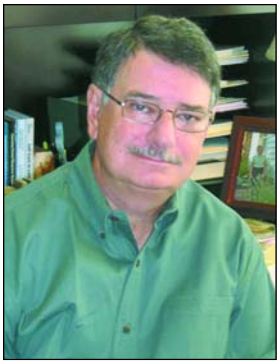
Special Letter from the Publishers of the *North Carolina Medical Journal*

To the readers of the *North Carolina Medical Journal*:



Gordon H. DeFriese, PhD

This issue marks a significant transition in the leadership of the *North Carolina Medical Journal*. Gordon H. DeFriese, PhD, served as the Editor-in-Chief of the *NCMJ* since 2002. Gordon brought the *Journal* under publication of the North Carolina Institute of Medicine (NC IOM) during a time when its future was uncertain. His ambition was to expand and enhance the *Journal* to meet the need for health policy discussions in the state of North Carolina. Through Gordon's passionate dedication, he gathered financial and editorial support for the *Journal*, which became the state's leading avenue for disseminating health information and health policy solutions.

Under Gordon's leadership, the *Journal* highlighted timely and critical health policy issues such as the epidemic of childhood obesity, the need for direct care workers in long-term care, medical malpractice, quality of health care, and access to dental care. Gordon's nurturing of the *Journal* honored its long history, dating back to 1849, by strengthening its value to physicians and giving more exposure to important health policy issues beyond the physician community. Today, the *Journal* is distributed to more than 30,000 readers across the state and the nation including physicians, nurses, dentists, pharmacists, physician assistants, hospital and health care facilities administrators and leaders, other health professionals, health policy makers, and business and community leaders.

The *Journal's* success is a testament to Gordon's vision, energy, and service to improving the health of North Carolina's citizens. Although Gordon's work will continue in various other roles, he has retired from his position as Editor-in-Chief of the *North Carolina Medical Journal*. His tireless work and commitment strengthened the *Journal's* foundation so that its impact on the state will be ongoing.

Beginning with this issue, we are excited that Thomas C. Ricketts III, PhD, MPH, has agreed to serve as the Editor-in-Chief and carry on Gordon's valuable work. Tom, a professor in the School of Public Health and Deputy Director of Policy Analysis at the Cecil G. Sheps Center for Health Services Research at the University of North Carolina at Chapel Hill, has also dedicated his career to improving the health of North Carolinians, as well as underserved populations throughout the country. He is an expert on health care topics including access, quality of care, rural health, workforce, and technology. His work is well respected by health care leaders throughout the nation and world, enabling him to bring national and international expertise to North Carolina issues. Tom's previous experience as editor of two national health journals provides new skills and perspectives that will allow him to place his own personal touch on the *Journal*.

With our sincerest thanks and gratitude for Gordon's work and a very warm welcome in anticipation of the direction of the *Journal* under Tom's leadership,

Pam Silberman, JD, DrPH
President and CEO, NC IOM
Co-Publisher, NCMJ

Eugene W. Cochrane, Jr.
President, The Duke Endowment
Co-Publisher, NCMJ

North Carolina
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a journal of health policy analysis and debate

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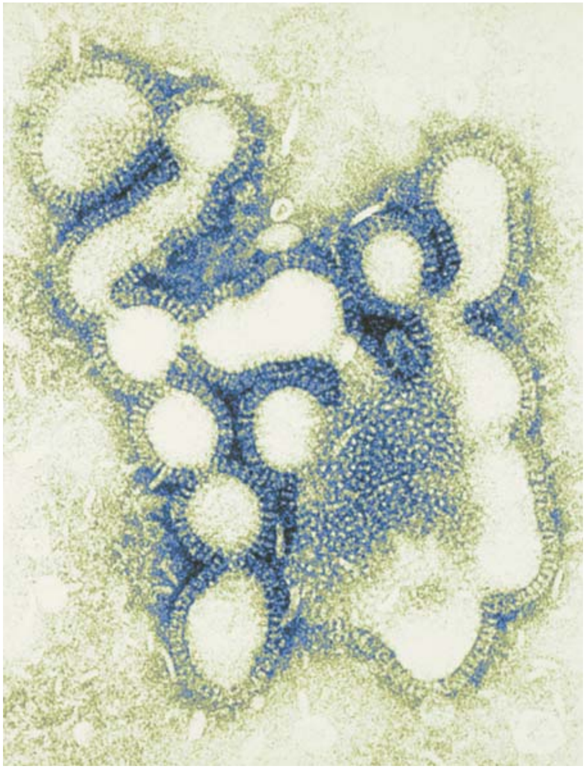
ARTICLE

POLICY FORUM

Pandemic Influenza Preparedness in North Carolina

COMMENTARIES

DEPARTMENTS



About the Cover:
Influenza Virus at 295,000 Magnification

Tarheel Footprints in Health Care

Recognizing unusual and often unsung contributions of individual citizens who have made health care for North Carolinians more accessible and of higher quality

Kathleen Colville, MSW, MPH
Public Health Preparedness Coordinator, Alamance County Health Department

Kathleen Colville, MSW, MPH

Public health leaders are specifically charged with promoting and protecting the overall health and well-being of the population during emergencies. When an influenza pandemic arrives, it will be up to the state and local public health agencies and partner organizations to coordinate a public health response to help reduce morbidity, mortality, and social disruption. Local health departments have hired preparedness and response coordinators to prepare for natural or manmade disasters.

As a Public Health Preparedness Coordinator, Kathleen Colville, MSW, MPH, has taken the lead in coordinating the development of Alamance County's pandemic influenza plan. She convenes a community steering committee, provides training to community groups, health care providers, and health department staff, negotiates agreements with other agencies regarding roles and responsibilities during an influenza pandemic, and provides regional leadership through planning drills and exercises. These efforts will better enable Alamance County and North Carolina to respond to an influenza pandemic event when it occurs.

Ms. Colville has distinguished herself by working particularly on preparedness for marginalized populations and has been awarded several grants to reach out to low-income communities to address the unique challenges faced by these communities in the wake of a disaster. She has increased her own skills by volunteering in Florida after the devastating hurricanes in that state and by learning how to use geographic information systems to better survey and assess needs following catastrophic events. She also has learned to apply this technology to typical public health activities, such as community assessment. Dorothy Cilenti, Health Director at the Alamance County Health Department, noted that, "Kathy is a valued asset to the entire community in Alamance County, and as a result of her dedication and professionalism, we are better able to quickly respond to widespread disease or disaster."

Kathleen Colville came to her position in August 2005 after completing Master degrees in Social Work and Public Health at the University of North Carolina at Chapel Hill. She was named a North Carolina Schweitzer Fellow for the 2004-05 academic year for her service project conducting a community needs assessment in response to the elevated number of domestic violence homicides in Alamance County.

Marcy Green, Health Education Supervisor at the Alamance County Health Department, had these comments about Ms.Colville,"I think the number one quality of a Preparedness Coordinator is the ability to work well with different types of people as well as the ability to form strong relationships with community agencies. Kathy's personality and competence have been vital to building a strong relationship with our emergency management partners." Chip Ferguson, Director of Emergency Management at the Burlington Police Department, reiterated this idea. He described Ms. Coleville as a true asset to the police department because of her tireless work to bring public health into the realm of public safety, a collaboration that previously did not exist. Ms. Green concluded, "If Alamance County were to face a small or large disaster, I feel much better knowing that we have Kathy has a leader in this area."

For her efforts and accomplishments in preparing Alamance County for an influenza pandemic, the Editors of the *North Carolina Medical Journal* are pleased to recognize Kathleen Colville, and all preparedness and response coordinators around the state, for their contributions to the health and safety of all North Carolinians.

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John W. Williams, Jr., MD, MHS
Scientific Editor, *North Carolina Medical Journal*

North Carolina is blessed with some of the finest medical research institutions in the world. The work of the medical scientists that labor in our research facilities becomes complete (in many ways) and public when it is published in peer-reviewed journals.

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The Journal seeks papers that convey the results of original research. We are especially interested in publishing research papers that have relevance to the health of the people of our state.

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We generally accept two types of manuscripts for review: (1) original clinical or health services research contributions and (2) systematic reviews (both regardless of specific topic).

The *North Carolina Medical Journal* is published six times a year. It is distributed free of charge to the members of the North Carolina Medical Society, the North Carolina Hospital Association, the North Carolina College of Internal Medicine, the North Carolina Board of Pharmacy, the North Carolina Association of Pharmacists, the North Carolina Division of Public Health, the North Carolina Dental Society, the North Carolina Health Care Facilities Association, and The Carolinas Center for Medical Excellence. The Journal is available by subscription to others.

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North Carolina
MEDICAL JOURNAL

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Submit a cover letter and the article (via e-mail attachment) containing the double-spaced text, preferably in Microsoft Word. The letter should indicate that the article is not under consideration for publication elsewhere and has not previously been published in any form.

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ARTICLE

Relationship between Nephrologist Care and Progression of Chronic Kidney Disease

Lori A. Orlando, MD, MHS; William F. Owen, MD; and David B. Matchar, MD

Abstract

Background: *Since chronic kidney disease (CKD) affects 11% of the United States population, and its incidence is rising, experts recommend early referral to nephrologists in the hope that it may delay the onset of end-stage disease and improve survival. However, limitations in the capacity of currently practicing nephrologists may prevent widespread early referral.*

Objective: *To examine the relationship between disease progression and timing of nephrology referral.*

Study Design and Data Collection: *We retrospectively identified 1,553 veterans at the Durham, North Carolina VA hospital between January 1998 and December 1999 who had CKD, defined as two outpatient serum creatinines $\geq$ 1.4 mg/dL at least three months apart. Our endpoint was a composite of progression to the next CKD stage or death. We compared the time to the composite endpoint for each CKD stage and for early CKD (stages 1-3) to advanced CKD (stages 4 and 5) using a Cox proportional hazards model for two groups: those with primary care only (PCP-only) and those with primary and nephrology care (nephrology).*

Results: *Ninety-two percent had hypertension, 52% diabetes, 49% coronary artery disease, and 89% proteinuria. Angiotensin-converting enzyme inhibitors and anti-lipid medications were used by 52% and 39%, respectively. The median number of days spent in each CKD stage and the proportion of each groups reaching the composite endpoint are—stage 1: 1,149 days, 68% of the PCP-only group and 73% of the nephrology group; stage 2: 1,206 days, 60% and 65%; stage 3: 1,158 days, 69% and 63%; and stage 4: 794 days, 86% and 72%. Adjusted survival curves for the composite endpoint were similar between the two groups for CKD stages 1 (HR 1.08 for nephrology versus PCP-only) and 2 (HR 1.20); however for CKD stages 3 (HR 0.80, $p < 0.05$) and 4 (HR 0.75, $p < 0.05$), the nephrology group gained 316, 215, and 120 more days of progression-free survival, respectively.*

Limitations: *The major limitation is difficulty accounting for unmeasured bias in specialty referrals. We were unable to analyze stage 5-to-dialysis due to the small number of individuals with the outcome.*

Conclusion: *Our data suggest that an appropriate time for nephrology comanagement of patients with CKD may be stage 3; however, prospective studies are needed to clarify the role and timing of nephrology referral.*

Keywords: *chronic kidney disease, provider, kidney disease*

Background

Chronic kidney disease (CKD) affects 11% of the United States population, about 20 million people.[1] Improving the management of CKD has been shown to increase survival in those with CKD, delay the development of end-stage renal disease (ESRD), and improve morbidity and mortality once ESRD develops.[2] Slowing the rate of progression and delaying ESRD are now more important than ever as the incidence of CKD and ESRD is increasing, in large part due to the increasing prevalence of CKD risk factors such as the aging of the population, hypertension, and diabetes mellitus.[3] This is true at both the national and state level. For example, in 2003 the point prevalence of ESRD in North Carolina was 14,635 with an incidence of 3,207—this makes us one of the top ten states for prevalence and incidence. Even more concerning, the prevalence increased 280% in the ten years between 1993 and 2003, slightly higher than the national average of 250%.[4]

ESRD accounts for $20 billion per year in Medicare expenditures. With the increase in its incidence, expenditures are

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projected to reach $42 billion per year by 2010.[5] Given concerns over the rising impact of CKD on the health of the general population and increasing expenditures for dialysis care, researchers have begun to investigate the impact of care in the pre-ESRD period on ESRD outcomes. Several of these studies have suggested that nephrology referral early in the pre-ESRD course may improve the morbidity and mortality on dialysis.[6] These studies, while methodologically limited by dichotomizing and varying the definition of early referral (from one month to one year predialysis), and the use of dialysis populations (not generalizable to predialysis populations), provided preliminary evidence in favor of early referral to sub-specialists.

Based upon these preliminary studies, experts have recommended early referral to nephrologists for all CKD patients. However, widespread implementation has been limited by the disparity between the capacity of currently practicing nephrologists and the number of CKD patients.[7] Since this disparity exists and the preliminary studies were methodologically limited, researchers have begun to investigate in more detail the impact and timing of nephrology care on renal-related outcomes.

In view of the conundrum between an inadequate number of subspecialists to deliver care and uncertainty about when their intervention may be of the greatest benefit, we examined the relationship between the severity of CKD, the presence of subspecialty care, and progression of CKD in a pre-ESRD population.

Methods

We performed a retrospective observational database study of 1,553 veterans with CKD at the Durham, North Carolina Veterans Administration Hospital (VA). Our primary objective was to identify whether care provided by a nephrologist increases the time spent in any chronic kidney disease stage (ie, slows progression). The Durham VA Internal Review Board (IRB) approved this study.

We identified subjects by searching the local VA laboratory database for patients with serum creatinine concentrations measured between January 1, 1998 and December 31, 1999. Patients with two values ≥ 1.4 mg/dL, the upper limit of normal for our laboratory, during outpatient lab visits at least three months apart were included in the study. Patients were excluded if they were not followed in our primary care or nephrology clinics or if renal replacement therapy was initiated within 90 days of the first identified serum creatinine measurement.

Measures

For every subject in the cohort, we obtained all serum creatinine, calcium, phosphorus, albumin, hemoglobin, low density lipoprotein (LDL), hemoglobin A1C (HgA1c), and urine protein quantification values in the laboratory database between the inclusion date and December 31, 2004. Creatinine measurements were converted into an estimated glomerular filtration rate (GFR) using the modified Modification by Diet of Renal Disease Study formula (GFR= exp[5.228 - 1.154 x ln(Scr) - 0.203 x ln(age) - 0.299 (if female) - 0.192 (if black)])[8] and assigned a CKD stage using the Kidney Disease Outcomes Quality Initiative (KDOQI) CKD staging guidelines.[9] Specifically, stage 1 = GFR ≥ 90 mL/min with proteinuria, stage 2 = GFR < 90 mL/min and ≥ 60 mL/min with proteinura, stage 3 = GFR < 60 mL/min and ≥ 30 mL/min, stage 4 = GFR < 30 mL/min and ≥ 15 mL/min, and stage 5 = GFR < 15 mL/min or renal replacement therapy. The values for calcium, phosphorous, albumin, hemoglobin, HgA1c, and LDL were each averaged over three-month periods during follow-up. CKD-related complications included hypocalcemia (serum calcium < 8.5 mg/dL), hyperphosphatemia (serum phosphorus > 4.5 mg/dL), hypoalbuminemia (serum albumin < 4 g/dL), and anemia (serum hemoglobin < 12 mg/dL), and were defined here according to the Renal Physicians Association's and KDOQI evidence-based guidelines.[10] Complications were considered present if ≥ 50% of the averages exceeded the recommended goal. HgA1c (goal ≤ 7.0%), LDL (goal ≤ 100mg/dL), and blood pressure values (goal ≤ 135/85mmHg), also defined according to the above guidelines, were handled in the same manner. We used this method in order to evaluate the relationship between chronic exposure to CKD-related complications and/or poorly controlled comorbidities and long-term outcomes, such as disease progression and death.

We obtained data from the local pharmacy database on angiotensin converting enzyme inhibitors (ACEIs), angiotensin 2 receptor blockers (ARBs), erythropoietin, and lipid lowering agents prescribed during the study period. Prescriptions from the VA pharmacy are generally considered to be excellent indicators of medication usage since most veterans do not obtain drugs outside of the VA pharmacy and, due to the copay, do not request refills for medications not being taken. Medications were only included in the analysis if they were prescribed for at least six months.

We also collected data for the study period from the national inpatient and outpatient VA databases maintained in Austin, Texas. Data collected included demographics, comorbid conditions, blood pressure, and resource use (number of clinic visits and hospitalizations). These databases are a cumulative index of admissions and discharges from all United States VA medical centers and have been validated for reliability.[11] Comorbid conditions, including the presence of diabetes mellitus, hypertension, left ventricular hypertrophy (LVH), coronary artery disease (CAD), and current tobacco use, were identified using ICD-9 codes, while patient encounters with primary care physicians or nephrologists, clinic visits, and hospitalizations were identified using clinic and provider encounter codes. Race was categorized as white versus nonwhite. The CKD stage at first visit to nephrology was defined as the stage at initiation of nephrology care. Initiation of renal replacement therapy was identified by using ICD-9 and clinic codes from all three (local, national inpatient, and national outpatient) sources, as well as chart reviews of all patients with at least one GFR < 31 mL/min. Death was identified using the national VA benefits database maintained in Austin.

Analysis

The date of the first GFR within the cohort identification period (January 1, 1998 and December 31, 1999) for each patient was identified as the index date (time 0). The date of each subsequent GFR was used to calculate the number of days from the index date in order to construct a time course of GFR and CKD stage for each patient. In an effort to reduce the effect of regression to the mean and laboratory imprecision, we identified the index GFR as the average GFR for the three months prior to index date and we assumed that an individual remained in their current CKD stage until two measurements at least three weeks apart were either both higher or both lower than the previous stage. When this occurred, a new stage was assigned based upon the GFR at the time of the first of the two measurements.

In order to assess the effect of nephrology care on CKD course, we created two groups: PCP-only and PCP with nephrology (nephrology). Individuals who had nephrology clinic visits were assigned to the nephrology group, whereas those followed by a primary care physician only were assigned to the PCP-only group. Baseline characteristics were compared between these two groups using the Student's T-test for continuous variables and the Mantel-Haenszel chi-square for categorical variables.

Survival curves were constructed using all patients in a given stage to determine the time spent in each stage (ie, from stage 1 to 2, stage 2 to 3, stage 3 to 4, etc.), and the time from pre-advanced CKD, stages 1-3, to advanced CKD (ACKD), stages 4 and 5. The time spent in a given stage was defined as the time period between the very first assignment to that stage and a composite endpoint of either first assignment to a higher stage or death. If neither endpoint was reached then patients were censored at the time of their last follow-up. If an individual advanced more than one stage between measurements, then the time to the endpoint was defined as one half of the interval observed. Since many patients progressed through several CKD stages, a single individual may be represented in more than one survival curve.

We used a Kaplan-Meier survival curve to calculate the unadjusted progression-free survival time for each stage and a Cox Proportional Hazards model to compare the adjusted and unadjusted progression-free survival times between the nephrology and PCP-only groups for each stage. The adjusted model included age in years, race (white versus nonwhite), ACEI (use versus non-use), ACEI started during the analyzed stage, Anti-lipid agents (use versus non-use), uncontrolled diabetes (versus controlled diabetes—as defined in the measures section for HgbA1c > 7%), current tobacco use (versus noncurrent or no use), and diabetes (versus no diabetes), hypertension (versus no hypertension), cardiovascular disease (versus no cardiovascular disease), or proteinuria (versus no proteinuria). We excluded measures of control (other than diabetes) from the model because we were limited in the number of covariates we could analyze by the frequency of the outcome. We also excluded CKD-related complications and resource use because we could not distinguish between cause and effect with our study design. Only individuals followed by a nephrologist during the stage being analyzed were assigned to the nephrology group, and only those taking a medication during the specified stage were assigned the medication. Since ACEIs may acutely decrease and then stabilize GFR, we created an indicator variable for those who initiated an ACEI during the analyzed stage (ACEI started during stage) in order to distinguish between its short-term and long-term effects.

We incorporated the propensity to be seen by a nephrologist into our model in order to account for potential bias in patients referred to subspecialists. These continuous scores, which represent the probability that an individual received nephrology care based upon modeled characteristics, are incorporated into the Cox Proportional Hazards model as a covariate to balance observed characteristics between the two groups. We calculated a propensity score[12] for the probability of receiving nephrology care using a logistic regression model adjusted for age (in years), race (nonwhite versus white), diabetes (versus no diabetes), hypertension (versus no hypertension), cardiovascular disease (versus no cardiovascular disease), ACEI use (versus non-use), anti-lipid medication use (versus non-use), hypocalcemia (present versus not present), hyperphosphatemia (present versus not present), anemia (present versus not present), number of hospitalizations, and rate of progression prior to nephrology care (average change in GFR prior to first visit).

Table 1.
Characteristics of the Study Cohort and the Two Subgroups at Baseline

	Total	Nephrology	PCP-only	p-value
Number	1,553	456	1,097	
Age (range)	70 (26-98)	68.7	70.3	0.01
Nonwhite race (%)	32%	33%	32%	0.77
Diabetes (%)	52%	58%	49%	0.002
Hypertension (%)	92%	98%	90%	< 0.001
Proteinuria (%)	89%	75%	58%	< 0.001
Current Tobacco use (%)	21%	21%	21%	1.0
Coronary Artery Disease (%)	49%	56%	57%	0.49
Left ventricular hypertrophy (%)	3%	3%	3%	1.0
Hyperlipidemia (%)	24%	25%	24%	0.60
Average stage at cohort entry	1.3	1.6	1.1	< 0.001

Results

The baseline characteristics for our cohort and the two subgroups, PCP-only and nephrology, are reported in Table 1. Follow-up characteristics, including disease management and the development of CKD-related complications, are reported in

Table 2. Our cohort was composed of mostly elderly individuals. All were male and 33% were nonwhite. More than 90% had hypertension, 50% had diabetes and coronary artery disease, 50% used ACEIs, and 39% used anti-lipid medications. Only 3% used erythropoietin and less than 1% used ARBs, which reflects limitations on access to these two classes of drugs at our VA. The average stage at entry into the cohort was very early (1.3), and the average stage for referral was also early (1.6). When comparing those followed by nephrologists to those followed only by a PCP, individuals in the PCP-only group were older and were less likely to have diabetes, hypertension, hypoalbuminemia, or hyperphosphatemia. Management of diabetes, hypertension, and hyperlipidemia were similar between the PCP-only and nephrology groups and both groups had a similar number of days of follow-up, 1,310 for the nephrology group and 1,285 for the PCP-only group. Of the cohort of 1,553 individuals, only 133 (8%) were lost to follow-up.

Table 2.
Characteristics of Management and CKD-related Complications during Follow-up of the Study Cohort and the Two Subgroups

	Total	Nephrology	PCP-only	p-value
Number	1,553	456	1,097	
Days of follow-up (mean)	1,296	1,310	1,285	0.30
Hospitalizations, mean (range)*	2.6 (0-28)	2.8	2.5	0.03
Clinic visits, mean (range)*	141 (7-1,412)	170	129	< 0.001
Lipid lowering agent (%)	39%	43%	38%	0.58
ACEI (%)	52%	51%	52%	0.07
Blood pressure < 135/85(%)$^{\#}$	37%	41%	36%	0.06
HgA1c < 7% (%)$^{\#}$	39%	38%	40%	0.10
LDL < 100 mg/dL (%)$^{\#}$	33%	32%	36%	0.06
Calcium < 8.5 mg/dL (%)$^{\#}$	6%	6%	6%	0.82
Albumin < 4 g/dL (%)$^{\#}$	50%	59%	49%	< 0.001
Hemoglobin < 12 mg/dL (%)$^{\#}$	9%	10%	9%	0.63
Phosphorus > 4.5 mg/dL (%)$^{\#}$	6%	9%	5%	0.006

ACEI=angiotensin converting enzyme inhibitor; HgA1c=hemoglobin A1c; LDL=low density lipoprotein

*This is the average and range of the total number of visits during the follow-up period per patient.

Individual values for each patient were averaged over three-month periods during follow-up. If ≥ 50% of the averages exceeded the recommended goal then the patient was considered uncontrolled. Table reports % of patients who are uncontrolled.

Legend: Medication use is presented as the proportion of the group using the medication for at least six months during the study period. The management of diabetes, hypertension, and hyperlipidemia as well as the complications of CKD are presented as the proportion with 50% or more of their three-month averages outside of the recommended values.

The outcomes of the survival and Cox proportional hazard analyses are presented in Tables 3 and 4 and the curves derived from Cox proportional hazard analysis for each stage are depicted in Figure 1. These show that individuals spent a median of 3.2 years per stage in stages 1, 2, and 3, but only 2.1 years in stages 4-5. There was no difference between the PCP-only and nephrology groups for the unadjusted time spent in stage 1 or stage 2; but for stages 3 through 5 and early to advanced CKD, those in the nephrology group spent 316, 251, 120, and 55 more days, respectively, in each stage than those in the PCP-only group. Of those who reached the composite endpoint, more individuals in stage 1 progressed to the next stage than died, an equal number progressed as died in stage 2, and more progressed than died during stages 3 through 5. At each stage, proportionally fewer individuals in the PCP-only group progressed to the next CKD stage, but more died, than in the nephrology group.

The hazard ratio, an estimate of the relative risk for each covariate, is shown in Table 4. For the stage 4 to 5 model we only incorporated age, race, ACEI use, and anti-lipid medication use because the small number of outcomes limited the number of covariates that could be included in the model. All other models were analyzed with all the prespecified covariates. Nephrology care at stages 3 and 4 and during early CKD improved survival (adjusted HR 0.80, 0.75, and 0.91, respectively). ACEIs transiently reduce GFR as signified by a hazard ratio of greater than 1 for the ACEI started during stage variable; however, long-term they are protective and reduce the rate of progression by almost 40% for stages 1-3 and for pre-ACKD to ACKD. Lipid-lowering agents appear to be protective, whereas diabetes appears to be harmful. Both effects were present across all the stages analyzed. In addition, proteinuria appears to predict a more rapid disease course for pre-ACKD to ACKD. We did not perform the Cox Proportional Hazards analysis for the stage 5 to ESRD group because of its small size, and we excluded comorbid conditions from the stage 4 to 5 analysis because the small number of individuals who reached the endpoint limited the number of covariates that could be analyzed.

Discussion

Our findings suggest that nephrologists' involvement in the care of individuals with CKD is associated with a prolonged course of early CKD and delayed onset of ESRD. Individuals who were followed by a nephrologist in addition to their PCP spent significantly more time in CKD stages 3-5 than those followed only by their primary care providers. This finding lends support to current recommendations for initiation of care by a subspecialist and suggests that referrals may be most beneficial around stage 3.

While our study suggests that the addition of nephrology care around stage 3 may play an important role in prolonging disease course, it does not provide an explanation for why this occurs. In order to gain some insight, we evaluated the management of comorbidities and the presence of chronic CKD-related

Table 3.
Results of the Unadjusted Survival Analyses

	Stage 1 to 2	Stage 2 to 3	Stage 3 to 4	Stage 4 to 5	Stage 5 to ESRD	Pre-ACKD to ACKD
Total Cohort (#)	1,217	887	416	86	26	1,530
CKD progression # (%)	583 (48%)	276 (31%)	70 (17%)	21 (24%)	6 (23%)	94 (6%)
died # (%)	255 (21%)	273 (31%)	205 (49%)	45 (52%)	7 (27%)	701 (46%)
composite endpoint # (%)	838 (69%)	549 (62%)	275 (66%)	66 (78%)	13 (50%)	750 (49%)
Median days spent in stage	1,149	1,206	1,158	794	709	1,961
PCP-only vs Nephrology p-value	0.41	0.32	< 0.001	0.03	NA	< 0.001
PCP-only group #	995	624	209	28	6	1,090
CKD progression # (%)	445 (45%)	156 (25%)	14 (7%)	4 (14%)	1 (17%)	27 (2%)
died # (%)	231 (23%)	217 (35%)	131 (63%)	20 (71%)	2 (33%)	509 (47%)
composite endpoint # (%)	676 (68%)	376 (60%)	145 (69%)	24 (86%)	3 (50%)	536 (49%)
median days spent in stage	1,168	1,247	895	558	655	1,936
Nephrology group #	222	263	207	58	20	440
CKD progression # (%)	138 (62%)	120 (46%)	56 (27%)	17 (29%)	5 (25%)	67 (15%)
died # (%)	24 (11%)	53 (20%)	74 (36%)	25 (43%)	5 (25%)	147 (34%)
composite endpoint # (%)	162 (73%)	173 (65%)	130 (63%)	42 (72%)	10 (50%)	214 (49%)
median days spent in stage	1,127	1,100	1,211	834	776	1,991

Legend: The number with composite endpoint is the number of individuals who either died or had CKD progression. The unadjusted median time to endpoint is the median time to either disease progression or death for that stage.

Table 4.
Adjusted Hazard Ratios (with 95% confidence intervals) from the Cox Proportional Hazards Analysis

	Stage 1 to 2	Stage 2 to 3	Stage 3 to 4	Stage 4 to 5	Pre-ACKD to ACKD
Nephrology vs PCP-only	1.08 (0.91,1.29)	1.20 (0.99,1.45)	0.80 (0.61,0.90)*	0.75 (0.45,0.89)*	0.91 (0.76,0.99)*
Age per 1 year	1 (1.00,1.01)	1.01 (1.01,1.02)	1 (0.98,1.01)	1.02 (1.00,1.04)	1 (1.00,1.01)
Nonwhite vs White Race	0.71 (0.62,0.83)*	0.89 (0.73,1.08)	1.11 (0.83,1.44)	1.24 (0.70,2.10)	0.82 (0.69,0.96)*
ACEI use	1.1 (0.91,1.31)	0.62 (0.51,0.74)*	0.68 (0.56,0.98)*	0.96 (0.56,1.64)	0.53 (0.45,0.63)
ACEI started during stage	0.73 (0.61,0.88)*	1.13 (0.93,1.37)	1.03 (0.77,1.42)	2.14 (0.89,4.58)	NA
Anti-lipid agents use	0.64 (0.55,0.75)*	0.57 (0.45,0.71)*	0.54 (0.40,0.70)*	0.71 (0.39,1.38)	0.46 (0.38,0.54)*
Diabetes	1.32 (1.13,1.55)*	1.18 (0.97,1.43)	1.13 (0.86,1.50)	NA	1.31 (1.10,1.56)*
Hypertension	0.8 (0.66,1.35)	0.93 (0.72,1.57)	0.91 (0.77,1.53)	NA	0.85 (0.78,1.01)
Current Tobacco use	1 (0.82,1.13)	0.79 (0.63,1.00)	0.92 (0.69,1.30)	NA	0.84 (0.70,1.02)
Coronary Artery Disease	1.35 (1.14,1.61)*	1.52 (1.23,1.93)*	0.86 (0.64,1.17)	NA	1.54 (1.27,1.88)*
HgA1c > 7%	1.14 (0.91,1.43)	1.28 (1.01,1.63)*	1.53 (1.08,2.11)*	NA	1.33 (1.04,1.62)*
Positive Urine Protein	1 (1.00,1.00)	1 (1.00,1.00)	1.12 (0.91,1.15)	NA	1.46 (1.26,1.74)*

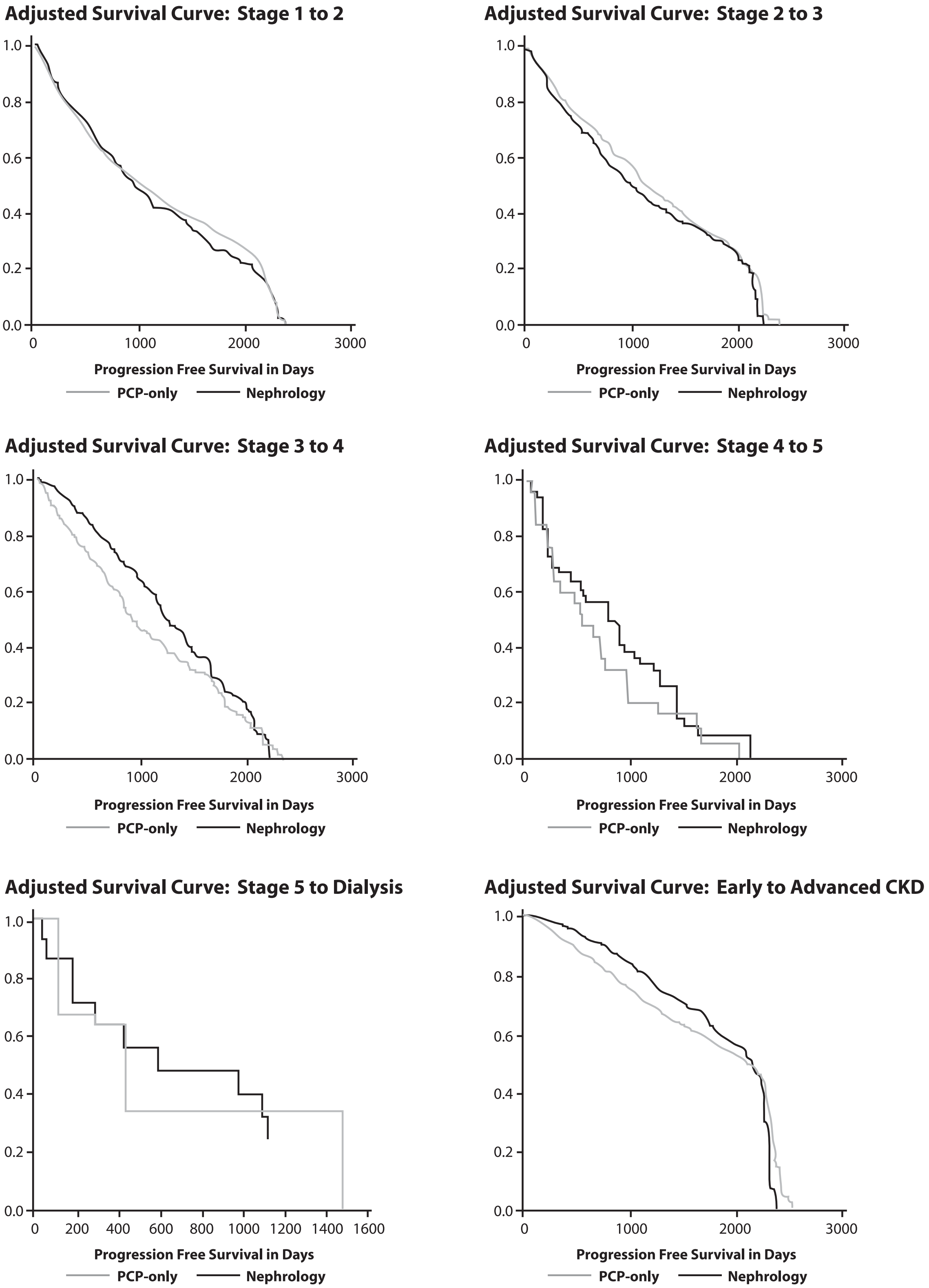
*$p < 0.05$

ACEI = angiotensin converting enzyme inhibitor; HgA1c= hemoglobin A1c

Legend: Hazard ratios > 1 indicate an increased risk of reaching the composite endpoint (death or CKD progression), whereas a hazard ratio < 1 indicates a reduced risk of reaching the composite endpoint. A value of 1 reflects no association between the covariate and the endpoint.

complications between the two groups during follow-up. Both the PCP-only and nephrology groups provided similar levels of control for diabetes, hypertension, hyperlipidemia, hypercalcemia, and anemia; however chronic hyperphosphatemia and hypoalbuminemia were more common in the PCP-only group. In addition, there was greater use of ACEIs in the nephrology group; however, the 1% absolute difference is not clinically significant. It is not possible to distinguish between cause and effect

Figure 1.
Adjusted Kaplan Meier Survival Curves



Adjusted Survival Curve: Stage 1 to 2

Adjusted Survival Curve: Stage 2 to 3

Adjusted Survival Curve: Stage 3 to 4

Adjusted Survival Curve: Stage 4 to 5

Adjusted Survival Curve: Stage 5 to Dialysis

Adjusted Survival Curve: Early to Advanced CKD

Legend: Graphs the survival curve (ie, time to the composite endpoint of death or CKD progression) for the nephrology (solid line) and PCP-only (dashed line) groups during each stage. The x-axis represents the time in days, and the y-axis reflects the proportion of the group that has not reached the endpoint. The curves display the proportion of the initial group that has not reached the endpoint over time. The median time for the group to reach the endpoint is reflected by the time point on the x-axis that corresponds with 0.5 on the y-axis.

with our study design; however, these findings are suggestive, and because nephrologists in practice will not be able to expand their capacity to accommodate all stage 3, 4, and 5 patients (almost nine million individuals), it is imperative that we perform well-designed prospective studies to further investigate the answer to these questions.

Similar to the results of a recently published study,[13] we found that mortality was profound, particularly at higher CKD stages. Only at stages 1 and 2 did fewer individuals die than progress, despite the fact that the percentage of individuals reaching the composite endpoint remained relatively similar across all stages (values for stage 4 and 5 are imprecise due to the few individuals in these two groups). When comparing the nephrology group to the PCP-only group across all stages, fewer individuals in the PCP-only group progressed to a higher stage; however more individuals died. This relationship may be related to a lower referral rate for individuals with comorbidities conferring an increased risk of death, such as cancer. The limitations of our data prevent us from examining this association in more detail.

Previous studies evaluating the impact of nephrology care on renal-related outcomes have focused upon the association between the morbidity and mortality of dialysis and the patterns of pre-ESRD care.[14,15] These retrospective studies consistently found that individuals referred to a nephrologist early had less morbidity and mortality than those referred late, however early referral was dichotomized (ie, before or after a prespecified cut-off time), the definition varied (one month to one year predialysis), and the findings were not generalizable to pre-ESRD populations. This is the first study to evaluate a CKD population in various stages of disease over an extended follow-up time. By performing a study to investigate the impact of nephrology care at each CKD stage, we were able to more closely assess the impact of a nephrologist on mortality and progression in those with pre-ESRD who receive medical care by primary care physicians. This is an important distinction since the impact of recommending early referral will be limited to those already receiving medical care. It will not affect those who receive no pre-ESRD medical care.

The retrospective design of our study raises the possibility that the difference in outcomes between the two groups may have been related to unmeasured variables or bias in patients referred to nephrologists. We attempted to account for this possibility by using a propensity score to adjust the analysis. Propensity scores are able to improve upon statistical analysis in potentially biased populations, but they are still subject to the problems of unmeasured bias. The average stage at referral, 1.6, is quite low, indicating that most patients seen by subspecialists were referred during their earliest stages and that crossover between the nephrology and PCP-only groups at later stages was limited. The study design also prevented us from controlling loss to follow-up; however, only 133 of the original 1,553 individuals transferred out of the system, and there was excellent long-term follow up, averaging 3.5 years.

The population we studied limits the generalizability of our results to other veterans since VA populations may be different than non-VA populations and the patterns of care may also be different. In particular, patients tend to have more comorbidities with more severe disease. Referrals may take longer and follow-up by subspecialists may not be as close as in other systems. In addition, we were unable to determine if an individual received care from a non-VA nephrologist or if they received medications outside of the VA, although both are uncommon in our experience. To address this concern, we performed an informal survey of primary care providers at the Durham VA and a limited chart review for 50 patients in each group. The informal survey found that providers believed only 1-2% of their patients may obtain additional care outside of the VA and that less than 1% obtained medications outside the VA. The chart review did not identify any patients with either care or medications from outside the VA.

Our study suggests that the addition of subspecialty care to standard care by a PCP around CKD stage 3 may improve outcomes. However, well-designed prospective studies should be performed to further clarify the role and timing of nephrologist care in the management of patients with CKD. If the relationship is supported by additional studies, the reason for the phenomenon could have important clinical and health policy implications. If it is attributable to care that requires nephrology training or is otherwise only feasible in the context of a nephrology practice, then we will need to train more nephrologists. However, if some or all of the effect can be attributed to activities that can be incorporated into PCP practice, then PCPs will need to become more adept at these activities. **NCMJ**

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Attitudes about Tobacco Policies among North Carolina Parents

Kelly L. Kandra, MA; Adam O. Goldstein, MD, MPH; Ziya Gizlice, PhD; Robert L. Woldman, MA; and Scott K. Proescholdbell, MPH

Abstract

Background: *While tobacco use reduction remains a major public health goal, little evidence exists on how citizens in North Carolina view policy issues related to tobacco control. This research examines attitudes toward tobacco policies among North Carolina parents.*

Methods: *Randomly selected North Carolina adults with a child living in his or her household were invited to participate in the Child Health Assessment and Monitoring Program (CHAMP) telephone survey. A sample of 3,973 parents or guardians was interviewed in 2005. Support for tobacco prevention and policies was analyzed by demographic characteristics.*

Results: *Of the 86% of initial respondents who were eligible to participate, 83% completed the 2005 CHAMP survey. Most parents in North Carolina (90.1%) support stronger policies for tobacco prevention. Parents also strongly support restrictions on tobacco in schools (85.6%) and recreational areas and fast food restaurants (83.9%). While many parents report being well prepared to talk to their children about smoking (97.6%) and report talking about the dangers of smoking monthly (84.7%), few report that their child currently smokes (3.9% of high school students and 0.6% of middle school students).*

Limitations: *Because the CHAMP survey is telephone-based, the results are limited to North Carolina parents who have a land-line telephone.*

Conclusions: *Despite the state's historical ties to tobacco, the overwhelming majority of North Carolina parents are in favor of stronger efforts at tobacco use prevention, including increased policy measures. These results suggest that prevention efforts should be expanded and that policy makers who take a stronger stance against tobacco will most likely receive broad support by North Carolina parents.*

Keywords: *parents, tobacco control, smoking restrictions, media campaigns*

Introduction

Smoking is the leading cause of preventable death in the United States and is attributable to over 400,000 deaths each year.[1] In North Carolina, it accounts for more than 11,500 deaths a year at a cost of $1.9 billion in direct medical expenditures.[2] In 2002, North Carolina's Medicaid costs associated with smoking were estimated to be more than $940 million.[3] According to recent survey research conducted by the North Carolina State Center for Health Statistics, 22.6% of North Carolina residents over the age of 18 are current smokers, giving the state a higher adult smoking rate than two thirds of states nationwide.[4]

In an effort to combat death and disease attributable to cigarette

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smoking, the Centers for Disease Control and Prevention (CDC) recommends that each state establish a comprehensive tobacco control program.[5] Comprehensive programs should not only encourage youth and adults to quit, but they should also focus on youth prevention of tobacco use and eliminating exposure to secondhand smoke. Policy research shows that for every 10% increase in the price of cigarettes, a 3 to 5% decrease in cigarette consumption occurs among adults and even higher reductions in consumption are seen among youth;[5] mass media anti-smoking campaigns can reduce the number of teens smoking across the country;[6] and enacting 100% tobacco free school policies can significantly reduce environmental exposure to secondhand smoke in the school setting.[7] Despite the evidence supporting these (and similar) efforts across the United States, significant barriers exist to tobacco prevention, including preemption (state laws encouraged by the tobacco industry that prevent strong local regulations) and lack of funds to sustain tobacco-prevention programs.[5]

Stakeholders in tobacco farming and production also inhibit policy measures, particularly in tobacco-producing states.[8] Despite significant declines, North Carolina remains the largest tobacco-producing state in the country, employing approximately 13,000 people in tobacco-related jobs, including 4,100 tobacco farmers.[9] While the economic impact of tobacco farming in North Carolina has declined significantly, the impact from tobacco manufacturing remains substantial, representing over one half of all United States tobacco manufacturing activity.[9] It is no surprise then, that North Carolina policy makers have traditionally not supported strong regulations on tobacco use.[8] For example, in 1993 the North Carolina legislature passed a "preemption" law that required state-controlled buildings to have 20% of the indoor space allocated for smoking and eliminated the ability of local governments to ban smoking in most public places.[3] Until recently, North Carolina ranked 50th in the country in its tobacco excise tax rate.[10]

Within the last few years, support for the tobacco industry among policy makers in North Carolina has begun to decline, resulting in stronger support for state tobacco control policies. Legislation to raise the state tobacco excise tax from 5¢ to 30¢ passed the North Carolina legislature in 2005, with an additional increase of 5¢ taking effect in July 2006.[10] Within the last two years public health advocates successfully expanded the number of venues with the ability to eliminate tobacco use (ie, schools, health departments, hospitals, social service agencies, and the General Assembly).[11] Perhaps the most significant example of the state's changing atmosphere is the decision to invest state tobacco settlement money into the prevention of tobacco use by adolescents.[2] From 2003 to 2004, the state, through its Health and Wellness Trust Fund, invested $6.2 million in its teen tobacco use prevention and cessation programs, with an increased investment to $15 million in 2005-2006. While this investment is far less than the CDC recommends for comprehensive state programs, the investment did move North Carolina from near the bottom nationally in state spending on tobacco control to near the middle within a short period of time.

Little data exists about the attitudes that North Carolina citizens have toward tobacco policies and regulation. A recent North Carolina public opinion poll found that almost two thirds of those interviewed supported a statewide ban on smoking in public places, suggesting that the attitudes of many citizens may have shifted even more strongly than that of policy makers.[12] This study provides insight into how a random sample of approximately 4,000 North Carolina parents who have children under the age of 18 feel about various tobacco-related policy issues.

Methods

This study uses data from the 2005 Child Health Assessment and Monitoring Program (CHAMP) survey conducted by the North Carolina State Center for Health Statistics (SCHS). The CHAMP survey is a follow-up to the North Carolina Behavioral Risk Factor Surveillance System (BRFSS), a random, telephone survey of noninstitutionalized adults 18 years of age and older. Telephone numbers are generated from a computer in groups of 100 consecutive phone numbers that contain at least one published household telephone number. The telephone number groups are then assigned to two strata: (1) high density or listed numbers and (2) low density or unlisted numbers. The listed numbers are sampled at a higher rate than unlisted numbers in an effort to lower cost and improve interviewer efficiency. Data collection for the BRFSS is ongoing throughout the year, with interviews conducted 7 days per week at varying times of the day.

While the BRFSS is a national surveillance system, the CHAMP survey is unique to North Carolina. The CHAMP survey allows all adult respondents in North Carolina who completed the BRFSS survey and have children living in their household to participate in a supplemental survey. One child in each household was randomly selected through a computerized randomization procedure and the adult identified during the BRFSS interview as most knowledgeable about the health of the selected child was interviewed in the follow-up CHAMP survey. Approximately one week after completion of the BRFSS interview, an SCHS interviewer would begin to attempt to contact the household for the CHAMP survey. During the 2005 data collection period, 86% of BRFSS households agreed to participate in the CHAMP survey, with 83% of those households completing the survey. The final CHAMP sample size was 3,973 North Carolina parents or guardians.

The purpose of the CHAMP survey is to measure the health characteristics of North Carolina children, ages 0 to 17. The survey measures a wide variety of health-related topics affecting children and parents, including breast feeding, early childhood development, access to health care, oral health, mental health, physical health, nutrition, physical activity, family involvement, and parent opinion on topics such as tobacco and childhood obesity. The majority of questions on the CHAMP survey originate from pre-existing telephone surveys from the National Center for Health Statistics.

The data presented in this report are population-weighted responses to the tobacco-related questions, with corresponding 95% confidence intervals. The use of weighted data adjusts the results of the sample to better represent the entire population of North Carolina. Adjustments are made to account for the unequal probabilities of selection due to the disproportionate sampling method and due to people living in households with different numbers of residential telephone numbers and different numbers of children in the home, as well as unequal nonresponse rates among different demographic groups. The tobacco-related questions on the CHAMP survey reflect opinions about policy measures and initiatives that are currently being debated on a local and state level, as well as questions assessing parental knowledge of their child's cigarette use.

Results

The demographics of the parents who answered the tobacco-related questions showed that approximately 11% were male, 71% were white, and 32% of households had at least one college graduate living in the home.[a]

Parents were asked about their children's smoking behavior and their own efforts to educate their children about the ill effects of smoking. When asked about whether or not their child had ever smoked cigarettes, 16.9% (95%, CI 14.2 to 20.0) of parents of high school aged students responded that their child had ever smoked, and only 3.9% (95%, CI 2.37 to 5.44) reported that their children currently smoked cigarettes. Parents of middle school students responded that 5.1% (95%, CI 3.4 to 7.5) of their children had ever smoked cigarettes, and only 0.6% (95%, CI 0.0 to 1.5) reported that their children currently smoked. Parents reported that they were well prepared to talk to their children about the dangers of tobacco use, with 97.6% (95%, CI 96.9 to 98.1) responding that they felt well prepared to talk to their children about ways to reduce their children's chances of smoking. A similarly high percentage, 84.7%, (95%, CI 82.7 to 86.6) reported talking to their children at least once a month about the dangers of tobacco use.

Parents in this survey were also asked to give their opinions on various tobacco policies and initiatives in North Carolina (see Table 1). Parents reported that they were strongly in favor of making tobacco use prevention more of a priority in the state, with 90.1% (95%, CI 88.8 to 91.2) of North Carolina parents surveyed responding that it was very important for the state to take additional actions to prevent and reduce tobacco use among North Carolina youth. One such action, making their child's school 100% tobacco free, was strongly supported by 85.6% (95%, CI 84.3 to 86.9) of parents. Similarly, 83.9% (95%, CI 82.5 to 85.3) of the parents strongly supported making all indoor recreational areas and fast food restaurants tobacco free. An increase in the state excise tax on cigarettes, as a way to reduce youth tobacco use, was strongly supported by 67.2% (95%, CI 65.4 to 69.0) of the parents surveyed, with only 12.7% (95%, CI 11.4 to 14.0) of the parents reporting that they did not support any increase in the state excise tax on cigarettes. While there was some variability across demographic categories, the majority of parents, regardless of the highest level of education in the household or age or race of their child, supported these policy measures (see Table 1).

Results from the CHAMP survey revealed that 58.4% (95%, CI 38.9 to 44.2) of the parents said they had seen or heard about the state-funded Tobacco.Reality.Unfiltered. (TRU) tobacco prevention media campaign at least once. Approximately one third, 36.0% (95%, CI 33.4 to 38.6), of the parents surveyed reported hearing about or seeing the campaign at least three times in the past year (see Figure 1).

Discussion

In North Carolina and neighboring states, for most of the latter half of the 20th century, economic ties to tobacco farming and the tobacco industry have limited the extent of many public health initiatives against tobacco.[8,13-15] In the last few years, coincident with the declining influence of the tobacco industry, policy makers have begun to take stronger stances on tobacco regulation with legislative gains occurring in many areas of the country, even in historically strong tobacco-producing regions.[11,13,14] One study in a tobacco-producing state found that citizens in the state were more likely to support restrictions on smoking in public places than legislators.[15] Support for stronger tobacco regulation occurs at the same time as support grows for helping tobacco farmers diversify away from tobacco farming. In one national sample, 57% of respondents supported government involvement in helping tobacco farmers try new farming ventures.[16]

While North Carolina is still the nation's largest producer of tobacco, the results of this survey indicate that parents in the state have strong opinions about tobacco and its health effects. Although it is reassuring to know that over 8 out of 10 parents state that they talk about the dangers of tobacco use with their children on a monthly basis, North Carolina parents appear to dramatically underestimate or are unaware of the likelihood of their own children's use of cigarettes. Published surveys of North Carolina youth document that 5.8% of middle school students and 20.3% of high school students currently smoke cigarettes, rates much higher than that reported by parents in the CHAMP survey.[17,18] Previous research has indicated that parents do underestimate their children's cigarette use.[19,20] It is likely that if parents were more aware of their children's smoking behavior, support for tobacco prevention policy measures would be even higher than that reported in the CHAMP survey. Further research would also be useful to assess parental estimates about their child's use of other types of tobacco products, including spit tobacco (chewing tobacco or snuff). Currently, the CHAMP survey only assesses cigarette use. Since the children of the parents surveyed were not interviewed, additional studies are needed to explore the relationship between reports of

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[a] Demographics vary slightly across questions due to skip patterns in the survey or respondent's refusal to answer.

Table 1.
Support Among North Carolina Parents for Strengthening Tobacco-Related Policies Affecting Youth

	How important do you think it is for North Carolina to take additional actions to prevent and reduce tobacco use among our youth? **% very important (95% CI)**	*To what degree do you support a 100% tobacco free policy in your child's school?* **% strongly support (95% CI)**	*To what degree do you support a tobacco free policy in indoor recreational areas and fast food restaurants?* **% strongly support (95% CI)**	*To what degree would you support increasing the tax on cigarettes in North Carolina to reduce youth access* **% strongly support (95% CI)**
Total	90.1% (88.8 – 91.2%)	85.6% (84.3 – 86.9%)	83.9% (82.5 – 85.3%)	67.2% (65.4 – 69.0%)
Gender of child				
Male	90.2% (88.4 – 91.7%)	85.5% (83.5 – 87.3%)	83.7% (81.6– 85.6%)	67.1% (64.5 – 69.6%)
Female	90.0% (88.1 – 91.5%)	85.8% (83.8 - 87.6%)	84.2% (82.1 – 86.1%)	67.4% (64.7 – 69.9%)
Age groups				
Under 5	89.7% (87.2 – 91.8%)	88.5% (86.0 – 90.6%)	86.6% (83.9 – 88.9%)	66.9% (63.3 – 70.4%)
5 – 10	89.9% (87.7 – 91.8%)	84.9% (82.3 – 87.2%)	84.3% (81.7 – 86.6%)	70.2% (67.0 – 73.2%)
11 – 13	90.9% (87.7 – 93.4%)	85.9% (82.3 – 88.8%)	83.5% (79.9 – 86.6%)	66.9% (62.4 – 71.1%)
14 – 17	90.0% (87.4 – 92.1%)	83.1% (80.0 – 85.8%)	80.5% (77.3 – 83.4%)	63.4% (59.5 – 67.0%)
Race of child				
White	88.7% (87.2 – 90.2%)	84.7% (83.0 – 86.3%)	83.9% (82.2 – 85.5%)	64.9% (62.7 – 67.1%)
Black	92.3% (89.8 – 94.3%)	86.7% (83.6 – 89.2%)	84.0% (80.7 – 86.8%)	70.0% (66.0 – 73.7%)
Other	93.6% (89.8 – 96.0%)	89.8% (85.4 – 93.0%)	83.7% (78.7 – 87.7%)	77.7% (72.3 – 82.4%)
Highest education achieved in household				
Less than high school	93.2% (88.7 – 96.0%)	85.8% (79.7 – 90.3%)	82.3% (76.0 – 87.3%)	73.0% (66.0 – 79.0%)
High school	89.2% (86.3 – 91.5%)	82.7% (79.5 – 85.5%)	78.8% (75.3 – 81.9%)	58.9% (54.9 – 62.8%)
Some college	91.5% (89.2 – 93.4%)	81.2% (78.1 – 84.0%)	78.8% (75.6 – 81.7%)	61.2% (57.4 – 64.8%)
College graduate	89.1% (87.1 – 90.8%)	89.5% (87.6 – 91.1%)	89.6% (87.7 – 91.2%)	73.8% (71.2 – 76.3%)

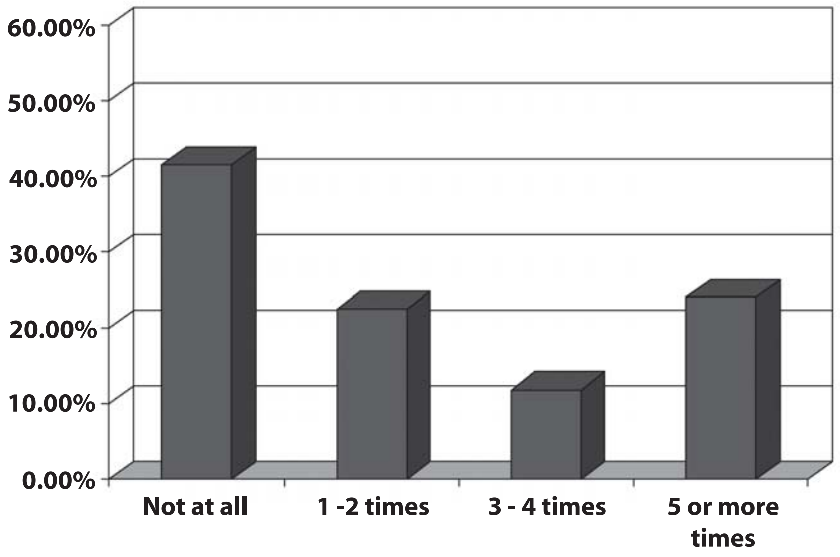
parental awareness of their children's smoking behavior and children's actual smoking behaviors.

The CHAMP data indicate that parental opinions extend from its effects on their own children to statewide public policy. Parents indicate strong support for policy makers to take increased steps to regulate tobacco products, decrease exposure to secondhand smoke, and spend more funds to accomplish both. These policy actions include increasing the state's tobacco excise tax, adopting regulatory measures for 100% tobacco-free schools, and adopting regulatory measures for 100% smoke-free environments in restaurants and recreational facilities. Strong support for policy actions was shown across the board and did not depend on the highest level of education in the household, race, or age of child.

This data, combined with results from a recent statewide poll, support the conclusion that citizens in the state are increasingly likely to demand more attention be paid to decreasing involuntary exposure to secondhand smoke.[12] One recent study of seventh and eighth graders in North Carolina public schools found that 15% of the asthma cases reported were caused by exposure to secondhand smoke.[21] A positive development is that in the last two years an increasing amount of North Carolina public school districts have adopted 100% tobacco-free school policies.[7] With the United States Surgeon General recently reporting that there is no safe level of exposure to secondhand smoke, the complete elimination of exposure to secondhand smoke in schools and public venues is a justified concern of all parents.[22] While statewide legislation can achieve significant reductions in secondhand smoke exposure, in North Carolina, the state's preemptive smoking law needs to be repealed in addition to policy makers adopting a comprehensive measure.[22,23]

North Carolina policy makers have already decided to invest significant resources into youth tobacco use prevention and cessation through the North Carolina Health and Wellness Trust Fund and its teen tobacco programs.[24] A major component of that program is a statewide media campaign, *Tobacco.Reality.Unfiltered.* or TRU. The CHAMP data indicate that parents have tuned in to this statewide television campaign to prevent youth tobacco use. The TRU campaign began television advertisements targeting youth across the state in 2004 and features real stories from North Carolina youth about

Figure 1.
How frequently in the last year have you heard about or seen the North Carolina *Tobacco.Reality.Unfiltered.* (TRU) media campaign?



tobacco experiences, illnesses, and diseases of their loved ones. While the campaign is directed at youth, the stories featured in the ads are also the stories known by North Carolina parents. The CHAMP survey suggests that the ads do reach parents, and thus, the ads may have a positive effect on parental attitudes against tobacco use by their children. Future research could assess the degree to which the TRU campaign may affect adult as well as youth tobacco attitudes.

A couple of limitations to the data and analysis exist. Despite parents reporting that they were strongly in favor of increased policy measures for tobacco prevention, these questions were asked in isolation. It is possible that if parents were asked to compare the priority for tobacco prevention to other policy issues in the state, the results may be different. It is also possible that parents' smoking status may be related to support for policy measures. Unfortunately, the data collection methods of the BRFSS and CHAMP surveys prohibit this relationship from being explored. While smoking status is assessed on the BRFSS, there is no guarantee that the person who responded to the BRFSS survey is the same person who participated in the CHAMP survey as the person most knowledgeable about their child's health. A final limitation is one common to all telephone surveys—the pool of respondents is limited to only those who have a land-line telephone. Even though the telephone numbers are randomly selected and the data is weighted to represent all North Carolina parents, there are some limits to its generalizability as a result.

While this is the first CHAMP survey of parental attitudes of tobacco policies in North Carolina, its findings clearly indicate that most North Carolina parents have moved beyond traditional pro-tobacco attitudes and are in favor of tobacco use prevention for their children and increased policy measures for the state. Current parental attitudes about tobacco suggest that policy makers who take a stronger stance against tobacco use will likely receive broad parental support in the state. **NCMJ**

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Appendix A. Questions Used in Analysis

Parent Opinon

1. How important do you think it is for North Carolina to take additional actions to prevent and reduce tobacco use among our youth? Very important / Somewhat important / Not at all important
2. To what degree do you support a tobacco free policy in your child's school so that no one, not students, nor teachers, staff or visitors, could smoke or use other tobacco products on the school grounds at any time? Strongly support / Moderately support / Do not support
3. To what degree do you support a tobacco free policy in indoor recreational areas (skating rinks, bowling alleys) and fast food restaurants where your child plays, works or eats? Strongly support / Moderately support / Do not support
4. To what degree do you support increasing the tax on cigarettes in North Carolina to reduce youth access to tobacco in our state? Strongly support / Moderately support / Little support / Don't support
5. Do you feel well prepared to talk with (CHILD) about reducing the chances of smoking? Yes / No / Don't know or Not Sure

Tobacco Indicators

1. How often have you discussed the dangers of tobacco use with (CHILD) in the last 12 months? Once a day / Once a week / Once a month / Once a year / Don't know or not sure / Never
2. To your knowledge, has (CHILD) ever smoked cigarettes? Yes / No / Don't know or not sure
3. To your knowledge, does (CHILD) currently smoke cigarettes? Yes / No / Don't know or not sure
4. How frequently in the last year have you heard about or seen (on TV, from your children, or in other media) the North Carolina *Tobacco.Reality.Unfiltered.* (TRU) media campaign directed to preventing tobacco use among youth? Not at all / Once or twice in the last year / Three or four times / Five times or more / Don't know or not sure

ARTICLE

Patient Attitudes toward Screening

Denise E. Bonds, MD, MPH; Shellie D. Ellis, MA; Erin Weeks; Peter Lichstein, MD; Kim Burke; and Chris Posey

Abstract

Background: *Physician organizations recommend screening for health care behaviors. Despite these recommendations, health care providers worry that questions on sensitive topics may not be accepted by their patients. To determine if there is a relationship between health care screening by providers and acceptance of that screening by patients, a survey of female patients was analyzed.*

Method: *Two telephone surveys were conducted two years apart. Each was a cross-sectional sample of female patients over the age of 18 years who had been seen by their primary care provider (PCP) in the previous 12 months. Patients were asked if they had been screened for eight different health behaviors (exercise, smoking, use of alcohol or drugs, excessive stress, sexual functioning concerns, safety or violence in the home, guns in the home) in the past year. They were also asked about their attitudes toward screening for those behaviors by health care providers. Odds ratios were calculated for patients who both agreed that screening should occur and reported having been screened in the last year.*

Results: *3,175 women were surveyed. There was high acceptance of routine screening for exercise (75%), smoking (72%), alcohol/drugs (68%), and stress (62%), but less for sexual functioning (40%), safety/violence (40%), or guns (23%). There was a higher likelihood of agreeing with routine screening if the patient reported having been screened in the past year: exercise (OR 2.3, 95% CI 1.8-2.9), smoking (OR 1.6, 95% CI 1.3-1.9), alcohol/drugs (OR 2.3, 95% CI 1.9-2.7), stress (OR 1.7, 95% CI 1.4-1.9), sexual functioning (OR 2.7, 95% CI 2.2-3.4), safety/violence (OR 3.4, 95% CI 2.8-4.2), and guns (OR 4.4, 95% CI 3.4-5.8).*

Limitations: *Only women in established relationships with primary care providers were surveyed. The cross-sectional nature of the survey prevents determination of the causality of the relationship.*

Conclusion: *Women who had been screened for a health behavior had greater acceptance of routine screening for that behavior. Although further research is needed to determine the casual relationship, providers should not worry about offending their patients when screening for sensitive health behaviors.*

Introduction

Physician organizations recommend screening patients for risky health behaviors to reduce morbidity and mortality and to increase quality of life. Behaviors such as smoking, alcohol and drug use, and sedentary lifestyle have been strongly associated with increased morbidity and mortality.[1,2] Evidence suggests that routine screening with appropriate follow-up counseling can improve health outcomes.[3,4] Although there is less evidence for routine screening for other health behaviors or risks, such as guns in the home[5] and domestic violence,[6] many professional societies advocate for their incorporation into routine clinical practice on other grounds.[7]

Despite the evidence and encouragement to conduct screening, rates vary by physician specialty, physician gender, health behavior, and patient race.[8-15] Multiple factors have been shown to contribute to this variability. Studies have shown that physicians' perception of the ease of the intervention, the intervention's potential to

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improve health outcomes, the health care providers' personal beliefs or practices, and their acceptance and comfort in asking about sensitive topics all influence screening rates.[8,12,13,15-24] Moreover, patients may have varying attitudes toward screening.[25,26]

Researchers have not fully elucidated the relationship between patient attitudes and provider practice. Health care providers may be less likely to screen if they sense disapproval or discomfort from their patients on particular health subjects. This reluctance to screen for fear of offending has been best documented in the literature with regard to screening for domestic violence.[27] With the increasing shift in the delivery of health care toward a consumer-oriented model and an emphasis on patient satisfaction as a measure of health care quality, providers may avoid asking questions on topics they view as sensitive to avoid lowering patient satisfaction. This fear may result in decreased health care quality if providers miss an opportunity to provide appropriate referral and assistance to patients, thus reducing the effectiveness of the patient-provider relationship. Conversely, patients' attitudes toward questions on sensitive topics may change with routine screening due to normalization of the behavior as a health risk. Patient satisfaction with and trust in their health care provider may increase as providers explore topics that patients did not link with their medical condition but may ultimately impact their health or quality of life. To determine if routine screening was associated with increased patient acceptance, we analyzed patient survey data from Providers Asking About ViolencE (Project PAAVE), a practice-based intervention to increase screening for domestic violence.

Methods

Project PAAVE was designed to increase the rate of screening for domestic violence by primary care providers. For this study, primary care providers were defined as academic or community-based internal medicine, family medicine, or obstetrics and gynecology practices with at least two providers. PAAVE was a multi-modality intervention conducted in western North Carolina that included both standardized educational sessions at the beginning and throughout the 18-month intervention period and components customized to the needs of participating practices. The intervention was evaluated through a pre/post telephone survey of female patients seen within the last 12 months at the practice. To protect women who were in violent situations, the question on screening for violence in the home was embedded in a larger questionnaire. This report utilizes the data collected in the additional questions asked of patients. The study was reviewed and approved by the Institutional Review Board at Wake Forest University School of Medicine.

Survey

A previously validated survey was used.[28-30] This survey was developed for use in the federally supported Women's Health Centers of Excellence and has been tested in over 1,000 female patients with an alpha of 0.95 for the measure of comprehensiveness of care that include the screening questions used in this analysis.[30] Patients were asked about their experiences being screened for particular health behaviors/risk factors, their medical utilization patterns, and other demographic information. Smoking, the use of alcohol or drugs, exercise, a gun in the home, concerns about safety or violence at home, family or relationship concerns, sexual functioning, and stress management were the health behaviors/risk factors included in the survey. Response options were "Yes," "No," and "Don't know." Patient demographic factors included age, marital status (married or marriage-like relationship versus not married), race (white, nonwhite), income (less than $25,000, $25,001 to $50,000, $50,001 to $75,000, greater than $75,001), and medical insurance (any, none). Medical utilization questions included the number of visits for any type of health care in the previous year, type of provider seen (family or general practitioner, internist, gynecologist, physician assistant, or nurse practitioner), and the gender of the health care provider.

To ascertain patient attitudes about the types of screening questions asked by health care providers, eight additional questions were added to the survey. The attitude questions mirrored the health behaviors/risk factors already included in the survey. Patients were asked if they thought providers *should* ask patients about smoking, use of alcohol and drugs, exercise, guns in the home, concerns about safety or violence in the home, sexual functioning concerns, and if they are under excessive stress. Four options were provided: "Yes, at every visit;" "Yes, once a year;" "Yes, if there is a reason;" and "No." We defined routine screening as screening that occurred regardless of a whether the condition is clinically apparent. For the purpose of these analyses, we defined acceptance of routine screening as either the response "Yes, at every visit" or "Yes, once a year."

Patients

Each clinic was asked to supply a list of at least 400 female patients who had been seen in the last year. One clinic was unable to compile a list of 400 patients, so all patients on its list were called. To be eligible for the survey, the patient had to be over the age of 18 years, speak English (due to lack of bilingual staff), be able to understand and respond to questions, and have been seen in the clinic in the previous 12 months. The training of the health care providers occurred during September 2002 to November 2002. Women interviewed at baseline were randomly sampled from women with a visit to any one of the participating health care providers between September 2001 and August 2002. Those women interviewed for the follow-up were drawn from a new pool of women who visited a health care provider between July 2003 and June 2004. Although it was possible for a patient to appear on both lists and participate in both surveys, no attempt was made to track patients between the two surveys. Patients were selected for inclusion using a random number table, then contacted by telephone and asked to participate. At least three attempts at different times of the day were made to contact the participant. If a selected patient was not reached or refused, the next consecutive patient was attempted. This sequence was continued until 100 completed surveys were obtained from each clinic at each point in time (baseline and follow-up; total from each clinic n = 200).

Statistical Analysis

Analyses were performed using STATA version 8.0 (Stata Corp, College Station, TX). Each survey (baseline and follow-up) was analyzed separately and then the data sets were combined. Generalized estimating equations were used to account for the effect of clustering by clinic site. The unadjusted effect of recent screening for the health behavior on acceptance of each specific health behavior was examined (eg, recent screening for exercise on odds ratio of agreeing with routine screening for exercise). We then adjusted for patient and practice characteristics. Specifically, we modeled the odds ratio of agreeing with routine screening as a function of having been screened in the past year after adjusting for age, marital status, race, income, insurance, PCP gender, PCP type, number of visits, and clustering by clinic. Possible variation by survey year was accounted for by inclusion of a variable for survey time in all models.

Results

Practices

Seventy-nine practices were contacted by mail or phone during the three-month recruitment period. Seventeen academic (n = 5) and community-based (n = 12) primary care practices were recruited, among them four internal medicine, 11 family, and two obstetric and gynecology practices. Two practices are excluded from our analysis. One practice dropped out after the initial training session and one closed shortly after the study began (both community-based family practices).

Patients

Approximately 6,000 patient names at each time point were randomly selected for inclusion in the study (pre: 6,319; post: 5,967). Only three attempts (one each in the morning, afternoon, and evening) were made to reach each participant; thus a large number of potential participants were contacted but not reached. (pre: 3,962 - 62%; post: 3,718 - 62%). Six hundred and fifteen patients (pre: 310; post: 305) were reached but did not meet inclusion criteria due to reasons including inability to understand questions, male gender, age less than 18 years, no clinic visit in the previous year, and inability to speak English. Eight hundred and thirteen (pre: 403; post: 410) were reached but refused to participate. The resulting number of women included in the analyses described in this paper is 3,175 (pre: 1,534; post 1,641, overall response rate 26%). No information is available on the non-responders. The median age was 48 years, about one third stated they were of non-white race, and half said they were married or living with a partner (see Table 1). Nearly half reported their income was less than $25,000 per year and nearly all had some type of insurance. Most participants stated they were seeing a family medicine physician, and more than half of the health care providers were female. The mean number of visits to any health care provider was 7.7.

Survey Results

When participants were asked whether physicians should screen for particular health behaviors or concerns, most agreed that physicians should routinely ask about exercise, smoking, use of drugs or alcohol, and if they are under excessive stress (see Table 2). Fewer participants felt that health care providers should routinely screen for sexual functioning concerns, safety or violence in the home, and guns in the home. Respondents did feel that sexual functioning and safety and violence in the home were questions that should be asked if the provider had a reason. Most respondents felt that physicians should not ask about guns in the home.

When asked about previous health behavior screening by their primary care provider in the past year, most recalled having been asked about exercise, smoking, use of drugs or alcohol, and the level of stress in their lives (see Table 2). Fewer stated their physicians had discussed sexual functioning concerns or safety and violence in the home. Only 7% of participants recalled having a discussion about guns in the home. Previous health behavior screening was highly associated with participants' attitudes toward screening in all seven areas (see Table 3).

Table 1.
Description of Sample Population

	N = 3,175[a] % (N)
Age (mean)	48 years (SD 17 years)
Nonwhite race	35%
Married/living with partner	51%
Income	
< $25,000	49%
$25,000 - $50,000	26%
$50,001 - $75,000	14%
> $75,000	11%
Working full or part time	42%
Any health insurance	90%
PCP[b] type	
Family Medicine	62%
Internal Medicine	18%
Obstetrics/Gynecology	8%
Midlevel	8%
Other	4%
Female PCP	51%
Number of visits in last year (mean)[c]	7.7 (SD 10)

[a] Some participants opted not to answer all questions (age n = 10, race n = 81, marriage status n = 22, income n = 571, work status n = 18, health insurance n = 3, PCP type n = 226, PCP gender n = 88, visits n = 76. The percentages in the table are of those that responded.

[b] Primary care provider

[c] To any health care provider

Table 2.
Attitude toward Health Care Screening and Rates of Screening in the Past 12 months

Screening Question:	Yes, at every visit			Yes, once a year			Yes, if there is a reason			No			Participant asked in past year[d]		
	Pre	Post	Both	Pre	Post	Both	Pre	Post	Both	Pre	Post	Both	Pre	Post	Both
Health care providers should ask their patients if they…															
Exercise	48%	48%	48%	29%	25%	27%	20%	23%	21%	4%	4%	4%	72%	71%	72%
Smoke	37%	48%	43%	34%	25%	29%	26%	24%	25%	3%	3%	3%	56%	69%	63%
Use alcohol or drugs	43%	43%	43%	28%	21%	25%	26%	30%	28%	2%	5%	4%	41%	60%	50%
Are under excessive stress	44%	45%	45%	19%	12%	16%	35%	39%	37%	2%	3%	3%	42%	38%	40%
Have sexual functioning concerns	16%	18%	17%	22%	24%	23%	41%	40%	41%	21%	18%	20%	21%	23%	22%
Have concerns about safety or violence in the home	20%	27%	23%	17%	15%	16%	49%	45%	47%	14%	13%	14%	16%	26%	21%
Have a gun in the home	11%	11%	11%	12%	12%	12%	24%	25%	24%	53%	53%	53%	6%	8%	7%

[d] Answered “Yes” to the question “In the past 12 months has a doctor or other health professional discussed with you…?”

Those participants that recalled having been screened for a particular health behavior in the previous year were more likely to agree that health care providers should screen for that health behavior at either every visit or at least once a year. For example, those participants who had been screened for exercise in the last year were more likely to answer “Yes, at every visit” or “Yes, once a year” to the question “Should health care providers ask their patients if they exercise?” This association was stronger for those issues that had relatively low level of acceptance for routine screening: sexual functioning concerns, safety or violence in the home, and guns in the home. The association remained after adjustment for patient demographics (age, marital status, race, income, insurance), provider characteristics (gender, specialty), number of visits, clustering by clinic, and survey year (see Table 3). When the response “Yes, if there is a reason” was excluded and the analyses rerun, the association of previous screening with acceptance of screening was even stronger, particularly for the three most controversial questions: sexual functioning concerns (adjusted OR 5.8, 95% CI 3.5-9.4), concerns about safety or violence in the home (adjusted OR 5.6, 95% CI 3.9-8.1), and guns in the home (adjusted OR 6.5, 95% CI 4.7-9.1).

When the characteristics of participants who answered “No” to the questions about whether physicians should screen were examined, these individuals were generally older, less likely to be married, more likely to state their income was less than $25,000 a year, less likely to be working, and reported having more visits to a health care provider. However, in statistical analysis, most of these differences were not significant (data not shown). Only three participants responded “No” to all “should health care providers screen” questions, and 187 responded “No” to the three most controversial questions of screening for sexual functioning concerns, safety or violence in the home, and guns in the home. When the demographic and socio-economic characteristics of these 187 were compared to the remaining participants, no significant differences were seen (data not shown).

Discussion

We found a positive relationship between self report of previous screening and patient attitudes toward screening in this large sample of female patients receiving care in western North Carolina primary care clinics. This relationship was especially strong between those health behaviors that could be considered sensitive, such as sexual functioning and violence in the home. We also found that more patients felt they should be screened than were actually screened for all health behaviors included. This finding is especially significant in light of the importance of routine health screening.[31]

There may be several reasons for the relationship we found. It is possible that the act of asking screening questions increases acceptance through provision of information. Providers may normalize the question (“Violence affects many of my patients, so now I routinely ask all patients”) such that patients view screening as a routine part of their health care. A reverse relationship is also possible. Patients may seek out health care providers who support their beliefs on health care. However, there is limited evidence that patients change providers[32,33] and, for those who do, it is unclear that screening behaviors would be a motivator for doing so[32,34-35] or that patients would have access to sufficient information to be able to do so.[32,36,37] Similarly, health care providers may screen for particular behaviors because they perceive that such screening would be accepted and expected by particular patients. Finally, it is possible that our results reflect a recall bias. Patients with greater acceptance of screening may preferentially remember being asked those questions by their health care providers.

Although we found good acceptance among the participants for screening for certain health behaviors including screening for tobacco and alcohol use, other screening questions such as guns in the home, safety and violence in the home, and sexual functioning had less support. The evidence supporting improved health care outcomes with screening for these items is mixed. While the United States Preventive Services Task Force (USPSTF) did give screening for firearms in the home a "B" recommendation in its 1996 review, meaning there is fair evidence supporting its use and it is recommended that clinicians provide the service to eligible patients, it has since stated that this recommendation needs updating.[5] Health care provider screening for domestic violence received only an "I" recommendation,[6] meaning there was insufficient evidence to determine the net benefit of the service or to recommend for or against routinely providing it. The USPSTF has not reviewed the effectiveness of screening for sexual functioning. Given our findings of lower patient acceptance for these behaviors and the lack of evidence supporting improved patient outcomes, screening for these behaviors may not represent optimal use of patient or provider time. However, our finding of higher rates of acceptance among patients who had been screened should reassure providers that if they do choose to screen, their patient will accept that screening.

This study is unique in the breadth of health behaviors patients were asked about and the size of the sample. Previous studies have focused on one type of health behavior, such as screening for guns[18,38] or safety or violence in the home.[39-43] Results of these limited surveys have been mixed, with some studies demonstrating patients' strong support for routine screening for safety and violence in the home[39,40] and other studies showing less support.[38-44] To date, there have been no other studies that have examined the relationship of previous screening to attitudes toward screening. Our ability to include survey data from two time points also supports the strength of the relationship. Even when the survey time point was included in the model, the odds ratio showed little change.

While this study includes a variety of health behaviors and large sample size, it is limited by the geographic location of the sample. All survey participants were obtained from western North Carolina. The responses given may not be representative of the general population in the United States. Additionally, we only surveyed women and only those in established relationships with primary care providers. Men and individuals who do not have ongoing health care relationships may have differing views. We are unable to tell if the same patient was interviewed at both time points, thus some patients may have been included in both. Additionally, our response rate was low. Nevertheless, the sample size is large (more than 3,000 individuals) and represents a broad range of ages and socioeconomic status. Due to survey length, only one question about each health behavior was included, and we did not ask if the patient personally engaged in the health behavior. Additionally, we relied on participant self-report about previous screening. Previous studies have demonstrated that patient recall has high specificity when compared to direct observation, but variable sensitivity with better recall for counseling on smoking cessation and lower recall for increasing physical activity.[45,46] Further questions exploring the reasons for their answers would assist in the interpretation of the results.

Table 3.
Odds Ratios of Agreeing with Routine Screening for a Particular Health Behavior if the Participant Had Been Screened for the Behavior in the Past Year

Screening Question	Unadjusted OR[e] 95% CI			Adjusted OR[f] 95% CI		
	Pre	Post	Both	Pre	Post	Both
Exercise	2.2 (1.6-2.9)	2.3 (1.8-2.9)	2.2 (1.9-2.5)	2.7 (1.8-4.0)	2.5 (1.8-3.4)	2.3 (1.8-2.9)
Smoke	1.5 (1.2-2.0)	2.0 (1.6-2.6)	1.7 (1.5-2.0)	1.4 (1.0-1.8)	1.9 (1.4-2.5)	1.6 (1.3-1.9)
Use alcohol or drugs	1.8 (1.3-2.4)	2.7 (2.0-3.6)	2.0 (1.7-2.4)	2.2 (1.7-2.8)	2.4 (1.7-3.4)	2.3 (1.9-2.7)
Are under excessive stress	1.6 (1.3-2.0)	1.9 (1.5-2.4)	1.7 (1.5-1.9)	1.8 (1.3-2.5)	1.5 (1.2-2.1)	1.7 (1.4-1.9)
Have sexual functioning concerns	2.8 (2.2-3.6)	3.1 (2.6-3.7)	2.7 (2.3-3.2)	2.6 (1.9-3.8)	2.9 (2.2-3.7)	2.7 (2.2-3.4)
Have concerns about safety or violence in the home	4.4 (3.1-6.1)	3.8 (2.7-5.3)	3.4 (2.8-4.2)	3.9 (3.1-5.0)	3.8 (2.6-5.6)	3.4 (2.8-4.2)
Have a gun in the home	6.0 (4.1-8.8)	4.9 (3.9-6.3)	4.9 (4.0-6.0)	5.3 (3.4-8.3)	4.2 (3.0-5.9)	4.4 (3.4-5.8)

[e] Respondents with missing data are not included in the analysis for which the variable is missing.

[f] Adjusted for patient demographics (age, marital status, race, income, insurance), provider characteristics (PCP gender, PCP type), number of visits, clustering by clinic, and time of survey.

This study provides a valuable contribution to the understanding of health behavior screening. We found a significant association of previous screening with a positive attitude toward routine screening. This relationship was especially strong for those health behaviors that had lower rates of acceptance among patients. Further research is needed in different populations and to determine the causality of the association. We know that health care providers can have a powerful influence on health behaviors. If our finding is substantiated, it provides evidence that health care providers can also affect patients' attitudes regarding what healthy behaviors are. **NCMJ**

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POLICY FORUM

Pandemic Influenza Preparedness in North Carolina

COMMENTARIES

> *"Deciding who should have priority to receive limited resources during an influenza pandemic will be among the most difficult ethical dilemmas facing government officials, policy makers, and health care providers."*

INTRODUCTION

Policy Forum:
Pandemic Influenza Preparedness in North Carolina

Concern about the potential for an influenza pandemic has been at the top of the nation's agenda since 2004. In November 2005, President Bush introduced the *National Strategy for Pandemic Influenza*, which outlines how the federal government plans to prepare, detect, and respond to a pandemic. It describes the various roles of the federal, state, and local governments, private and international partners, and individual citizens during a pandemic. Congress has supported preparations for an influenza pandemic through appropriations since fiscal year (FY) 2004. Congress has approved over $6.1 billion in emergency supplemental appropriations to support flu pandemic preparedness and research. The bulk of that funding was provided to the United States Department of Health and Human Services (HHS), which will manage the federal public health and medical response during a pandemic.

The *Pandemic Influenza Plan* will guide the HHS response to an influenza pandemic at the national level. It focuses on developing infrastructure for vaccine production capacity, stockpiling antiviral drugs and other medical supplies, ensuring the capacity of public health to detect and respond to a potential pandemic, monitoring disease spread, coordinating federal, state, and local preparation, and enhancing outreach and communications planning. The North Carolina Division of Public Health will lead the influenza pandemic response at the state level. It has developed the *NC Pandemic Influenza Plan*, which it will use to coordinate activities during an influenza pandemic. The article by Jeffrey Engel, MD, in this issue of the Journal describes the potential consequences of an influenza pandemic and the state's planned response to the crisis.

A moderate influenza pandemic in North Carolina is expected to impact over three million people, with 1.6 million doctor visits, 35,000 hospitalizations, and 8,000 deaths. It is projected that more than 40% of the state's workforce would be out of work due to illness or caring for an ill family member. Such a widespread epidemic would have a huge impact on the state's economy, local businesses, and individuals' lives. In this issue of the *North Carolina Medical Journal*, we are focusing our attention on the impact an influenza pandemic will have on a number of different communities in North Carolina, including industry, faith, health care, and the underserved, and how those communities can prepare for such an emergency. Commentaries present the issues faith communities will face and the important role they can play in guiding the responses of their congregations, the models critical industries have used to develop pandemic influenza business plans, and the perspectives of private and public health providers who will be called to serve during a pandemic. Other commentaries highlight the need to understand the differences between quarantine, isolation, and social distancing and examine public health's authority to implement such measures, the importance of including representatives from underserved communities in the planning processes to avoid discrimination and bias during the pandemic, and the preparations that are being made outside of public health to prepare for the emergency.

Finally, this issue features the work of the NC Division of Public Health and NC Institute of Medicine Task Force on Ethics and Pandemic Influenza Planning. The Task Force was convened to assist the Division of Public Health in developing an ethical framework for evaluating ethical dilemmas that are likely to arise during an influenza pandemic, such as requirements that workers in critical industry perform despite increased risks of contracting the virus and the reciprocal benefits they are owed for such hazards; restrictions on individual rights due to isolation, quarantine, or social distancing measures instituted to limit the spread of disease; and prioritization of limited health care resources such as vaccines and antivirals.

We hope this issue of the *Journal* will help inform North Carolina communities and providers of the potential for an influenza pandemic, the steps being taken at the state and local levels to prepare for such an emergency, and what individuals and organizations can do to prepare themselves.

Thomas C. Ricketts, III, PhD
Editor-in-Chief

Kristen L. Dubay, MPP
Acting Managing Editor

Pandemic Influenza:
The Critical Issues and North Carolina's Preparedness Plan

Jeffrey P. Engel, MD

A Brief Primer

Influenza pandemics have been recorded throughout human history, on average occurring three times in a century, with ten in the last 300 years. Influenza pandemics are simultaneous worldwide epidemics and occur when a new influenza virus evolves that infects humans, is spread efficiently from person-to-person, and because of no prior immunity causes severe disease and death. Between pandemics, called the inter-pandemic period, the milder seasonal influenza (also known as the "flu") exists in the wintertime months in populations living outside of the tropical zones, whereas in the tropics, influenza is a year-around disease. Seasonal viruses are adapted pandemic strains that have weakened mainly due to developed immunity in the human population.

Influenza is characterized by the abrupt onset of fever, chills, muscle pain, and joint pain, followed within hours by respiratory symptoms including cough and congestion. It is a disease primarily of the upper respiratory tract, which in uncomplicated cases resolves in about a week. Complications include bronchitis, pneumonia (both primary viral and secondary bacterial), heart inflammation (myocarditis), and brain inflammation (encephalitis); death can result from any of these complications. In a typical season in the United States, 36,000 people die of influenza, deaths occurring chiefly among infants and the elderly.

The type A influenza virus is unique among viruses because it allows for genetic recombination to occur by the exchange of any or all of its eight gene segments of two different influenza virus strains. Additionally, the influenza virus can mutate and gradually adapt to new environments. Such recombination and adaptation in type A influenza viruses are the cause of pandemics.

Type A virus subtypes are named by the viral surface proteins, hemagglutinin (HA) and neuraminidase (NA), which elicit an immune response, and thus, comprise major components of the influenza vaccine. In nature, 16 HA and 9 NA proteins exist; however, the human pandemic and seasonal viruses have contained only the subtypes, H1, 2, or 3 and N1, 2, or 3.

The Animal-Human Interface: Zoonotic Influenza

Only type A influenza virus is capable of infecting a broad host range, primarily water fowl and shore birds. Wild water fowl usually harbor type A influenza in their digestive tract and have no symptoms. Spread to other susceptible hosts, usually related species like domestic poultry, happens directly with species intermingling or indirectly via contact with contaminated surface water because type A influenza virus can survive in fresh water for days to weeks.

Type A influenza virus is a type of infectious disease that is transmittable under natural conditions from vertebrate animals to

> *"The impact of a pandemic or any disaster is proportional to how prepared individuals and society are. Preparedness is a shared responsibility that requires local, state, and federal public health systems to form a robust response network."*

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humans, also called "zoonosis." Zoonoses are usually sporadic; however, they are also the origins of epidemics and pandemics. If a human is exposed to an infectious agent from another animal, an infection results if the person is susceptible. Disease may range from asymptomatic to severe, resulting in immunity and recovery or death. An epidemic or pandemic erupts when the disease microorganism adapts via genetic mutation to the new human host and becomes capable of human-to-human transmission. Notorious examples of recent zoonotic-origin pandemics include the human immunodeficiency virus (HIV), the cause of AIDS (from chimpanzees in West Africa),[1] and the severe acute respiratory syndrome (SARS)-coronovirus (from bats in Southeast Asia).[2]

Type A influenza viruses are often the source of sporadic zoonotic infections, most often from avian, or bird, viruses. Humans are exposed to avian influenza viruses in developing countries across Eurasia and Africa due to animal husbandry practices that involve close contact with diseased or dead domestic fowl, especially ducks and chickens. In developed countries, zoonotic influenza infections have occurred in commercial poultry workers managing infected flocks.

Not all zoonotic influenza cases are of avian origin. In 1976, several soldiers at Fort Dix, New Jersey developed infections, some fatal, from a type A swine influenza virus. It is unknown how these individuals were exposed to a swine virus; however, this cluster led some scientists and policy makers to the false conclusion that this was the harbinger of the next pandemic. It was from this event that the infamous "Swine Flu" vaccination program emanated.

Contemporary methods in the study of human viruses provide information about influenza viruses dating back to 1889. The four pandemics between 1889 and 1968 were of avian origin, and they differed only in the number of avian influenza genes present in the pandemic strain (Table 1).

Table 1.
Hypothesized Evolution of Pandemic Influenza A Viruses[3]

Pandemic	Subtype	Avian Genes
1889	H2N2	?
1918 "Spanish"	H1N1	8
1957 "Asian"	H2N2	3 (PB1,* HA, NA)
1968 "Hong Kong"	H3N2	2 (PB1, HA)

* PB1 is a viral gene encoding a replication enzyme

H5N1: The Next Pandemic?

In the last 50 years, the science of influenza has made many great strides. In addition to the molecular study of the virus, worldwide human and animal surveillance and the study of population health have greatly expanded. The World Health Organization (WHO) has devoted huge resources to influenza monitoring and study. WHO coordinates the global influenza laboratory surveillance network that characterizes circulating human seasonal virus strains. This information is used to determine the annual human vaccine.

Through this global network, human disease due to avian influenza strain H5N1 was first reported in Hong Kong in 1997. Because this was an avian strain capable of causing severe infections in humans (six of 18 cases reported were fatal), WHO increased the pandemic alert level to Phase 3 (Table 2). Virtually all Hong Kong chickens were slaughtered in an attempt to eradicate the virus. This appeared to have been successful because no further clusters of H5N1 in people or domestic poultry were reported for several years. However, beginning in December of 2003, outbreaks in poultry and humans were reported in Vietnam and Thailand, and through 2006 human reports have increased across Eurasia and Africa with an alarming 60% case-fatality rate (Figure 1).

Table 2.
WHO Pandemic Phases

Period	Phase	Event
Interpandemic	1	No new subtype in humans
	2	No new subtype in humans, animal subtype poses risk
Pandemic alert	3	Human infections with new subtype, no human-to-human spread
	4	Small clusters of limited human-to-human spread
	5	Larger human clusters, but spread still localized
Pandemic	6	Increased and sustained transmission in the general population

H5N1 is currently widespread in wild and domestic birds in Eurasia and Africa with sporadic and often fatal cases in humans. It has notched up the WHO pandemic alert system to Phase 3 since 1997 and satisfies all but one important property of a pandemic-causing influenza virus (Figure 2). Will H5N1 mutate and become capable of efficient human-to-human transmission?

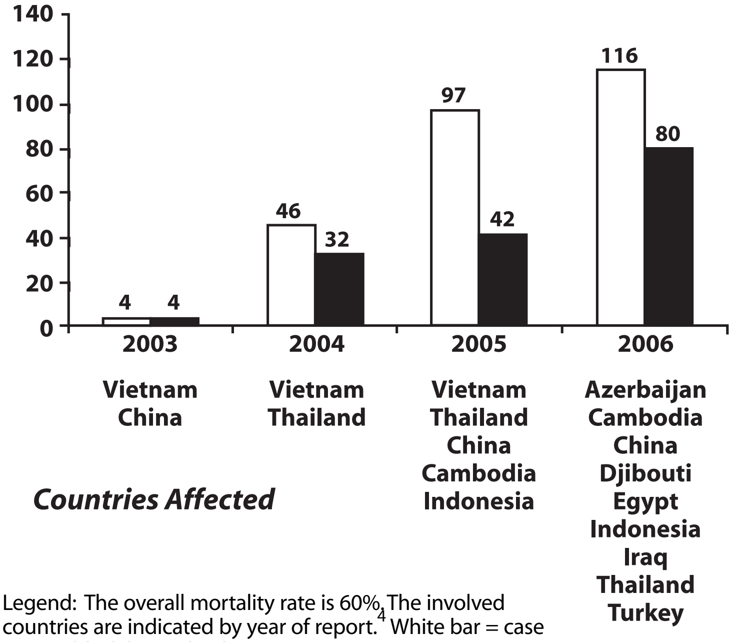
The Present Threat: When, Not If

If we know that pandemics are of avian origin and that they occur cyclically, on average three times in a century, then the question is when will the next avian influenza virus emerge that will cause the next pandemic? Certainly, H5N1 is the leading candidate. In regards to preparation, several subquestions can be generated that assist planning for the next pandemic:

- When will the virus arrive and spread?
- How much time from its source to arrival in the United States or North Carolina?
- What will the principal age and other risk groups be?
- How many will be affected?
- What will be the morbidity?
- What will be the mortality?

In terms of transmission dynamics or spread, nothing is more concerning to an epidemiologist than a community respiratory

Figure 1.
Epidemiological Curve of Reported H5N1 Human Cases by Reporting Country, 2003-2006."



Legend: The overall mortality rate is 60%. The involved countries are indicated by year of report.[4] White bar = case counts, black bar = deaths.

virus. Transmitted through respiratory droplets from a cough or a sneeze, or direct contact from a person's hands, these viruses can literally spread like wildfire through a susceptible population. The basic reproductive number, R_0, pronounced "R-zero" or "R-naught," is the expected number of people a contagious person could infect during the infectious period.[6] An R_0 greater than 1 ($R_0 > 1$) results in a self-sustaining outbreak until there are no more exposed susceptible people. In prevaccination days, a community respiratory virus like mumps with a short incubation period and an $R_0 = 6$ would literally burn through a school-age population.

Influenza virus with an incubation period of 1-5 days and $R_0 = 3$ moves quickly through a community as well. With seasonal influenza, however, R_0 is proportionately reduced by population immunity. For example, if half of the population is immune (from natural infection or vaccination) in a given season, $R_0 = 1.5$.[6] In a pandemic, however, potentially everyone is susceptible and, at least in the beginning, there will be no vaccine, thus the wildfire analogy.

Worse Case Scenario: A Syndemic

It behooves planners to assume the worst, and for pandemic influenza, that would be a 1918 "Spanish flu"-like pandemic. Worldwide, the second epidemic wave (there were three waves) of the Spanish flu, caused by an H1N1 subtype, swept across the globe with amazing speed and destruction. In its wake, 50 million people died; in the United States the death toll was 500,000 during the later summer and fall of 1918. Equally disturbing were the high attack and mortality rates that occurred in previously well people in the second and third decade of life, quite unusual for influenza that usually kills the very young and very old.

Historical accounts of young adult victims of the Spanish flu revealed a rapid death due to respiratory failure. People were well one day and dead the next, with facial cyanosis (blue discoloration from lack of oxygen) and a rapid breathing pattern occurring in the hours before death (a condition we now call the acute respiratory distress syndrome or ARDS). Examination of diseased lung tissue showed air sac damage from viral pneumonia. The body's response to the pneumonia caused leaks in the air sacs, drowning the victims (non-cardiogenic pulmonary edema).

In preparing for the next pandemic, it would be helpful to understand why the Spanish flu was so catastrophic. Certainly one reason was the virus itself. The second wave virus has been reconstructed from 1918 victims' lung tissue (both from exhumed remains frozen in the Alaskan tundra and lung tissue preserved from an autopsy sample).[7] The reconstructed 1918 virus was found to be highly lethal in the mouse model following intranasal infection. Genetic sequencing revealed it to be a zoonotic type A influenza virus strain whose entire genetic makeup was from a mutated bird strain. This truly novel virus adapted to the new human host acquiring the capability, through evolution, to spread efficiently from person-to-person.

However, in understanding the calamity of 1918, a separate analysis of the social milieu is required, specifically exploring the agents of human activity existing at the time. Historian and author John M. Barry carefully chronicles the global situation in 1918, particularly as the United States prepared for World War I.[8] Barry's meticulous research of influenza death records and outbreaks associated with massive troop deployments, staging, and overcrowding is compelling. Epidemics in Boston and Philadelphia were traced to ill troops arriving from overseas and

Figure 2.
Checklist of Pandemic Properties of Avian Influenza Type A/H5N1[5]

☑ Widespread prevalence in migratory birds; broad host range
☑ Continued outbreaks among domestic poultry
☑ Mammalian infection (cats, pigs, etc.) lethal
☑ Virus is evolving
☑ Sporadic human cases
  – Most in young and healthy
  – Case-fatality 60%
  – Rare person-to-person transmission
☐ Sustained and rapid person-to-person transmission

an overcrowded patriotic street parade, respectively. Many more examples are cited and all are consistent with massive human crowding and/or movement in the presence of a virulent respiratory virus. In epidemiologic terms, in some settings (barracks, troop ships, etc.), a virus reproductive number (R_0) of 5 or higher was common. Thus, the sociologic and biologic conditions in 1918 formed the perfect storm, a syndemic.

A syndemic is defined as "two or more afflictions, interacting synergistically, contributing to excess burden of disease in a population."[9] The term was first used by anthropologist Merrill Singer describing the HIV epidemic among the urban poor in the United States: the SAVA syndemic, for substance abuse, violence and AIDS.[10] He described a new virulent infectious virus, HIV also of zoonotic origins,[1] which spread efficiently by needle sharing intravenous drug abuse and unprotected sexual behavior that wrecked havoc among the poor, particularly in urban minority communities in the United States.

For 21st century pandemic influenza planning, then, I argue that to prevent a 1918-like scenario, we must do syndemic planning. Taking examples from recent natural disasters, such as the 1995 Chicago heat wave that killed 700 elderly people in a week,[11] the 2005 tsunami in Indonesia, Hurricane Katrina in New Orleans, or the SAVA syndemic, the common lesson learned is that the natural disaster impact, whether in a developing nation or the United States, is greatly multiplied by crowding and poverty. In 1918, the global population was 1.8 billion; today it is 6.5 billion, 2.7 billion (42%) living in moderate to extreme poverty as measured by income less than $2/day.[12]

The syndemic model predicts that the next influenza pandemic will be catastrophic in countries such as India and China where 36% of the world population lives, many in poverty and in crowded urban areas. Although these sociologic conditions exist in some areas in the United States and North Carolina, more worrisome in developed countries are the equally vulnerable including those without health insurance or who are underinsured; those who lack the capacity to access information due to illiteracy, low English-speaking skills, and other forms of social isolation; and finally, select special populations such as the homeless, institutionalized, and the underserved mentally ill.

If a 1918-like influenza virus causes the next pandemic, how our nation and state mitigate the impact will depend on pandemic and syndemic prevention. To accomplish this, at the national, state, and local level, public health is leading the planning efforts for the health care sector, government, and society.

Summary of North Carolina's Pandemic Influenza Preparedness Efforts

The fundamental objective of pandemic influenza planning is to save lives. To be successful, all corners of society must plan, including individuals and families, business and industry, schools and universities, and state and local government. These overarching plans, referred to as pandemic implementation strategies, are underway or complete in many sectors, but beyond the scope of this review. Here, I will highlight the critical components of *North Carolina's Public Health Pandemic Influenza Plan.*[13]

Quenching

In public health, prevention is the key, thus a critical strategy is the early detection of initial outbreaks and rapid containment of the disease where it emerges, a process known as quenching.[14] Through global and national collaboration with the WHO and the Centers for Disease Control and Prevention (CDC), once an influenza pandemic is declared somewhere in the world, the North Carolina Division of Public Health (DPH) will enhance frontline detection and response and rapid laboratory diagnosis. The early cases in North Carolina will likely be among travelers to regions where person-to-person transmission is ongoing.

In WHO pandemic phases 4, 5, and early 6, international travel advisories will be issued by federal authorities. DPH will notify health care providers of the situation and explain how to suspect and manage patients who may be manifesting pandemic influenza symptoms. Suspect patients shall be reported immediately to local or state public health agencies (North Carolina General Statute 130A-135), isolated (NCGS 130A-145),[15] and treated with antiviral medication pending laboratory confirmation. The North Carolina State Laboratory for Public Health will activate three regional labs in Charlotte, Asheville, and Greenville, as well as the core facility in Raleigh, to rapidly (within hours) process clinical specimens (nasopharyngeal swabs) for detection of the pandemic strain. These labs will not attempt to cultivate pandemic viruses because of the biosafety hazard; cultural confirmation will be done solely by the CDC in Atlanta, Georgia.

The goal of quenching is for public health and other response agencies to aggressively keep the $R_0 < 1$. Once a suspected patient has been reported to public health agencies, active surveillance will begin to identify close contacts (eg, airplane passengers, household and workplace contacts). If an index case is presumptively confirmed by the labs, symptomatic contacts will be isolated and referred for medical evaluation and asymptomatic contacts will be quarantined for 10 days (or the maximum incubation period) from the time of last contact to a case. Based on what is known about the contagiousness and virulence of the pandemic virus, quarantined people may be offered antiviral prophylaxis at no cost from a federal or state stockpile. Antiviral prophylaxis of exposed contacts in quarantine may be the single most effective strategy in preventing a full-blown pandemic, an $R_0 > 1$.

Isolation and quarantine are restrictions of movement and/or action of the sick (isolation) and the well but exposed (quarantine). An effective quenching plan requires rapid active surveillance and diagnosis, treatment or post-exposure prophylaxis with antivirals, and enforcement of isolation and quarantine. During the 2003 SARS response in North Carolina confirmation of a single case led to the isolation of three persons and the quarantine of 30 others. All affected people complied with local public health authorities, law enforcement was not necessary, and the spread was contained.

WHO Phase 6: Widespread Pandemic in North Carolina

Planning assumptions identify a point in time when quenching fails or is no longer feasible. This may happen if there are multiple simultaneous outbreaks across the state, a local jurisdiction's capacity to quench is overwhelmed and there are no state or federal assets available to assist, or supplies of antiviral medications are depleted leaving enough only to treat the sickest. To decrease illness and death, the strategy at such a point will be to slow the spread and buy time until an influenza pandemic vaccine is available. To accomplish this, countermeasures known as nonpharmaceutical and pharmaceutical interventions will be used.

Nonpharmaceutical Interventions

The nonpharmaceutical intervention for preventing or slowing a pandemic is the physical separation of people. This is accomplished in fundamentally two ways: personal protective equipment for those who must be close to the sick (health care workers, first responders) and social distancing and hygiene. The worst-case scenario is that 50% or more of those who become ill will seek medical care. The number of hospitalizations and deaths will depend on the virulence of the pandemic virus and Table 3 projects these numbers based upon the experiences of the moderate and severe pandemics of 1957 and 1918. Depending on severity, health care medical surge plans must scale accordingly, the largest challenge being the maintenance of adequate staffing. To provide for the safety of those on the frontline, occupational health protection through infection control is a critical planning component. In hospitals, respiratory droplet and airborne precautions that are part of everyday activity will be essential during a pandemic. For routine patient care, properly donned and doffed eye protection and a plain surgical mask are adequate along with hand washing with soap and water before and after patient contact. For higher risk contact where infectious aerosols are more likely to be generated (eg, airway suctioning, resuscitation, bronchoscopy), a fit-tested N-95 respirator is required. In the community, there is no evidence that personal protective equipment, such as the donning of masks by well people, will prevent transmission of influenza. Hence, stockpiling masks or respirators outside of the health care setting is not recommended and is not part of the *NC Pandemic Influenza Plan.*

Table 3.
Impact of an Influenza Pandemic in North Carolina*

Characteristic	Moderate (1957-like)	Severe (1918-like)
Illness	3,000,000	3,000,000
Outpatients	1,600,000	1,600,000
Hospitalized	35,000	300,000
Deaths	8,000	65,000

* Numbers based on NC population = 9,000,000; 35% attack rate (CDC FluAid 2.0)

The broader community containment strategy will rely on social distancing interventions. In WHO Phase 6 for a moderate to severe pandemic, at some threshold a state of emergency will be declared where so-called mass quarantine will be utilized. Mass gatherings including entertainment venues like sporting events and theaters will be canceled or closed, religious services will be discouraged or prohibited, nonessential workers will be told to remain at home, and schools and universities will be closed. In 1918, the city of St. Louis implemented these measures and succeeded in reducing influenza-related mortality. Indeed, government may not need to impose these measures because individuals are likely to self-quarantine if the pandemic is bad enough.

The societal disruptions will be immense, but can be lessened by cross-sector preparation. Continuity of operations planning is the core of the national implementation strategy and is essential for critical industries such as utilities, businesses, educational institutions, and government.

Pharmaceutical Interventions

Pharmaceutical interventions refer to the specific countermeasures for prevention and treatment of influenza A infections: antiviral medications and vaccines. The planning assumption for antivirals is that they will be effective in the treatment and prevention of pandemic influenza. Although clinical trials will be difficult to conduct against the current H5N1 threat, there is accumulating evidence that these drugs will have broad-spectrum activity against pandemic influenza.[16] The current federal government guideline calls for the stockpiling of enough antiviral medications to treat 25% of the population, roughly two million five-day courses for North Carolina. The stockpiling challenges lie in accumulating an adequate supply to meet the need, establishing rationing criteria until the supply is adequate, and extending the shelf-life beyond five years.

Assuming the antiviral medications are found to be life-saving and the supply is inadequate at the time of the pandemic, then difficult rationing decisions will have to be made. To ensure fairness and equity and to assist frontline providers, the *NC Pandemic Influenza Plan* aligns with the federal tier groups to receive antiviral treatment in the event of suspected influenza illness only.[17] The top five tier priority groups to receive treatment are hospitalized patients, health care workers and emergency medical technicians, high-risk outpatients including the immunocompromised and pregnant women, public health responders (eg, vaccinators, vaccine and antiviral manufacturers, government decision makers) including public safety (police, fire, and corrections), and increased risk outpatients (children 12-23 months, adults aged 65 years and above, and people with chronic medical conditions). To reiterate, this rationing scheme is for treatment only, it is assumed during a widespread WHO phase 6 event, there will not be enough medication for prevention.

The second pharmaceutical intervention is a pandemic vaccine, which can abort the pandemic once available for the entire population. The planning assumption, however, is that it will probably take a year or more to scale up production to immunize everyone. Further, because the population will be naïve to the pandemic virus, a booster shot will be required one month after the priming dose. Thus, once again, rationing of the first supplies of the pandemic vaccine is a planning component aligning with federal tier groups.[17] In Tier 1, there are four subtiers who will get the vaccine first:

1) Vaccine and antiviral manufacturers, essential medical and public health workers;
2) High-risk persons (> 65 years old, medical co-morbidities)
3) Pregnant women, household contacts of severely immuno-compromised, household contacts of children < 6 months old;
4) Public health emergency response workers, key government leaders.

Syndemic Prevention: Preparedness and Communication

Ultimately, how North Carolina responds to a severe influenza pandemic will depend upon countermeasures applied equitably to all who reside in the state. Since human beings are the vector and reservoir of the disease, neglecting or limiting resources to any sector of society (outside of established rationing protocols) does not make any epidemiologic sense. In addition, it is unrealistic to believe that society can mitigate the syndemic conditions of crowding, poverty, and the needs of special populations in advance of a rapidly moving pandemic wave. How do we approach this daunting challenge?

The impact of a pandemic or any disaster is proportional to how prepared individuals and society are. Preparedness is a shared responsibility that requires local, state, and federal public health systems to form a robust response network. Implementation strategies must build international and domestic, animal and human health, and public and private sector partnerships. Health, security, and economic protection are at stake, and all these risks should be managed cooperatively.

Syndemic prevention will rely on our ability to reach those outside of traditional networks, and to accomplish this, clear communication channels must be established to the public using trusted messengers. Health disparities during a disaster are preventable if people are prepared with accurate and timely information. How well public health is able to coordinate consistent messages, encourage people to take action steps to prepare now, and provide updates when new information becomes available will determine how we weather the perfect storm. **NCMJ**

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COMMENTARY

Ethical Guidelines for an Influenza Pandemic

E. Kiernan McGorty, JD, MA; Leah Devlin, DDS, MPH; Rosemarie Tong, PhD; Natasha Harrison; Mark Holmes, PhD; and Pam Silberman, JD, DrPH

The major challenge facing public health officials is that they do not know when the next pandemic influenza will occur or how severe it will be. History indicates there are approximately three pandemics each century. Since the last outbreak of pandemic influenza occurred in Hong Kong in 1968-1969, many experts suggest that we are overdue for another influenza pandemic. They warn that it is not a question of *if* but *when* the next influenza pandemic will arrive.

The North Carolina Department of Health and Human Services, Division of Public Health (DPH) will have the responsibility of coordinating the public health response to an influenza pandemic. The goal of the public health response will be to reduce morbidity, mortality, and social disruption. In order to carry out its *North Carolina Pandemic Influenza Response Plan*,[1] DPH will need the assistance of health care workers and workers in other critical industries, such as public safety, food, and transportation. Certain individuals will need to work, despite risks of infection, to ensure that society can continue to function during the pandemic. To prevent the spread of disease, DPH may need to pursue social distancing strategies, such as quarantine, isolation, or closing of schools, which may at times conflict with individuals' civil liberties. In addition, DPH will be responsible for allocating scarce resources, such as vaccinations and/or antiviral medications. An outbreak of pandemic influenza will pose many ethical dilemmas (Table 1).

Table 1.
Ethical Dilemmas that May Arise During Pandemic Influenza

Scenario 1: Nancy has been a nurse in an orthopedist's office for 10 years. She heard the local hospital needs nurses to take care of pandemic influenza patients. Nancy wants to help, but she is concerned that she is unfamiliar with the type of care flu patients will require. She also is worried she might catch the flu and bring it home to her family. Does Nancy have a responsibility to work? What responsibility does society or the hospital owe to Nancy and her family to minimize the threat of infection?

Scenario 2: Bill is a cook at a diner and gets paid by the hour. During the height of the pandemic, the government has asked that people stay home from work for two weeks in order to prevent the spread of disease. Bill wants to stay home, but he needs his wages to pay his rent and he is afraid his boss will find someone else to do his job. If Bill responds to a governmental request that nonessential workers remain at home, what responsibility does government have to assure that his basic subsistence needs are met?

Scenario 3: The state has defined priority populations for pandemic influenza vaccinations, but the local health department does not have enough vaccines to cover everybody who falls into the priority populations. How should the health department allocate the limited vaccines among different priority populations?

During an influenza pandemic, it is likely there will not be enough time to discuss publicly the ethical tradeoffs inherent in critical decisions. It is impossible to anticipate all the critical decisions that may need to be made during an outbreak. Therefore, it is important to identify the ethical principles that should be considered when faced with difficult choices. Developing an ethical blueprint that incorporates public input in advance of a pandemic and later applying these recommendations during the crisis will help assure the public that decision makers are making reasoned responses to the crisis. Public acceptance of the ethical framework will increase the likelihood that society maintains order during the emergency.

DPH determined the need to develop an ethical framework from which to base implementation of its Pandemic Influenza Response Plan and asked the North Carolina Institute of Medicine (NC IOM) to help in this effort. The NC IOM convened a task force to explore some of the ethical issues the state may face during an influenza pandemic and to consider the rights and responsibilities of private organizations and individuals. The Task Force was comprised of different stakeholder groups including representatives of (1) public health and safety, (2) other governmental agencies, (3) health care providers,

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(4) business and industry, (5) the faith community, (6) advocacy groups, and (7) ethicists. In addition, NC IOM partnered with DPH and the Old North State Medical Society to host four regional forums in order to obtain public input into these difficult ethical decisions.

The Task Force weighed different ethical considerations in developing its framework, including (1) the need to ensure accountability, (2) equitable treatment among similarly situated individuals, (3) proportionality of actions, and (4) inclusiveness and timeliness in decision making. Government must act as the public steward, operate in a transparent fashion, and make decisions that are reasonable and responsive in order to garner the public's trust. It is important to foster cooperation and collaboration among different governmental agencies, the public and private sectors, and private citizens. The Task Force developed an ethical framework for guiding decision making in the following areas: responsibilities of and to health care workers and other critical workers, the balance between the rights of individuals and protection of the public, and prioritization and utilization of limited resources. The Task Force's report will be available shortly at www.nciom.org.

> *"...experts suggest that we are overdue for another influenza pandemic. They warn that it is not a question of if but when the next influenza pandemic will arrive."*

Responsibilities of and to Health Care Workers and Other Critical Workers

An influenza pandemic would have widespread, significant effects on North Carolina's workforce. During an influenza pandemic, 40% of workers may be out ill, creating challenges for businesses and organizations to maintain normal operations. However, critical industries, such as food, utilities, and transportation, will need to continue functioning to provide society's essential goods and services during a pandemic.[2]

North Carolina's critical industries have experience maintaining essential functions during natural disasters, such as hurricanes and ice storms. However, an influenza pandemic would place unprecedented stresses on the ability of industries to function due to its duration, likely limited outside support, lack of workers, and risk of secondary infection. An influenza pandemic may consist of multiple waves lasting eight weeks or longer; in contrast, the immediate impact of many natural disasters is shorter in duration. Also, natural disasters often impact only a limited area, allowing other communities to provide support to the impacted area. In contrast, a pandemic likely will impact most, if not all, of the state and country, limiting the availability of outside support. Further, it may be difficult to find sufficient workers in general. During a pandemic, many workers may become infected with the virus and, as a consequence, will be unable to work. A pandemic also will lead to high absenteeism because workers may fear contracting the flu and may need to take care of sick family members. Thus, North Carolina's critical industries are likely to face unprecedented challenges in the event of a particularly virulent pandemic.

An influenza pandemic in North Carolina would be especially hard on the health care system. The health care system would face tremendous challenges in providing appropriate care for thousands of patients with acute, life-threatening infections, as well as continuing to provide care to others who are ill or injured. North Carolina might experience as many as 1.6 million doctors visits and 29,000 hospitalizations during one wave (ie, 8-12 weeks) of a moderate pandemic, although the numbers could be eight times higher in the event of a particularly virulent pandemic (Table 2).

Table 2.
Impact of Regular Flu versus Projected Impact of Pandemic Flu in North Carolina

	Regular Flu	Moderate Pandemic Flu
Doctor visits	750,000	1.6 million
Hospitalizations	6,000	35,000
Deaths	1,100	7,900

To get industries thinking about operational issues that could arise during an influenza pandemic, the Task Force recommended that **employers and contractors design business continuity plans to prepare for events such as a pandemic.** Plans should identify those positions that are critical to the continued operation of the industry and determine whether jobs need to be performed on-site or can be adequately performed off-site. Workers who would be required to work should be made aware of the expectation to work during events such as an influenza pandemic upon hiring or upon the adoption of the plan. Employers and contractors should specify the supports that will be available to the critical workers to enable them to work, as well as the sanctions that will be enforced if critical workers fail to show up for work during a time of crisis.

Despite the difficulties that will arise during an influenza pandemic, critical industries will need to continue providing their essential goods and services during an influenza pandemic. Workers in critical industries should acknowledge a responsibility to continue to work in times of crisis so that essential goods and services are provided to maintain the functioning of society. In general, the enhanced obligation to work during a crisis stems from three main responsibilities: professional, employment, and general human responsibilities to care for others (Table 3). Health care professionals have an added obligation to provide

Table 3.
Responsibilities of Critical Workers to Work

Professional Responsibilities: Licensed professionals in critical industries have a professional obligation that results from their choice of profession. This obligation is based largely upon the special expertise of licensed professionals, the unique roles granted by reason of licensure, and the authority to self-regulate the profession.

Employment Responsibilities: In return for their salary, employees are expected to meet their job responsibilities and to support the work of the organization. Society has an expectation that critical industries will continue to function in the event of a public health emergency. Businesses can only operate with sufficient staffing. Thus, workers who have chosen to work in a critical industry are assuming a heightened responsibility to continue to work even during times of crisis. In addition, employees may have a formal contractual obligation that specifies their duty to work during emergencies.

Human Responsibilities: The welfare of everyone in the community is enhanced when all its members recognize their moral responsibility to assist each other in times of great need.

care because of their professional license and because their ability to provide care is greater than that of the public. By freely choosing that profession, health care personnel have assumed an ethical obligation to act in the best interests of the ill and to assume a proportional share of the risks to which their professions and/or employment setting expose them. As a result of these obligations, the Task Force recommended that **workers in critical industries have an ethical responsibility to perform their regular employment duties during an influenza pandemic *and* to assume new responsibilities for which they are trained, as long as their actions will not lead to greater harm than the failure to act.** Although workers in critical industries may have enhanced obligations to work during a crisis, the Task Force also agreed that their responsibility to work must be balanced against other considerations, including their own safety and their responsibility to care for family members who are ill.

Critical industry employers and contractors, as well as government, have a reciprocal responsibility to protect and support workers to enable them to continue working during an influenza pandemic. Depending on the nature of the influenza virus, certain workers in critical industries may face disproportionate health risks. Workers may be asked to work longer hours or under more stressful work conditions than generally allowed. If critical organizations are short-staffed because of increased demand, worker illnesses, or absenteeism, other workers may be called upon to provide services outside their normal scope of work. The Task Force determined that **government and employers have a reciprocal responsibility to ensure that workers are protected from pandemic influenza-related harm and liability to the extent possible.** For example, workers in critical industries at increased risk of infection should receive priority for available personal protective equipment, vaccinations, antiviral drugs, and other nonmedical control measures. All critical workers should receive behavioral health services and other goods or services needed to enable them to work. In addition, employers have a responsibility to ensure that workers are appropriately trained to fulfill the tasks assigned to them during a crisis. Government should also provide health care personnel and organizations with qualified immunity from liability, in order to encourage health care professionals to work under less than ideal conditions (eg, limited resources, lack of health care professionals, the need to assume new responsibilities).

Balancing the Rights of the Individual and the Need to Protect the Public

Public health leaders are specifically charged with promoting, protecting, and improving the overall health and well-being of the population during emergencies. In a pandemic, public health officials may need to implement measures to limit illness and death or to slow the progress of the epidemic that could conflict with personal liberties and individual privacy. These measures include isolation, quarantine, or other forms of social distancing. Public health officials may require individuals with the influenza virus or who have been exposed to the influenza virus to remain at home, in temporary housing, or in a health care facility to prevent the spread of the disease to others. Isolation and quarantine are most effective in the early stages of an influenza pandemic when few people have been infected. Government should ensure that people who are subject to isolation or quarantine have their basic necessities met. To accomplish this, the Task Force recommended that **all levels of government ensure that individuals who are affected by isolation or quarantine orders receive needed assistance in accessing resources to meet their basic needs while they are subject to restrictions.**

Other types of social distancing measures may be necessary once the influenza virus is more widespread. The goal of social distancing measures is to reduce contact with potentially infected individuals. Such measures may include, but are not limited to, closing schools or day care centers and asking churches to suspend their normal services. Social distancing measures may also include voluntary requests that employees stay home or work off-site and that people take care of sick family members at home, rather than bring them to overcrowded health care facilities. For the individuals and families involved, restrictions on personal liberties can pose significant difficulties, such as loss of income and social support. Business and industry may be affected by the loss of workers or other sources of income.

Safeguards are needed to ensure that infringements on personal liberties are proportional to the need and are applied equitably to all similarly situated individuals. Thus, the Task Force recommended that **government leaders implement restrictions on personal liberties deemed likely to be effective to limit illness and mortality in the context of a pandemic, but limit these measures to the least restrictive alternative reasonably necessary to protect the public.**

Every attempt should be made to ensure the public is aware of the need for pandemic-related restrictions of individual liberties. Informing the public about the reasoning behind these social distancing measures likely will improve compliance. The Task Force recommended that **the North Carolina Department of Health and Human Services partner with local health departments to develop a public outreach campaign, ensuring that the public is well-informed of the potential need to use community mitigation efforts or to prioritize the use of limited resources.** During a pandemic, it will be critically important that accurate health information be conveyed to the public in a timely manner to minimize the spread of misinformation or panic. Thus, the Task Force recommended that **the Governor's Office, in conjunction with the North Carolina Department of Health and Human Services and Crime Control and Public Safety, develop a coordinated communications plan to ensure that the public obtains timely, accurate, and continuous information about the influenza pandemic.**

Prioritization and Utilization of Limited Resources

In crisis situations, citizens often look to the government to manage the allocation of essential limited resources. Many essential resources are likely to be limited in the event of an influenza pandemic. In particular, there will be a sudden increase in demand for medical supplies, such as personal protective equipment, vaccines, antivirals, and hospital beds. These demands, as well as the large numbers of ill persons, will stretch the health care system's limits. Furthermore, large numbers of the population may be ill at any given time during the pandemic, making it difficult to maintain the normal functioning of many critical industries. As a result, there may be insufficient supplies of food, fewer essential services provided, and restrictions on certain utilities. Deciding who should have priority to receive limited resources during an influenza pandemic will be among the most difficult ethical dilemmas facing government officials, policy makers, and health care providers. These allocation decisions should be based on widely accepted, reasonable criteria. The Task Force also recognized the importance of individual responsibility for pandemic influenza planning, recommending that **individuals reserve supplies and have plans to care for family members during a pandemic.**

The priority given to the allocation of certain preventive resources (ie, primary prevention), such as vaccines, may not be the same as the priority that should be given to the allocation of limited health care resources needed for a patient who is already sick (ie, secondary treatment), such as ventilators or hospital beds. One way to conceptualize the allocation decisions is to classify medical resources as either *pharmaceutical* or *nonpharmaceutical.* Given this framework, the Task Force recommended a prioritization system recognizing different goals for different resources (Table 4). To the extent possible, individuals who do not make the priority list for life-sustaining care should be provided palliative care.

Nonpharmaceutical primary prevention resources will be critical in the early stages of a pandemic when vaccines are not yet available. Personal protective equipment and other nonpharmaceutical prevention resources may be the only way to minimize the likelihood of contracting the virus. As a result, the Task Force recommended that these limited resources be first allocated to health care workers or other critical workers who are at increased risk of contracting the disease and to private individuals who are at increased risk of spreading the disease. Once vaccines are available, the Task Force agreed that priority should be given to health care workers or other critical workers who are increased risk of contracting the disease. The Task Force recommended that priority for antivirals be given to those at highest risk of dying if they get sick and to critical workers so they can recover and return to work. Priority for curative resources should be given to those most likely to benefit.

To avoid the appearance of nepotism or favoritism, the Task Force recommended that **disease control and medical decisions be based on clinical factors, the epidemiology of the spread of disease, and assuring the functioning of society.** Decisions about which people to treat and what services to provide during an influenza pandemic *should not be made* based on socio-economic or other factors unrelated to these criteria.

Table 4.
Goals to Guide the Allocation of Limited Health Care Resources

	Primary Prevention	**Secondary Treatment**
Nonpharmaceutical Intervention	Examples: personal protective equipment Goals: assuring functioning of society and minimizing the spread of disease	Examples: ventilators, hospital beds Primary goal: minimizing illness, hospitalizations, and deaths
Pharmaceutical Intervention	Examples: vaccines Primary goal: assuring the functioning of society Secondary goal: minimizing the spread of the disease	Examples: antivirals, antibiotics Priority goal: minimizing illness, hospitalizations, and deaths Secondary goal: assuring the functioning of society

Conclusion

In major emergencies, decisions have to be made in a timely manner under high stress conditions and often in the face of incomplete information. This is the situation the state will most likely confront in the event of an influenza pandemic. Decisions by the federal government, state agencies, health care professionals, emergency management responders, and other critical institutions will need to be coordinated and will directly affect large numbers of residents. Under such conditions it will be important to have a set of ethical principles that serve as the blueprint to the coordinated response.

The work of the NC IOM/DPH Task Force on Ethics and Pandemic Influenza Planning encouraged stakeholders from a variety of groups to consider and discuss the ethical dilemmas that are likely to arise in the event of an influenza pandemic. Advance notice of these dilemmas may help people adjust to and prepare for the difficult decisions that may affect them later. However, the unpredictable nature of influenza pandemics requires that individuals, industries, and governmental entities continue to examine and adapt their roles in influenza pandemic preparation. **NCMJ**

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Pandemic Flu:
Why Faith Groups Must Care

J. George Reed

It's not time to panic, but it is time to plan. In 1918-1919, Spanish flu spread around the world. In the United States, more than 500,000 people died. Most health professionals agree that the world will face another flu pandemic at some point in the future. It could be H5N1, the strain of avian flu currently spreading around the world in birds, or it might be some later flu. But it will come.

Put aside for now the question of whether it's this bird flu and it hits relatively soon or another strain of flu many years hence. I want you to think about the potential impact of a pandemic.

One of the things that distinguishes flu pandemic from regular flu is that people will have little or no immunity to it. Health care systems could be overloaded and medical supplies will be in short supply. A flu disaster would be unlike a natural disaster. First, the area impacted would be much wider. North Carolina wouldn't be sending volunteers to Louisiana, nor would we be receiving help from other states. Second, the duration of the disaster itself, not just the response, would be much longer. A pandemic could come in waves over 12 to 18 months. There could be bans on travel, closings of schools, cancellation of events, and disruption of businesses.

Estimates are that as much as 20% of the population could get the flu and as many as 40% of workers might stay home at its peak because they are sick, a family member is sick, or they don't want to risk exposure. Think of the impact these absences would have on a community's infrastructure: utilities, water purification systems, food supplies and preparation (including transportation of food to groceries and restaurants), trash pickup, public transportation, medical care, and availability of prescription drugs.

An influenza pandemic, whenever it comes, will also disrupt church life and raise serious questions for churches and their leaders. Consider the potential impact on regular worship services; communion/Eucharist; hospital visits by clergy and laity; funerals, grief counseling, and other pastoral care; committee meetings and other church gatherings; child-care centers, soup kitchens, food pantries, and free clinics; national and international meetings; and missions trips.

> *"So, what should the faith community be doing? Our first step is still to get flu pandemic on our radar screens."*

And, some of the hard questions for churches:

- What is the duty of clergy regarding parishioners sick or hospitalized with the flu: to visit them as a sign of God's presence or to not visit so as not to spread the flu?
- In deciding whether to cancel activities, should the church act more quickly in order to set the example in preventing the spread of disease or less quickly because of the importance of gathering to worship during a crisis? Should parishioners help others, but risk spreading flu?
- Who makes decisions about canceling services or altering communion? Would a congregation follow a public health recommendation to limit services or wait until it was mandatory?
- Are there essential services within the church that must be continued during a pandemic?

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Also, think about some of the justice issues involved:

- Would lower-paid workers (support staff at hospitals, for example) be required to show up for work while higher-paid workers could stay home and telecommute? What happens to hourly-wage workers if businesses must close?
- In a time of greater rationing of health care, would poor people get to see a doctor, be admitted to a hospital, have use of a ventilator? How would limited supplies of vaccines and antivirals be allocated?
- What would happen to poor people who didn't have the resources to stockpile food and water, if those delivery systems were affected?

So, what should the faith community be doing? Our first step is still to get flu pandemic on our radar screens. Early last year, one state's council of churches asked bishops and other leaders about meeting with health officials to discuss a flu pandemic. Only two out of more than twenty expressed any interest. We all have a lot on our plates, but as one public health person pointed out, "If we try to make plans during the crisis, we're not planning, we're improvising."

Second, we must be at the table in the development of contingency plans. The state's public health and emergency planning agencies are hard at work and looking for community allies across the state.

Third, we must have firm plans for our congregations and judicatories. What supplies should be stocked now, or with the first news of the spread of flu among humans?

What can be done to help families make plans? The federal government has established checklists for a variety of groups, including faith communities. See them at www.pandemicflu.gov.

Fourth, we must be well enough involved and informed to be a voice for moral and ethical decision making, helping to balance the community's needs with our calling to treat all of God's children equally. In the event of a pandemic, we should also use our credibility in the community to be a source of good and true information.

Let me be clear: As of this writing the H5N1 avian flu has not been found in North or South America, even in birds. It has shown up in only about 274 humans worldwide (though more than half of them have died).[1] Almost all of the human cases were caught from birds, not other humans. The risk is if H5N1 mutates in a way that enables it to be transferred easily among humans. Then, because we have virtually no immunity, the world would have a pandemic, one that could spread rapidly around our interconnected globe.

The difficulty in raising these questions is that no one wants to spread panic. I feel a bit like Chicken Little ("The sky is falling") in writing this. But we are better prepared to deal with a crisis if we are informed and have made careful plans. Otherwise we could find ourselves improvising in the midst of a worldwide health disaster. **NCMJ**

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Shall We Gather By the River? Yes… No… Maybe So…

Paul L. Anderson

Many years ago, I would look into a black and white television and watch Andy Griffith sing while he sat on the front porch with Aunt Bee, Barney, and other characters from this timeless television show. Since then, many things have drastically changed in our world. We all have digital high definition means of viewing the historic television. Most of us are streaming television shows and or other visuals through our handheld, state-of-the-art multimedia devices.

Numerous facets of our lives have changed, while other things almost remain the same. The classic example is the manner in which faith groups worship their concept of God. The three basic faith groups that consider themselves monotheistic, Judaism, Christianity, and Islam, are still "gathering by the river" when they come together to worship. It is that sense of gathering that is essential to their "life giving stream," or the faith that carries them through the good times and bad. It is through the practice of fellowship, or sharing our faith with one other, we believe that we are "fellowshipping with the Devine—God."

My faith tradition is based upon the concept of gathering together. I am a Christian. It is the basic Christian belief that whenever two or three people are gathered in the name of Jesus, God's presence is manifest through the Holy Spirit. It is through fellowship with other believers that true worship of God occurs. This fundamental practice would drastically be altered if a flu pandemic invades our society.

An influenza pandemic would alter the entire context of the Christian faith and most other faith groups. The concept of a gathered assembly is predominant through all of Christianity. It starts when a child is born and continues through life cycles culminating with end of life rituals.

When a child is born, the Christian community awaits the day the child is blessed or baptized, or attains the blessings of God and the community in a service of worship. The parents, grandparents, aunts, uncles, and family friends all gather at the place of worship to witness this rite of entrance into the culture and receive blessings of both God and "the church," the gathered assembly. It is during this service that the child is either blessed or baptized by the priest or the pastor. This practice is essential in the belief structure of Christians. If this practice is omitted or deleted, the faith of parents and children is somewhat uncertain. This is similar for many other life cycle faith events. Would a flu pandemic eliminate the visitation of priest and laity to the hospitalized? Should the many acts of mercy such as soup kitchens, homeless shelters, and safe havens for the abused and fragile be dismissed? The religious community needs to ask itself the question of how will we justify not risking our lives for the benefit of others, which is the true essence of self sacrifice.

An influenza pandemic would interrupt the entire ritual of the gathered assembly, from birth to last rites in burial. Whenever the Christian community is not gathering, is it in willful disobedience to one of its commands by God? Most religious leaders have yet to engage in this meaning dialogue because it will completely shake the foundations of organized religious systems as we know them today.

The question is: How will the religious community manage a flu pandemic and maintain true faithfulness to the Holy Book? I am not sure how this flu pandemic will modify the view of God's requirements in acts of mercy and justice. Shall we gather at the river since our ultimate quest is to be with God? If our ultimate quest is to be God, do we continue as we have in the past and accept death as fate? This is the true essence of the real question.

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COMMENTARY

Eliminating Injustice Toward Disadvantaged Populations During an Influenza Pandemic

By George L. Saunders III, MD; Thea Monet, MAEd

In the spirit of its founders, A.M. Moore, M.T. Pope, L.A. Scruggs, and J. Williams, Old North State Medical Society (ONSMS) has dedicated itself to equity in health care, equal opportunity for black medical professionals, and equal care for minorities, including blacks, and very poor patients. The organization, which represents the interests of more that 1,200 minority physicians in North Carolina and thousands of patients from all walks of life, has been a voice for those without means for 120 years. In many instances, its members have provided health care when few or no other options were available. For members of Old North State Medical Society, finding ways to improve access to appropriate health care has required bringing truth to the phrase "with justice for all." Finding ways to infuse *justice* into protecting the health and wellbeing of those most easily overlooked, deliberately untouched and ignored, minimally regarded, and likewise treated has been one of our greatest challenges. ONSMS has not wavered in its commitment of "assuring equity in the delivery of health care to all people."

> *"Can there be justice for all in the midst of a flu pandemic outbreak?"*

Today, we are asked very necessary and important questions including:

- What might be done to eliminate injustice toward disadvantaged populations during an influenza pandemic?
- What policies and plans need to be in effect to ensure that those with limited incomes have what they need to stay healthy during a flu pandemic?
- What will happen to people and families who cannot stockpile food and water in preparation for a pandemic and the thousands of North Carolina children receiving their best or perhaps only meals through free breakfast and lunch provided at schools? When a flu pandemic emerges and schools close, what will they do?

We do not have all the answers, however, there are cornerstones for preparedness that can strengthen us despite racial, ethnic, educational, health, and financial disparities. First, a pre-emptive action leading to promoting justice for the disadvantaged during an influenza pandemic involves gathering together the grassroots leaders of diverse racial, ethnic, economically stratified, disenfranchised, vulnerable, underserved, and underrepresented groups. Community physicians, pastors, community action program workers, local business leaders, particularly those providing personal care to residents like barbers, beauticians, and elder leaders, are key to any meaningful efforts to raise awareness about a pandemic crisis. They are also potentially the most valued teachers. Assessing their perceptions and expectations of community needs during an influenza pandemic represents a first step in the process of winning their long-term commitment to support local community preparation for flu pandemic preparedness. Engaging leaders who will be respected, followed, trusted, and favored by local community members will be integral to the best possible decision making or planning for and with communities across the state. Self-determination and determination in the interest of one's community engenders internal strengths. That strength will increase potential for compliance with rules of the day. Nothing can be more defeating than feeling helpless to provide assistance and guidance in a situation during a period of panic and absence of confidence in favorable outcomes.

Building bridges that forge partnerships and alliances between grassroots leaders, government, and public and private resource providers is a second key for enabling preparedness and eliminating injustice. Communities have to understand the inherent challenges posed during a pandemic long before it arrives. How vaccine is distributed, how ventilators are assigned, where priority is placed and where it is not are issues

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that should be shared with the community. Understanding the implications of these shortages enables fuller response and commitment to behavior that protects against and minimizes further spread of disease. When community leaders understand the challenges that await us during an influenza pandemic, they can actively promote preparedness and cautious behavior through their organizations' activities and venues. This action can save lives during an outbreak. Community leaders can also couple preparedness messages with other health improvement messages that remind us of the importance of vaccinations and getting medical care early for oneself and loved ones.

A pivotal key in eliminating injustice toward members of underserved communities is having community leaders and health organization leaders collaborate with one another and increase community representation on committees, panels, task forces, and planning groups tasked with setting guidelines that will prepare us for the challenge that lies ahead. Involvement in policy development can increase community access to the array of resources that will be needed during the influenza. The goal is to keep people fed, protected, and informed about where to turn and what to do next to minimize the threat of further contamination. By getting individual and families, especially those who are historically undeserved and discriminated against through this event safely, we reduce health disparities that can occur during a pandemic.

Reducing injustice involves developing protocols for resource distribution that reflect knowledge of the needs of special populations. Acknowledging intent to be fair and equitable in providing resources to communities will reduce the incidence of real and perceived instances of injustice. Public discussion about potential for injustice toward disadvantaged populations, whether on radio, television, or in the newspapers, will greatly deter injustice. Public buy-in on limiting and reporting any evidence of injustice in the treatment of people can also have a positive effect. Statements from public officials announcing how important it is to exercise just and equitable distribution of resources and services during an influenza pandemic can also curtail injustice. All off this becomes a cornerstone to getting us through the emergency because many people of color feel a heighten sense of distrust in public response systems, government, and the established rules of the day. The justified memories of unequal treatment in all areas of life may dominate.

All communities need information about the potential for an influenza pandemic and the need to prepare in advance for such an emergency. Early outreach is important because avenues of communication with public health and government may be limited. It is suggested that caution be used to avoid inciting panic in the general public. However, people must be informed and aware. Therefore, selecting community leaders to provide such messages will likely minimize premature panic.

Community leaders need the benefit of early training and support. They will be integral to squashing rumors, preventing stereotyping, and restoring a sense of order if communication breaks down.

Can there be justice for all in the midst of a flu pandemic outbreak? Neither children, the disabled, those who cannot stockpile food, those who do not speak English, nor the elderly should be hungry; nor should they have unequal access to treatment during a flu pandemic. Treatment, prophylaxis, and basic needs (ie, food, shelter) should be provided in a nondiscriminatory fashion. The following guidelines will help prevent disparities during a flu pandemic.

- Make all resources available on the basis of a distribution plan that permits fair distribution to all. The disenfranchised and people of color should have an opportunity to contribute to the distribution plan. It is imperative that their voices be heard from the beginning of the planning process and that they understand the resource limitations that will exist during this crisis.
- Develop a process to immediately correct misallocation of any resource(s). Ensure that the public can witness and validate the correction(s). This includes eliminating any known obstacles and developing distribution formulas that adjust for social disparities, financial and economic disparities, mental health disparities, and primary health disparities.
- Prepare culturally relevant materials to educate the broader public about this situation and techniques for reducing its impact. All materials should be current and easy to read and understand. They should also emphasize issues important to disadvantaged individuals and those with preexisting health conditions.
- Encourage public health departments to invite community leaders to the planning tables to share in local discussions on protocol development and to provide feedback from their community's perspective.
- Invite every community organization, public and private, to assist in planning for and meeting the actual and anticipated needs of disadvantaged populations in their communities. Make every possible effort to identify available resources for use during a crisis and see that community leaders have ways to access resource providers.
- Engage community members to assist others in identifying instances of prejudicial thinking, biased behavior, and acts of unfair distribution. Provide them with information about reporting such instances through the appropriate channels in time for effective interventions.

Combining our strengths, pulling together, and preparing based on these guidelines will help prevent disproportionate challenges to disadvantaged populations. However, we must recognize that such injustices will still occur and we must identify and rectify such problems.

An example of such uniting and recognition is the collaborative work of the North Carolina Division of Public Health (DPH), Old North State Medical Society, and a number of community organizations. Those organizations include the National Association for the Advancement of Colored People (NAACP), North Carolina Commission of Indian Affairs, El Pueblo, the Mexican Consulate, Alliance of Black Elected Officials, North Carolina Institute for Economic Development, North Carolina General Baptist State Convention, Webb Patterson Inc, JMG

Marketing, Brad Thompson and Associates, NC Mutual Life Insurance Company, and numerous other community-based public, nonprofit, and private organizations. These organizations have a steadfast interest in uplifting the community and protecting its members in every possible kind of way. Our collective interest brought us together to plan for these issues.

The Old North State Medical Society and DPH are partnering through a contractual relationship to guide the development of statewide strategies to reach vulnerable populations, as mandated in the funding guidance. They will implement a health disparities prevention project focusing on flu pandemic planning, preparedness, and response in African American, American Indian and Hispanic/Latino communities. Furthermore, ONSMS will bring to bear the leadership, vision, perspectives, knowledge, skills, abilities, and commitment of the state's African American medical community to assist the Division of Public Health in assuring that African American, American Indian, and Hispanic/Latino communities in North Carolina are reached in the event of a flu pandemic and that the communities are not disproportionately or adversely affected by the outbreak.

This action gives promise for achieving justice for all through the aforementioned guidelines. It also directly responds to the need for the development of culturally relevant documents and culturally appropriate involvement of minority communities in disaster planning, preparedness, and recovery, as recommended by the August 2005 report prepared by the National Center for Disaster Preparedness.

The partnership between DPH and the ONSMS is establishing a Disparities Prevention Advisory Committee and developing an action plan to promote, facilitate, and implement at least four pilot projects that address flu pandemic planning, preparedness, and response in African American, American Indian, and Hispanic/Latino communities. The partnership will also identify barriers to and facilitators for communicating flu pandemic-related risks to African American, American Indian, and Hispanic/Latino communities and link and facilitate communication and interaction between key leaders in those communities and public health leaders who are engaged in flu pandemic planning.

This work will also involve conducting three events in the African American, American Indian, and Hispanic/Latino communities. Feedback from these events will enhance public health's understanding of how to meet community needs in the event of a flu pandemic. The final report from this collaboration will include recommendations for next steps in preparing for and responding to the needs of racial and ethnic minority communities during a flu pandemic.

Ensuring fair and equitable distribution of resources or "justice for all' is possible when people are educated about the facts, included in developing protocols and response plans, while respecting and valuing those affected as problems arise. The answers to the primary questions reside in the continuing commitment of leaders across the spectrum to collaborate in the interest of full and equitable distribution of goods and services during an influenza pandemic. **NCMJ**

COMMENTARY

Manufacturing a Flu Vaccine

Marguerite Donoghue Baxter, RN, MSN

Vaccines are considered the most cost-effective public health intervention, saving millions of lives every year by preventing major human diseases. The new Novartis Vaccine and Diagnostics Division is on the vanguard of vaccine development to prevent seasonal flu and, potentially, also pandemic influenza. New research techniques and manufacturing technologies have sparked a revival and strong double-digit growth in this sector of the pharmaceuticals industry, as well as provide life-saving intervention for people most at risk for preventable viruses.

Despite availability of safe and effective vaccines, seasonal influenza causes millions of infections and kills an estimated 250,000 people worldwide every year. Health authorities in many countries are preparing to increase coverage rates for seasonal flu vaccine to comply with a recommendation from the World Health Organization (WHO) to reach 75% coverage of at-risk groups—the elderly and people with chronic diseases—by 2010. The United States is leading the way, recommending seasonal flu vaccinations for all Americans over the age of 50, children from the age of two months to five years, and other at-risk groups, including health care workers.

> *"Despite availability of safe and effective vaccines, seasonal influenza causes millions of infections and kills an estimated 250,000 people worldwide every year."*

During the 20th century, there were three pandemics, or simultaneous worldwide epidemics of influenza. The 1918 "Spanish flu" killed more than 20 million people. Subsequent pandemics in 1957 and 1968 were less severe but also killed millions around the globe. It is the concern about future pandemic influenza that has mobilized health regulators to encourage manufacturers to improve the development and production of vaccines in advance of an outbreak. As such, production capacity is expected to rise sharply by 2009—yet the WHO acknowledges that the projected rise in capacity for seasonal flu vaccine will not reach levels sufficient to serve the worldwide population in case of a pandemic. Newer technologies, however, can help boost production and availability of the necessary vaccines.

Cell Culture-Based Influenza Vaccines

Cell culture-derived influenza vaccines (commonly referred to as "flu cell culture" vaccines) use modern biotechnology cell cultures rather than chicken eggs for primary production. Current egg-derived vaccine production requires several months of logistics for ordering and receiving eggs. This lead-time can hinder the response to unanticipated demands such as the discovery of pandemic strains, production failures, and seasonal influenza virus strain changes. In contrast, flu cell culture production enables flexible, faster start-up of vaccine manufacturing, and is independent of the availability of eggs, providing a particularly important advantage in the event of an influenza pandemic.

Also, cell culture vaccines are noninferior to the traditional alternatives. In one large-scale Phase III study conducted in Poland during the 2004-2005 influenza season, cell culture-derived influenza vaccine was shown to be as effective as egg-based vaccines in provoking an immune response (immunogenicity) against influenza.

Dispensing with eggs in production also promises benefits to people who are allergic to eggs. Currently, strains of seed virus used in seasonal influenza vaccine are selected partly because of their ability to grow well in eggs. This egg adaptation will not be needed with cell culture-based influenza vaccines, which could translate into better efficacy of seasonal vaccines by more closely

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matching the vaccine with the influenza strain in circulation.

In July, 2006, Novartis announced plans to build the first cell culture-derived influenza vaccine manufacturing plant in the United States at a new site in Holly Springs, North Carolina. In parallel, Novartis is making additional investments to expand capacity for flu cell culture vaccine production in Marburg, Germany. Novartis Vaccines submitted the first application for a flu cell culture vaccine to European regulators in June of last year, following successful completion of Phase III clinical studies. In the United States, clinical trials of the cell culture influenza vaccine began in 2005 and are ongoing.

The United States government offered key support for the new technology when the Department of Health and Human Services (HHS) awarded Novartis a contract of up to $220 million to support development and manufacture of cell culture-derived influenza vaccine in the United States. The contract is part of a larger HHS initiative to expand domestic infrastructure for influenza vaccines, as well as ensure domestic capacity to produce 600 million doses of pandemic influenza vaccine within six months of a pandemic declaration. Part of the HHS contract will support planning and equipment for the new cell culture-based influenza vaccine manufacturing plant in North Carolina.

Pandemic Preparedness

Cell culture technology represents a potentially critical tool to boost production capacity, and thereby help to reduce the current gap between potential vaccine demand and supply anticipated during an influenza pandemic. The WHO's latest action plan for a global influenza pandemic warns that potential vaccine supply today is "several billion doses short of the amount needed to provide protection to the global population."

A new influenza strain, known as H5N1, is spreading through bird populations in Asia, Africa, and Europe. Only 244 human cases have been recorded so far, but, chillingly, the fatality rate has been more than 50%. Though avian flu remains primarily an animal disease, if the virus develops the capacity for sustained, efficient human-to-human transmission, it could spread quickly around the globe.

In 1999, Novartis Vaccines was the first manufacturer to successfully test an experimental vaccine against a variant of the H5N1 influenza virus following the initial outbreak of avian flu in Hong Kong. Ironically, because the H5N1 strain that caused the outbreak was lethal to the egg cells that are needed in egg-based production, Novartis Vaccines was forced to use a closely related H5N3 strain to produce its vaccine.

That initial H5 vaccine also included a proprietary adjuvant called MF59. An adjuvant is a substance added to a vaccine to boost the body's immune response against the vaccine's active constituent, called the antigen. In 2003, a follow-up study showed that the adjuvanted H5 vaccine also offered cross-protection against H5N1 strains that have circulated across Asia since the initial Hong Kong outbreak.

Importantly, the use of an adjuvant could provide effective protection at lower doses than nonadjuvanted vaccines, potentially enhancing production capacity and supply in the event of a pandemic. The WHO has proposed clinical studies of H5N1 vaccines, including MF59 and other adjuvants with a proven safety record in humans, as part of its global pandemic action plan.

The Novartis cell culture-based pandemic vaccine is still in preclinical development but clinical trials are expected to begin this year. In Europe, Novartis was one of several vaccine producers in 2006 to file "mock-up," or stand-by, registrations for a pandemic vaccine that would enable companies to begin production immediately if the WHO declares a pandemic. Novartis has also submitted a dossier to the European Medicines Agency for a H5N1 prepandemic vaccine that could be sold freely to private individuals and companies, in addition to governments and other payors.

Meanwhile, Novartis Vaccines has received orders from the United States and United Kingdom to supply prepandemic H5N1 avian influenza vaccine—in some cases containing MF59 adjuvant—for national stockpiles.

Conclusion

Cell culture-based influenza vaccines provide greater reliability, faster production, and more accurate viral strain matching. As health agencies prepare for potential pandemics of influenza, new strains of seasonal influenza and avian influenza, this cutting edge technology will be of critical importance to the health of at-risk populations. **NCMJ**

COMMENTARY

Likely Ethical, Legal, and Professional Challenges Physicians will Face During an Influenza Pandemic

Janelle A. Rhyne, MD

Health care workers are some of the most integral front-line responders during natural and biological disasters. As such, they often face serious risks to their health and well-being. Many physicians volunteer to assist during crises because they recognize the value of their skills to the needs at hand. However, other physicians are reluctant to expose themselves, and by extension, their families, to such risks. In preparing for a public health crisis like an influenza pandemic, it is important to take steps to eliminate or minimize the risks physicians will incur if they choose to assist with serving the needs of the population.

Events of recent years provide examples of inadequate measures to properly minimize risks to physicians. The outcomes of these situations illustrate the importance of preparedness for public health emergencies and natural disasters. In 2005, Hurricane Katrina hit the Gulf Coast Region and in its aftermath, 6,000 physicians left the area. This led to a need for additional medical personnel to travel to the region to assist with the injured and deceased. Furthermore, many of those who left have yet to return and some have no plans to do so.[1] Now, much of the region has a shortage of providers, which may adversely affect reconstruction efforts.

> *"If, for the public good, society expects physicians to voluntarily expose themselves to potentially lethal risks, what ought society provide physicians in return?"*

The 2003 Severe Acute Respiratory Syndrome (SARS) outbreak in Canada offers another example of risks to health care professionals and the challenges faced in minimizing their risks. Forty-three percent of those falling prey to SARS were health care workers with a case fatality rate of about 15%.[2] As a result, staffing at Canadian facilities treating SARS patients became a problem because many providers did not want to expose themselves to danger. In addition to the health risks, 49% of SARS health care workers reported social stigmatization and 31% reported ostracism by family members.[3] Regardless of these physical, social, and emotional challenges, failure to report to work resulted in permanent dismissal of hospital staff. As a result, many health care workers voluntarily left the profession for new careers rather than expose themselves and their families to risks associated with caring for patients with potentially lethal infectious diseases.

Ensuring a positive work environment for physicians is important because a recent analysis published in *Health Affairs* projected a shortage of physicians that will grow even worse within the next fifteen years.[4] Therefore, developing a plan to minimize the stresses that could affect physicians during a public health crisis is more critical than ever. Furthermore, it is important to remember that practicing physicians and other health care workers are not the only ones providing services during an emergency. Medical students, interns, residents, and other training health care professionals provide emergency assistance and are the future caregivers. In addition, the health care workers themselves are not the only ones at risk when they expose themselves to potential infections. Many health care workers are concerned about the safety of their families in the event that they were to become infected. Therefore, society needs to safeguard families as well as physicians and medical trainees.

In preparing for a public health crisis, it is important to understand the ethical and professional standards that guide physicians in their practices. Current North Carolina Medical Board policies and regulations only address the obligations of a physician to an established patient. The Board does not assert

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an ethical requirement for a physician to accept a new patient or treat or care for anyone. In its policy statement entitled "Termination of the Physician-Patient Relationship," the Board "recognizes the physician's right to choose patients and to terminate the professional relationship when he or she believes it is best to do so."

Several national professional societies addressed ethical imperatives to provide care after the September 11, 2001 terrorists attacks by adopting policy statements that focus on the medical professional's duty to care in a public health emergency. The American Medical Association (AMA) Policy E-9.067 Physician Obligation in Disaster Preparedness and Response says:

> National, regional and local responses to epidemics, terrorist attacks, and other disasters require extensive involvement of physicians. Because of their commitment to care for the sick and injured, individual physicians have an obligation to provide urgent medical care during disasters. This ethical obligation holds even in the face of greater than usual risks to their own safety, health, or life. The physician workforce, however, is not an unlimited resource; therefore, when participating in disaster responses, physicians should balance immediate benefits to individual patients with ability to care for patients in the future.

The AMA Ethics Manual statement H-140.873 says: "Front-line physicians have an increased ethical obligation to avail themselves of safe and effective protective and preventive measures (for example, influenza vaccine)."

The American College of Physicians (ACP) Ethics Manual addresses medical risk to physician and patient and the responsibility to work with the following statements:

> Traditionally, the ethical imperative for physicians to provide care has overridden the risk to the treating physician, even during epidemics. In recent decades, with better control of such risks, physicians have practiced medicine in the absence of risk as a prominent concern. However, potential occupational exposures such as HIV, multidrug-resistant tuberculosis, severe acute respiratory syndrome, and viral hepatitis necessitate reaffirmation of the ethical imperative. Physicians should evaluate their risk for becoming infected with pathogens, both in their personal lives and in the workplace, and implement appropriate precautions. Because the diseases mentioned above may be transmitted from patient to physician and because they pose significant risks to the physician's health, some physicians may be tempted to avoid care of infected patients. Physicians and health care organizations are obligated to provide competent and humane care to all patients, regardless of their illness. Physicians can and should expect their workplace to provide appropriate means to limit occupational exposure through rigorous application of infection control methods. The denial of appropriate care to a class of patients for any reason, including disease state is unethical.

According to these statements, medical professional associations and societies support the safety of physicians, but also assert an ethical obligation and responsibility to work during a public health crisis despite personal risks. The preeminence of the AMA and the ACP notwithstanding, the ethical imperatives to work they elucidate do not bind physicians who may, in good conscience, believe otherwise.

Nonetheless, whatever obligations physicians may have, surely the public has reciprocal obligations. If, for the public good, society expects physicians to voluntarily expose themselves to potentially lethal risks, what ought society provide physicians in return?

The following suggested remedies address some of the concerns that may contribute to a physician's reluctance to provide care in a health crisis situation such as an influenza pandemic.

1 Establish liability immunity for good faith medical treatment and triage[a] judgments.
2 Provide antiviral medications and vaccinations for physicians and their families.
3 Provide personal protective equipment such as masks, gloves, gowns, etc.
4 Provide community support services (ie, health services, food, and supplies) for physicians' families in the event of extended absence from home.
5 Suspend Health Insurance Portability and Accountability Act (HIPAA) regulations enforcement in cases of necessary and/or inadvertent violations in a crisis situation.
6 Provide a compensatory program modeled on workman's compensation for physicians who die or become disabled as a consequence of providing care in a pandemic.

The development of policies by our legislature to ensure the safety of our practicing physicians and physicians in training will benefit the present and future care of patients in North Carolina. If, however, reciprocal obligations to physicians are not acknowledged, failure to do so may adversely affect physicians' decisions to continue practicing medicine and it may dissuade others from becoming physicians in the first place. **NCMJ**

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[a] The American College of Emergency Physicians Policy on triage states that "when the number of patients and severity of their injuries overpower existing resources, triage decisions must classify patients according to both their need and their likelihood of survival. The overriding principle should be to focus health care resources on those patients most likely to benefit who have a reasonable probability of survival."

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Roles of Hospitals During an Influenza Pandemic

Barb Bisset, PhD, MS, MPH, RN, EMT

With most area hospitals operating at about 95% to over 100% capacity on any given day, it's evident that a flu pandemic will quickly overwhelm our ability to treat the thousands of patients who will surely stream toward the nearest emergency room.

Plans are being made now to cope with this potentially explosive threat. If worst-case projections were to materialize, Wake County could have as many as 225,000 residents in varying degrees of illness during a pandemic. In addition to readying our facilities and professional staff, the highest priorities are to prepare people to care for themselves and others at home, and to work with community partners to pool resources.

"We know that, logically, the first place people will turn to is their nearest hospital, but realistically, it will be impossible for any health care facility to expect to manage the huge influx of patients," says WakeMed Health & Hospitals CEO William K. Atkinson, PhD. "We see our leadership role as putting into place now a wide range of plans, including in-house preparation and training, and a vital network of community partnerships and public education. The absolute key to our success will be collaboration with other community partners."

Like most hospitals, WakeMed is approaching its organizational planning on five levels:

- ***Individual and personal preparedness*** – Informing the public that individuals will need to assume a great deal of responsibility for their own care or for that of their loved ones.
- ***Employee preparedness*** – Helping staff work through their own logistics to ensure they can be at work. This includes thinking through childcare options if daycares and schools are closed and taking other steps to put their personal lives in order.
- ***Organizational preparedness*** – Organizing the hospital system, at the executive level, to clearly understand necessary actions to be taken at both the community level (in coordination with other area hospitals) and within its own organization (eg, implementing the Hospital Incident Command System).
- Departmental preparedness – Educating each department within the hospital about how it specifically fits into the institution's bigger plan, such as considering every employee as essential and knowing that job duties may change rapidly as needed. For instance, we should expect that one person might take on tasks that are handled by many people on a normal day (eg, drawing blood, delivering food, emptying trash) in order to reduce the risk of exposure to affected patients.
- ***Planning with key community partners*** – Coordinating with other hospitals, home health agencies, the county's public health department, and emergency responders such as fire and police departments and emergency medical services. In addition to local partners, we need to understand what the state is doing and how the state fits into federal plans.

> *"If worst-case projections were to materialize, Wake County could have as many as 225,000 residents in varying degrees of illness during a pandemic."*

Finally, the most difficult part of planning involves grappling with the inevitable ethical quagmires that await us in deciding who gets treated and how. How do we determine the sufficient level of care without lowering quality of care? Who will get respirators and limited medicine? Currently, many of society's health care efforts are directed at the elderly. This will, in all likelihood, not be the case when resources and treatment options are severely restricted.

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Special Challenges Faced by Hospitals

As Dr. Atkinson noted, people are likely to turn first to the nearest emergency room. Hospitals need to be prepared to deal with large numbers of people at once because many people will likely fall ill within a relatively short time span. Hospitals should also be prepared for the fact that ill people are likely to be in panic mode or close to it. This will require having traffic control and security measures in place to ensure safety of both personnel and patients.

Once patients are inside our doors, we need guidelines for triage decision making, with an emphasis on saving the most lives. Subsequent decisions will revolve around who gets treated, and then *how* they get treated. For those who are turned away, will we be prepared to arm them with information and possibly supplies that will help them cope?

When patients are admitted, another range of issues needs to be addressed, such as authority to use sufficient standards of care that may be different from the normal levels, maintaining a healthy, hygienic environment, and doing our best to minimize the risk of exposure to the caregivers. In addition to ensuring proper quarantine procedures and protective equipment for staff, we need to allow for staff rotation to prevent burnout, and provide stress management programs to help staff cope with the emotional aspects of such an overwhelming event.

Additionally, hospitals need to make sure other contingency plans are in place, including figuring out how to sustain core business activities over several weeks, mapping how financial issues related to reimbursement will be handled, and determining how to respond to interruptions in service, such as sanitation, water, or power. We must anticipate shortages, including in personnel (assuming various degrees of absenteeism) and supplies (because of the very real probability of disruption in deliveries due to suppliers' own absenteeism issues).

One of the most critical aspects of dealing with a pandemic—and one of the biggest challenges—will be both internal and external communications. From an internal standpoint, we need to anticipate employee fear and anxiety and be prepared to respond to rumors and misinformation quickly, calmly, and factually. WakeMed already has in place an "E-Notify System" for key response teams, allowing us to quickly alert needed personnel.

Externally, we will need to disseminate timely and accurate information to the community, including the status of our response and consistent messages about when and where to seek care. It will be critically important that all responding agencies coordinate their information efforts with community partners by using a Joint Information Center (JIC), with a single spokesperson for the JIC or from each agency. This will reduce confusion and present a more cohesive approach to the public.

Another challenge will be helping families, particularly those from out of town, obtain information about friends and family members they are unable to reach. As part of the planning process, decisions should be made about how to handle these calls and all communications, including designating a public spokesperson for the hospital who will represent us at a JIC if one is established.

Public Policy Options Needed

In the spirit of collaboration and preparedness, a flu pandemic drill was held in February 2006, bringing together 250 individuals from 36 agencies across the region. Wake County's hospitals participated (WakeMed Raleigh Campus, WakeMed Cary Hospital, Rex Healthcare, and Duke Health Raleigh Hospital), as did state health officials, Wake County Human Services, Wake County Emergency Medical Services, and a number of representatives from law enforcement, municipal governments, and nonprofit agencies.

Separately, the North Carolina Hospital Association created a Disaster Roundtable in response to the September 11th attacks that resulted in mutual aid agreements signed by all eligible North Carolina hospitals in 2004. These agreements address the sharing of resources, including staff, and provide a good foundation for any mass casualty disaster.

While these efforts are beginning to address the public policy issues raised by a flu pandemic, many remain. Wake County's Community Health Director Gibbie Harris sees the thorniest issues as the ethical dilemma of who gets treated, and how? "Everybody is really struggling to even have a conversation about this, because it's so difficult and it's so huge," she said. "We know there will not be enough respirators, enough hospital beds, enough medicine. Whether we are going to be able to get to a place in this country where we make some public policy decisions on this remains to be seen. If we can't, then the decisions are left to organizations or, when you get right down to it, to individual doctors."

Some decisions over who receives care will be performed initially by the 9-1-1 emergency response centers. In Wake County, callers are evaluated and placed in one of five categories. This same approach can be used in a pandemic to make preliminary decisions about who is even transported to a hospital or another care facility says Wake County Emergency Medical Services (EMS) Medical Director Brent Myers, MD, MPH.

Another public policy issue under consideration is the role of community health providers in a pandemic. For instance, public health departments could serve as a bridge for hospitals by establishing alternate care facilities that can serve those who are not the most critically ill but are unable to care for themselves at home. Harris believes all communities should explore possible alternative care venues as part of the planning process and then work out agreements that establish roles and sharing of supplies and other resources. "The key is to look in your county or your region, and collaborate and consolidate resources as part of your planning process, knowing that you will need more capacity than hospitals can provide and knowing there will be people who need different levels of care," she said.

An innovative example of planning ahead and using resources wisely is the approach taken by Wake County EMS. Currently, all EMS personnel are trained to give shots. Even though a specific vaccine would likely not be available, having this skill available adds value to the health care sector. "We know we need to protect our workforce and keep them well enough to come to work," says Dr. Myers. "So today, we are all able to administer vaccinations, and we practice annually with flu shots. If a vaccine is available before or during a pandemic, we will be able to step up and help."

Dr. Myers says his agency learned lessons shared by the Toronto EMS during the February 2003 SARS outbreak, and recommended that others use those lessons as a basis for planning. "Putting certain protocols into place early, such as what type of protective gear should be worn, provides EMS personnel with the confidence that their own risk of exposure will be minimized," he says. "Our own responders need to know that we will modify some procedures as needed or outline the steps they should take to reduce their own chance of infection, and that will increase our chances that they will come to work when and where we need them."

He echoes advice about forming partnerships now and modifying existing plans rather than starting from scratch. "The number one key is to make sure that you sit across the table and talked with your public health representatives," he says. "Often, we operate in different spheres, but you have a lot of catching up to do if you are sitting down for the first time in a crisis situation."

Conclusion

As is the case with any emergency planning, the key to preparing for a flu pandemic is to think through all of the "what if" scenarios and get plans in place now for future use. The day the first wave of flu patients presents to your emergency room is *not* the day to begin planning how best to handle it. The large number of resources available through the federal and state governments are a good place to start. They provide guiding principles and checklists, such as a United States Health and Human Services' booklet on bioterrorism and other public health emergencies, called *Altered Standards of Care in Mass Casualty Events*.[1]

In addition, exploring potential collaborations with partners takes time, so reaching out to other area hospitals, public health departments, and nonprofits is a good way to form working partnerships. Deciding which resources can be pooled, including personnel, and drawing up legal or other formal agreements ahead of time can make for much more efficient operations later.

Also, it's important to draft a plan in advance that can be shared with your organization and the general public, so that everyone has a clear understanding of what to expect, where to go, and who to call for information. If you do not have plans in draft stages, please make this a priority for your organization. If you have plans well underway or in place, congratulations! Let's hope that you will never need to use them. **NCMJ**

Contributions from Kim Gazella.

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COMMENTARY

All Politics, Pandemics, and Plans are Local

John Morrow, MD, MPH

As the threat of a flu pandemic becomes more of a possibility with each passing month, local health departments are busy preparing local flu pandemic plans. Local health departments tasked with the mission of protecting the public health have taken the lead in local preparedness for such an event. This is a daunting task.

North Carolina's local health departments were originally established in the early 1900s to help deal with significant communicable disease threats like typhoid, yellow fever, and tuberculosis. As these diseases were controlled with interventions such as improved sanitation, vaccines, and antibiotics, the infrastructure and funding support for these communicable disease programs drastically deteriorated. Most current local health department staff members have never dealt with a large, serious local epidemic of a communicable disease, and none have dealt with a true pandemic. This situation is analogous to a fire station that has not fought a fire in a very long time. With only limited state and federal government support, local public health departments have struggled to maintain or rebuild their epidemiology functions.

Federal bioterrorism funding provided to state public health departments since September 11, 2001 has somewhat improved this situation because the processes and interventions for bioterrorism are similar to those for other emerging infectious diseases of natural origin like a flu pandemic. Furthermore, North Carolina laws have been strengthened to help state and local departments deal with serious communicable disease threats. Also, local health department staff members have been trained in incident command system (ICS). The ICS emergency structure, initially developed by the United States Forest Service to fight fires, is now used by all types of emergency responders during various incidents or disasters. For example, both hurricane Ernesto and the *Tall Ships* event in Morehead City used ICS in 2006. This system allows all emergency responders to speak the same language and to read from the same page when a crisis occurs.

The newest challenge for local health departments is to slow the onset and progression of an influenza pandemic within their communities until a vaccine is available. Although many in our society may expect a solution for pandemic problems to come from space-age science labs far away or from the Centers for Disease Control and Prevention, the truth is that the most powerful interventions will likely be basic sanitation methods that have proven themselves for thousands of years. During a pandemic, simple things like cough etiquette, hand washing, and social distancing can make the difference between life and death. Educating people with this critical information expeditiously and in an easily understandable format is one of our greatest challenges today. These interventions will be most effective if the behaviors are well ingrained among the population *before* the pandemic arrives.

> *"During a pandemic, simple things like cough etiquette, hand washing, and social distancing can make the difference between life and death."*

North Carolina prides itself as being one of the best prepared states for disasters. Much of this confidence is attributable to the state's extensive experience responding to hurricanes and other weather-related events. However, unlike a weather event, a pandemic will likely impact the entire state simultaneously and be much longer in duration (eg, 12–18 months). Unlike a hurricane or similar local disaster, the cavalry is not coming to save the day during a pandemic. It will be left up to the local communities to sustain themselves and care for their families and neighbors for an extended period of time.

The most valuable lesson that I learned as a local health

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director from Hurricane Floyd is that, in a time of crisis, most people will do what you ask them to and even more. Although laws may exist for enforcing social distancing measures, it is unlikely that they will actually be enforced on the local level during such a crisis. However, I believe the public will self-enforce most of these public health interventions. People will respond to the public messages they receive. Therefore, it is critical that public information come from a trusted source and be accurate.

A bigger public health problem during a pandemic will be controlling limited assets that will be in high demand when many people fall ill. Included in this list will be hospital beds, ventilators, and antiviral medications. We will need to distribute these fairly and in an open manner. This is where local boards of health can be helpful. Local boards of health exist in every county and serve as the policy-making body for the health departments. In the setting of a pandemic (or any other public health crisis), the local Board of Health (BOH) can be a critical component to maintaining social order and in the continuation of local government operations. The eleven member BOH is appointed by the County Commission and is composed of seven professional members representing medicine, nursing, pharmacy, dentistry, optometry, veterinary medicine, and engineering. Three additional at-large members and one representative from the County Board of Commissioners fill the remaining seats. During a pandemic, this board can help reassure a skeptical public that limited services and supplies like vaccines and antiviral medications are distributed in a fair and equitable fashion. The Board of Health can help ensure an objective and nonpartisan review of these very acute and complicated public health problems and can also help to insulate elected officials from these potentially volatile issues. The other advantage the Board of Health has is that, unlike ordinances passed by the County Board of Commissioners, the rules approved by the Board of Health have jurisdiction for the whole county, including all of its municipalities. Infectious diseases like influenza have no respect for political boundaries, thus our public health interventions must also not be restricted by these.

The types of interventions that will be necessary will depend upon which pandemic phase we are in. For instance, if the initial cases of a flu pandemic present themselves in a North Carolina county, as in World Health Organization (WHO) phase 4,[1] then isolation, quarantine, and antiviral treatment and prophylaxis may all need to be quickly instituted. On the other hand, if our counties are not affected until late in the pandemic (WHO phase 6[2]), then isolation and quarantine may be of little use and the supply of antiviral medications will likely not be sufficient for all those in need. Guidance from the World Health Organization, Centers for Disease Control and Prevention, and North Carolina Division of Public Health will likely be adjusted throughout the pandemic as we learn more about the virus and its transmission and treatment.

Local pandemic plans must be flexible enough to quickly adjust to these different scenarios. These plans should be designed by a multidisciplinary team including representatives from local governments, businesses, hospitals, schools, religious groups, and volunteer and other community organizations. These plans must be cross-checked with other agency and entity plans to make sure that resources are not planned to be in two or more places at the same time, and to make sure that roles and procedures are clear to everyone involved. The plans need to be agreed to and signed by the major partners and should be updated annually. They should also be exercised on a regular basis to identify what works well and what doesn't. As we witnessed with hurricane Katrina, it doesn't matter how well the federal and state plans are written if they cannot be effectively implemented on the local level.

In facing this challenge of preparing for the next pandemic influenza, we must prepare ourselves, our families, our workplaces, and our communities. Effective preparation efforts are already under way, but certainly much more can be done to help every community feel ready. Our goal in the east is to be as well prepared for a pandemic as we are for a hurricane. I just hope and pray that the pandemic and hurricane don't happen at the same time." **NCMJ**

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COMMENTARY

Pandemic Influenza and the Law:
Isolation, Quarantine, and Other Legal Tools for Containing Outbreaks

Jill Moore, JD, MPH

Today, governments, health care providers, businesses, and others are developing plans to respond to an influenza pandemic. These plans may discuss isolation or quarantine, or use related terms such as social distancing. But what do they mean by those terms?

The words isolation and quarantine, in particular, are used different ways by different people. For a physician, the word isolation may suggest precautions that are taken against the spread of infection, or a particular place in a health care facility where people with infectious diseases are treated. For the general public, the words may conjure up images of what I call the "TV movie of the week" form of isolation or quarantine: a home with a red-lettered sign on the door, a subdivision surrounded by a chain-link fence, or roadblocks manned by armed law enforcement officers. But for the public health system, isolation and quarantine are simply two of the legal tools available to control the spread of communicable disease. In North Carolina, these tools are part of a comprehensive legal framework for communicable disease that includes:

- laws that allow the public health system to detect communicable disease within the population,
- laws requiring public health agencies to investigate cases and outbreaks of communicable disease, and
- laws that specify—and require individuals to comply with—communicable disease control measures, which may include isolation or quarantine.

The varying common-sense and professional understandings of terms such as isolation and quarantine are good for the purposes they serve, but they may conflict with how the terms are defined in law—and it is the legal definitions that both authorize and constrain how these strategies may actually be used in an outbreak. It is therefore important for anyone involved in pandemic preparedness to understand the legal meaning of isolation and quarantine, and also the broader legal framework in which they are used.

The Framework: Legal Authority to Control Communicable Disease

The individuals and agencies that make up North Carolina's public health system—including the state health director and division of public health, local health directors and the health departments they administer, and the seven Public Health Regional Surveillance Teams (PHRSTs)—would likely be the first to identify and respond to a disease outbreak. North Carolina laws give the public health system specific duties during an outbreak, as well as specific powers to help it perform those duties.

> *"North Carolina laws give the public health system specific duties during an outbreak, as well as specific powers to help it perform those duties."*

The starting point for communicable disease control is to be aware that a disease exists in a population—thus, one of the duties of a public health system is to detect disease. One of the ways public health meets that duty is by requiring certain diseases to be reported. North Carolina law presently requires physicians and specified others to report known or suspected cases of communicable diseases or conditions that have been declared "reportable" by the state's Commission for Health Services.[1] The list of reportable communicable diseases and

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conditions is dynamic and has grown rapidly in recent years, so that it now includes over 70 diseases and conditions. Novel influenza viruses are a recent addition to the list—known or suspected cases must be reported to the local health department immediately.[2]

In addition to this routine reporting, another state law authorizes the state health director to temporarily require health care providers to make reports of conditions that are not on the list.[3] The idea behind this law was to allow the public health system to act rapidly to detect an emerging illness or syndrome. State law also supports disease detection by authorizing public health to obtain access to medical information so that it can carry out public health surveillance.[4]

When a communicable disease or condition is detected, whether through the receipt of a disease report or a surveillance system, the public health system's duty to investigate is triggered.[5] Again, state law gives public health specific legal powers to help it meet this duty. Both state and local public health officials are authorized to obtain access to medical and other confidential records that may be relevant to a case or an outbreak. Health care providers are required by state law to make medical and other records available to public health officials in these circumstances.[6,a] Investigations may also include interviewing ill or exposed people, collecting specimens for laboratory analysis, and identifying others who may be ill or exposed.

By carrying out its duties of detection and investigation, the public health system lays the foundation for its ultimate duty: controlling the spread of the communicable disease. Supporting this duty is a state law that requires all persons in North Carolina to comply with communicable disease control measures—that is, the steps individuals, their health care providers, or the public health system must take to control the spread of disease.[7]

Communicable disease control measures are disease-specific and cover a wide range of strategies. In the event of an influenza pandemic, how will public health officials decide which control measures are appropriate? They should look first to guidelines and recommended actions issued by the Centers for Disease Control and Prevention (CDC). North Carolina law specifies that CDC guidelines will be the source of control measures when they are available,[8] and it is expected that CDC will issue guidelines during a pandemic. If for some reason it does not, the law also permits public health officials to devise their own control measures that are reasonable and meet certain guidelines depending on the disease's route of transmission (airborne, bloodborne, etc).

Because CDC guidelines are the primary source for control measures, and because those are likely to evolve in an emerging illness event, public health officials cannot know for certain what the control measures for an outbreak of a novel influenza virus will be. However, it is expected that the control measures would include at least:

- Immunization, if an effective vaccine is available
- Use of antiviral medications, if effective and available
- Isolation of infected individuals
- Quarantine of exposed individuals

In addition, public health officials will likely urge individuals and communities to embrace social distancing strategies, such as avoiding unnecessary outings.[b]

The Definitions: Isolation and Quarantine in the Law

The main distinction between isolation and quarantine is that isolation is a control measure applied to sick people, whereas quarantine is applied to people who might get sick—usually because they have been exposed to an infected person. North Carolina's legal definitions begin with this fundamental notion, but then they take it a bit further. State law defines "isolation authority" as the authority to limit the freedom of movement or the freedom of action of a person who is infected with, or is reasonably suspected of being infected with, a communicable disease or condition.[9] "Quarantine authority" includes the authority to limit the freedom of movement or the freedom of action of a person who has been, or is reasonably suspected of having been, exposed to a communicable disease or condition.[10] Either a local health director or the state health director may exercise isolation or quarantine authority.[11]

The definitions of isolation and quarantine authority refer to limiting either a person's "freedom of movement" or "freedom of action," and several North Carolina laws make important distinctions between orders based on which freedom they limit. For example, the law that authorizes health directors to order isolation or quarantine provides that orders limiting freedom of movement expire after 30 days unless they are extended by a court—even if the subject of the order is still a threat to the public health.[12] The same limit does not apply to orders limiting freedom of action. It is therefore critical for public health professionals to understand when they are limiting freedom of movement and when they are limiting freedom of action—but no law defines these terms. However, the definitions can be inferred from longstanding public health practice.

An order limiting freedom of movement essentially prohibits

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[a] Health care providers sometimes worry that providing access to records with individually identifiable health information violates the federal HIPAA privacy rule, but the privacy rule explicitly states that providers may comply with state laws that require the disclosure of such information. (45 CFR. 164.512(a).)

[b] As this commentary was going to press, the Centers for Disease Control and Prevention released *Interim Pre-pandemic Planning Guidance: Community Strategy for Pandemic Influenza Mitigation in the United States* (Feb. 2007), available on the Internet at http://www.pandemicflu.gov/plan/community/community_mitigation.pdf. The document states that it is "highly unlikely" an effective vaccine will be available in a pandemic and recommends control strategies that include isolation of the ill, quarantine of the exposed, and use of social distancing strategies such as school closures and cancellations of large public gatherings.

an individual from going somewhere. It may confine the person to a particular place, such as his home or a health care facility, or it may prohibit the person from entering a particular place. For example, a person with active infectious tuberculosis may be required to remain at home until laboratory tests reveal he or she is no longer infected, or an unimmunized child may be required to stay home from school for the duration of a measles outbreak. In contrast, an order limiting freedom of action restrains a person's behavior, but not her ability to move about freely in society. For example, a person taking medication for tuberculosis that is no longer in the active infectious stage may be ordered to participate in directly observed therapy. This is a limit on freedom of action.

Thus, in North Carolina, an order requiring a person to be physically separated from the public would be called an "isolation order" (for an infected person) or a "quarantine order" (for an exposed person). But an order simply directing a person to comply with control measures that do not include physical separation would also be called an isolation or quarantine order. This counterintuitive use of the terms isolation and quarantine can be tricky even for public health professionals, but it is important to understand. Health care providers and patients who receive isolation or quarantine orders need to know what is actually being required of them.

During the Pandemic: Isolation, Quarantine, and Other Forms of Social Distancing

During an outbreak of influenza, an isolation or quarantine order might limit either freedom of movement or freedom of action—but it seems most likely that the isolation and quarantine authority would be used primarily to separate ill or exposed people from the general public. It also seems likely that isolation and quarantine would be used early in an outbreak in an effort to contain it as quickly as possible, but these strategies may well be abandoned if widespread illness affects a community. There is some question about whether public health officials would have the legal authority to order a television movie-style isolation or quarantine—but of greater importance, such measures are widely considered to be both impracticable and likely ineffective.

In contrast, isolation or quarantine orders that are directed to individuals, or groups of individuals with a common exposure (such as the passengers and crew of an airplane carrying an ill person), are clearly within public health's legal authority and may play an important role in preventing widespread community illness, depending on how the outbreak unfolds. Indeed, North Carolina used isolation and quarantine in this fashion during the severe acute respiratory syndrome (SARS) outbreak of 2003. Although only one person's infection was ultimately confirmed to be SARS, several people were isolated because they were suspected of being infected, and several dozen were quarantined because they were exposed to one of the isolated people.

There is, of course, no guarantee that an outbreak of novel influenza would be as limited as SARS was in North Carolina, and there are good reasons to believe that it would not. If an outbreak becomes widespread in the community, it is likely that isolation and quarantine would become less important than other forms of social distancing. Social distancing could happen spontaneously, if members of the worried well population elect to stay home. It could also occur voluntarily in response to the urging of public health officials to avoid unnecessary outings. There are also various governmental actors who have the legal authority to compel different types of social distancing. North Carolina local governments can adopt ordinances that permit them to take a number of actions in emergencies, including restricting the movement of people.[13] The Governor has the authority to declare a state of disaster and may, with the consent of the Council of State, prevent people from congregating in public places.[14] School boards can close schools and, to answer one of the questions I am most frequently asked: if the universities do not do it on their own, state or local officials could probably cancel the Carolina-Duke game, or at least prevent the public from attending. Although everyone hopes it does not come to that, the legal authority is there to be exercised if necessary. **NCMJ**

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Business Preparation for an Influenza Pandemic

Jon Kerin

In fall 2005, the Department of Homeland Security identified the electric industry as a key component of the national infrastructure and requested that utilities, including Progress Energy, prepare an emergency response plan for a pandemic.

While our company has experience with and continually refines its plans to respond to hurricanes, ice storms, and other natural disasters, putting together our flu pandemic plan proved to be a long process and forced us to address issues that had not arisen in storm situations.

For example, natural disasters destroy infrastructure. Our employees pull together to ensure our customers get service restored as soon as possible. Many employees stop doing their regular daily jobs and take on specific storm jobs to ensure we can meet our customers' needs quickly.

In planning for a flu pandemic, though, the scenario is much different. Rather than destroying infrastructure, a pandemic has much more human impact and little if any effect on infrastructure. A flu pandemic incident is outside of our experience. Instead of bringing our employees together, as we are used to in storm events, a flu pandemic could push our employees apart, with many being unable to come to work.

Whatever the effects of such an occurrence, it is critical that electric utilities and other industries, such as banking and transportation, be prepared to continue providing society's essential needs during a pandemic.

Progress Energy took a hard look at its emergency and business continuity plans and determined that we needed to start fresh in looking at our pandemic plan. We learned some very important lessons during this process, and we believe we have developed a robust, comprehensive plan that will ensure we take care of our customers and our employees.

Involve Everyone

We formed a Pandemic Working Group, made up of departments throughout the company, including:

- Health & safety
- Power plant operations (nuclear and fossil)
- Transmission
- Distribution
- Supply chain
- Information technology & telecommunications
- Corporate communications
- Human resources
- System planning
- Customer service
- Accounting
- Security

This group met frequently for many months to develop our corporate-wide flu pandemic plan along with plans for their individual departments. Having this many groups involved helped us identify enterprise-wide gaps and develop solutions for our company as a whole.

> *"And we decided we shouldn't wait until a threat was imminent—we wanted to educate our employees now about a pandemic and what they could do to prepare themselves and their families."*

Jon Kerin is Director of Health & Safety Services at Progress Energy Service Company, LLC and was responsible for developing the company's comprehensive flu pandemic plan. Mr. Kerin can be reached at jon.kerin@pgnmail.com or 401 S. Wilmington Street, PEB 4A, Raleigh, NC 27601.

Break Down Plan by Phases

Progress Energy chose to use the North American Electric Reliability Council's pandemic phases to guide our planning; this structure is different from the World Health Organization's six levels of pandemic alert phases. We then identified key steps for the company to take in each phase. These steps are outlined in Table 1. These steps are by no means an exhaustive list, but rather a look at the action items that the entire company needs to undertake in each phase.

Table 1.
Key Company Steps, by Pandemic Phase

Pandemic Phase	Status of Pandemic	Key Company steps
Phase 1: Pandemic Alert	Governments, owners, and operators are notified a pandemic is possible and preparedness plans should be reviewed and updated.	• Provide information to employees • Develop a list of health-related inventory items • Identify essential staffing needs and identify personnel to meet those needs (assuming a 35% to 40% absentee rate), including backups for key personnel • Develop and update the company's meeting policy • Develop and update the company staff travel policy • Identify augmented workforce requirements • Modify Human Resources policies associated with working from home, remaining sequestered at a job site, and absenteeism • Identify critical operation supplies • Implement an enterprise-wide hand-washing campaign • Develop a training plan for backups • Ensure business continuity plans have been revised to incorporate pandemic plans • Perform a self-assessment
Phase 2: Pre-Pandemic	Localized outbreaks of the disease are occurring with human-to-human transmission. Governments and electricity sector entities begin to assign resources, prepare staffing, and implement contingency plans. Begin an information distribution program to promote appropriate responses by employees.	• Periodically test and verify preparedness plans and procedures via a simulation exercise, tabletop exercise, or process walk through • Develop and update workforce deployment policies regarding teams and crews working together and the potential need to keep employees separated • Set up telecommuting capabilities for identified personnel • Stock up on water, beverages, and food • Consider the need and conditions for more extreme measures, such as sequestering on-site critical staff
Phase 3: Pandemic Outbreak	General outbreaks of the disease across borders and continents. Implement response plans.	• Activate Crisis Management Center • Notify employees • Implement the protocol for telecommuting • Notify all staff on site to leave their full name, employee ID, and after-hours contact numbers • Provide each workstation with disinfection supplies • Close noncritical common areas • Assess the need to vacate all noncritical staff from facilities • Sequester on-site critical staff, as needed
Phase 4: Maximum Disruption	High absentee rates would occur (35%) and fatalities would begin to impact workforce. This phase could last for several months.	• Analyze/reevaluate staffing levels • Analyze/reevaluate supplier effectiveness
Phase 5: Prolonged Recovery	Recovery will be slow. Altered business conditions will be prevalent. This phase will last at least three months and possibly up to six months.	• Deactivate Crisis Management Center • Implement business continuity plan and business resumption plans • Communicate with personnel and departments not addressed in resumption plans • Return to normal business operations

Employees are Customers, Too

Time and time again in our discussions, the planning group found itself not only talking about how to maintain reliable electric service, but also how our company should take care of its employees in a pandemic.

We looked for nontraditional communications channels, so we could make sure our employees had the information they would need during a pandemic. We had detailed conversations about Human Resources policies and how those might change, going as far as to write new policies to have ready in the event of a pandemic.

And we decided we shouldn't wait until a threat was imminent—we wanted to educate our employees *now* about a pandemic and what they could do to prepare themselves and their families. Using our company's daily electronic newsletter, we began sharing information about a pandemic and providing preparation checklists. We also published questions and answers and linked our employees to the Federal government's pandemic Web site (www.pandemicflu.gov) and the United States Centers for Disease Control and Prevention.

Be Realistic

We often found ourselves in many "what if" conversations during our planning, all of which helped us to address some key issues. However, it is important to recognize that a company plan cannot include every step to handle every possible contingency. Instead, we are realistic about the limitations of a written plan and use it as a higher-level guide that can be used in many different situations.

Challenge One Another

While we did not have any formal "challenge sessions" during our planning, Progress Energy's pandemic planning team frequently engaged in tough debates about the number of critical employees, whether sequestering employees would be necessary, and if and when supplies should be purchased. As is often the case in hypothetical situations, there were no right or wrong answers, but each department was able to further refine their plans based on these tough questions.

Test and Refine Your Plan

Finally, plans are only as good as the last time they were tested and updated. We have already held one company-wide drill to test our pandemic plan, and we plan to continue these drills in the future.

Providing critical services like electricity will be a challenge in a pandemic situation, but we believe our experience with other disasters and our comprehensive planning process will help us meet the needs of our employees and our customers if a pandemic ever occurs. **NCMJ**

COMMENTARY

Pandemic Influenza:
The Consequences beyond Public Health

Major General Gerald A. Rudisill, Jr. (ARNG Ret.)

Nearly everyone who has lived in North Carolina during the past ten years has some experience responding to a natural disaster. The many hurricanes, floods, tornadoes, and snow and ice storms that hit the state in the past decade have tested our ability to respond to emergencies in virtually every corner of the state. Those experiences may prove invaluable if there is an influenza pandemic. No one knows exactly how a flu pandemic would impact our lives or how long it would last. However, such an epidemic would greatly challenge the emergency response capacity of our state—and country—and stretch our resources in ways never experienced before.

> *"It is conceivable that the services we take for granted such as electricity, potable water, sanitation, and natural gas could cease."*

Most weather-related disasters that impact North Carolina have a warning period. The disaster is usually of short to moderate duration, and the aftermath's impact on facilities, infrastructure, crops, animals, and people is somewhat predictable. Technological disasters such as transportation accidents, hazardous materials events, and fixed nuclear facility accidents would likely impact people suddenly with little warning, but would only directly affect people and property relatively near the incident. An influenza pandemic would be an entirely different type of disaster. It would impact large percentages of the population over long periods of time and require innovative, immediate, and continual responses.

Aside from the staggering impacts to public health, the potential impacts of an influenza pandemic on manpower levels and critical systems could be tremendous. As people are affected, the workforce supply would be reduced, whereas demand for goods and services would rise. The impact would be not only local, but global in nature. Consider this: as the flu spreads, providers of essential services such as food, transportation, fuel, medicine, utilities, and banking could be devastated by manpower shortages reaching 40%. Attempts to prevent the spread of flu through the implementation of social distancing measures could further reduce the workforce, thus reducing production and supply. It is conceivable that the services we take for granted such as electricity, potable water, sanitation, and natural gas could cease. Social interaction would also be curtailed because social distancing measures would limit participation in faith communities, civic groups, sports, and public entertainment activities.

The workforce challenges facing health care agencies would be no different. Furthermore, while some businesses can expect to see a decline in activity during a pandemic emergency, health care institutions will experience an overwhelming increase in demand for services.

The North Carolina Department of Crime Control and Public Safety is the state agency charged with coordinating disaster response among local, state, and federal governments. The State Emergency Response Team (SERT) is an arm of state government that is comprised of more than 40 state agencies, nonprofits, and volunteer organizations that work as a team to mobilize the state's assets to support local governments and affected citizens. It is this group that assesses and responds to local community or regional health, safety, utility, transportation, food, and housing needs following any man-made or natural disaster.

Maj. Gen. Gerald A. (Rudy) Rudisill, Jr. (ARNG Ret.), is Deputy Secretary of the North Carolina Department of Crime Control and Public Safety. The Department's mission is to improve the quality of life for North Carolinians by reducing crime and enhancing public safety. It coordinates the state response to emergencies and directs relief efforts to disaster victims. Deputy Secretary Rudisill was a member of the NC Division of Public Health and NC Institute of Medicine Task Force on Ethics and Pandemic Influenza Planning. He can be reached at grudisill@nccrimecontrol.org or 4701 Mail Service Center, Raleigh, NC 27699-4701.

Bad News of the Past may Mean Good News for the Future

Fortunately, years of experience responding to numerous hurricanes, floods, ice storms, and other severe weather events have provided North Carolina with a solid foundation for any ongoing response necessitated by an influenza pandemic. For natural disasters, the SERT frequently activates 24 to 48 hours before a disaster and remains operational long enough to respond to the immediate needs of the disaster victims. Depending on the nature of the event, the group can be working around the clock for several days to several weeks. Following Hurricane Floyd in 1999, the SERT was activated for more than five months while the state recovered from devastating floods. During that same time, the SERT also responded to the January 2000 blizzard that dumped nearly two feet of snow in central North Carolina. In the past decade, the SERT has been activated more than 50 times in response to hurricanes, ice storms, blizzards, tornadoes, and chemical explosions.

Those incidents provided the SERT numerous opportunities to work with dozens of agencies and hundreds of communities. That experience and those relationships will be vital during an influenza pandemic. In such an event, the SERT would likely be activated for weeks and possibly months. Representatives from the North Carolina Division of Public Health (DPH) would serve as technical advisors to the SERT leadership and the governor. DPH would help develop strategies to protect the public, predict future impacts, and make recommendations for protective action. The governor, SERT, and DPH leaders, in coordination with local governments, would then implement any recommended actions.

Coordination and collaboration at the local level will be imperative. A flu pandemic would cross state boundaries, thus greatly reducing the ability of the Federal Emergency Management Agency (FEMA) to support North Carolina. Assistance from many of the other traditional government and private support organizations, such as the National Guard, Red Cross, Salvation Army, and faith groups, could also be very limited due to the widespread nature of a flu crisis.

Rising concerns about safety and fears of the unknown could spark chaos. It is imperative that all levels of government – local, state, and federal—as well as private institutions, such as health care facilities, be prepared to provide essential law enforcement and public safety services to maintain public order. Public safety systems must be planned, organized, and exercised well before an event occurs. DPH and the Division of Emergency Management each have already sponsored flu pandemic exercises and training to educate our response and recovery personnel on the potential issues that may arise and appropriate responses. Leaders throughout the state's communities should actively discuss ways to partner during an influenza pandemic to keep people connected, calm fears, and offer hope for the future.

Preparing for Pandemic

The most significant need during a flu pandemic will be for solid, steady leadership that relays critical, honest, and concise information and direction to the public throughout the developing crisis. Some of that vital information is available already. To help individuals and families prepare for all types of disasters, the Department of Crime Control and Public Safety launched an emergency preparedness website—readync.org/. The site provides basic information about what to do during floods, hurricanes, tornadoes, earthquakes, fires, winter storms, a terrorism act, or a disease outbreak. It instructs users how to prepare for evacuation, as well as what to do if they must seek shelter in their homes for an extended period of time. Information and links are included to help citizens understand what preparations the government is taking and what individuals must do to ensure their safety. For instance, to prepare for a flu pandemic outbreak, families are encouraged to stockpile enough food, bottled water, medicine, cash, and fuel for several weeks.

Community cooperation where neighbors help neighbors will be the key to weathering a pandemic outbreak. A shortage of goods will spark tendencies to control limited supplies and competition for resources could become violent, even deadly, if not properly managed from the beginning. Safety and survival will depend upon the willingness of neighborhoods and communities to come together for the common good. Government will have to establish supply lines and deliver critical resources to local receiving and distribution centers just as they would after any large disaster.

To ensure other essential government services are not disrupted, last summer Governor Easley required every state agency to prepare a Continuity of Operations Plan to guarantee ongoing operations in the event that substantial numbers of employees become incapacitated due to illness. Contingency plans must evaluate and prepare for reassignment of personnel responsibilities and for conducting business long term from remote locations. Personnel are encouraged to develop alternate family care plans for periods during which they are away performing critical functions. Those plans have been developed and will be tested through mock disaster drills in the coming months.

Hospitals, public health departments, physicians' offices, and emergency medical service providers also have been preparing for an influenza pandemic emergency for the past two years. Each hospital has a plan for providing health care during an emergency, including an alternate care facility for when the hospital is overwhelmed or otherwise unavailable. Although readiness levels can never be achieved to address every possible health care contingency, tremendous progress has been realized over the past year.

When many people consider the possibility of a disaster, they think, "It isn't going to happen here. If it does happen here, it won't be that bad. If it does happen here, and it is that bad, then the government will be here to take care of me." Unlike the response to a natural disaster, the communicable nature of the flu pandemic may mean that the government response will not be as quick and seamless as expected.

The truth is our nation is totally dependent upon the systems we have built. Grocery stores, restaurants, gas stations, water systems, electricity, flushing toilets, television, radios, cell phones, internet, pharmacies, law enforcement, emergency management services, hospitals, fire departments, banking, and credit systems are all part of our way of life. If a flu pandemic develops as a major statewide event, and likely national and worldwide event, none of these systems could be relied upon to operate continually and consistently. Everyone will experience shortages and those who are dependent upon the luxuries in our modern life may have a more difficult time surviving.

I honestly believe the key to success lies in communities pooling existing local resources and sharing what is available. This is a foreign concept to many Americans, except in a disaster environment. Government can and must lead the population during a pandemic event. A three-tiered response involving cities and counties, the state, and federal government will be necessary despite the new and unanticipated demands placed on these systems.

No one knows what the future holds. However, as we plan for emergencies, our responsibility is to consider the possibilities, define the assets and liabilities, and plan for the deficits. Government cannot be expected to do it alone. Individuals and families must prepare themselves and communities must band together. We must all accept some responsibility and do what is necessary to ensure our safety, health, and welfare. **NCMJ**


Government
Services

COMMENTARY

Ethics and Avian Flu

Rosemarie Tong, PhD

Health care professionals and public health officials are gearing up for the next influenza pandemic to strike the United States. For them, it's not a question of if a pandemic will strike the United States, but when. For this reason, they are paying very close attention to the avian influenza A (H5N1) virus which has killed around 150 people so far, but has not yet mutated into a virus capable of triggering a pandemic. Should such a mutation occur, chances are that the virus would spread quickly worldwide, rapidly finding its way to United States shores where it could sicken 90 million of us and kill at least 1.9 million. The United States government is preparing for the possibility of an avian flu outbreak, but so far its preparedness plan has focused largely on the development and distribution of a vaccine and the stockpiling of antivirals. But Arthur Caplan, Director of the Center for Bioethics at the University of Pennsylvania School of Medicine, stresses that no preparedness plan is complete without addressing the ethical issues likely to confront our society during a flu pandemic. These are excruciatingly difficult moral questions that the North Carolina Division of Public Health and the North Carolina Institute of Medicine are asking *now* while there is still time to think critically, carefully, and calmly about what ethical values should guide decision makers, health care workers, workers in other critical industries, and the general public when an influenza pandemic strikes.

Consider that during the first year of a pandemic fewer than 10% of us will have access to an effective vaccine. Federal stockpiles of experimental vaccines that may or may not work may be available for more of us, but it will take months for a truly effective vaccine to be developed, manufactured, and distributed. Early in the vaccine's attack on United States shores, we will also probably lack an adequate supply of antiviral medications such as Tamiflu, which some individuals, private practices, and hospitals may already be stockpiling. To add to our concern, during the height of a pandemic, we probably won't have enough ventilators for the hundreds or thousands of patients who will desperately need them for up to 18 days if the avian flu hits their lungs with the same intensity that it hit the lungs of SARS victims a couple of years ago. We will be confronted with some difficult questions: What about the patients who are already on ventilators when the pandemic strikes? Should a ventilator be removed from a baby who hasn't been doing all that well on it and given instead to a baby with the avian flu whose survival odds look really good if he or she can get on a ventilator immediately?

> *"Should a ventilator be removed from a baby who hasn't been doing all that well on it and given instead to a baby with the avian flu whose survival odds look really good if he or she can get on a ventilator immediately?"*

The specter of a pandemic and the reality of truly scarce resources force all of us to confront the very hard question: "Who shall live when not all can live?" This is a question that most Americans hate to ask themselves. It sounds downright unpatriotic to them. "Hey this is America! What do you mean we can't all live? Each of our lives is unique, special, valuable, important!!! We deserve whatever we need to keep on living, and don't you dare try to use any one of us as a means to serve

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the common good. The end doesn't justify the means." To which the reply must be, the rules of ethics shift during a pandemic. Under dire circumstances, the value of the common good must be weighed more heavily than the value of respecting individual rights and personal autonomy. The dread "R" word—rationing—must be uttered. There is no escaping its harsh sound. But, if we take a step back and think through the situation, rationing can be our friend. During a pandemic, it can help us maintain the value of justice, provided it is done ethically—that is, by directing scarce resources to where they will do the most good for us all, and letting everyone know why it is we have chosen a particular distribution method.

But how can we get rationing to work for us rather than against us? Lawrence O. Gostin recently articulated eight ethical options for rationing scarce health resources in a pandemic.[1] As he sees it, the relative importance of the ethical options shifts during the different stages of pandemic. The ethical options Gostin articulated include: (1) prevent new infection; (2) protect both essential medical personnel so they can care for the sick and essential scientific and pharmaceutical personnel so they can develop, make, and distribute the vaccines and antivirals we will desperately need; (3) protect other essential workers without whom our society might devolve into chaos, such as police, sanitation workers, utilities workers, food makers and distributors, bankers, communication personnel, etc.; (4) protect those with the greatest medical need; (5) save younger persons, protecting their opportunity to live a long, full life; (6) make it a priority to be sure that the typically underserved—the people who live in poor, rural, isolated and all-to-often forgotten communities—get their fair share of available resources; (7) think globally as well as nationally and regionally about flu pandemic because Asian and African lives are not less valuable than American lives and because people in many developed nations have already been devastated by HIV/AIDS, malaria, and tuberculosis; (8) make it a priority to be transparent and to secure public cooperation—for unless everyone understands the reasons behind a resource allocation plan, and is convinced that it is fair, the plan will fail miserably.

Of course, rationing scarce medical resources is not the only ethical challenge our society will confront during an influenza pandemic. When Americans are faced with the implications of isolation, quarantine, and social distancing measures, how will they react? In Canada during the SARS epidemic, people complied with restrictions on their freedom largely because their fellow citizens made it a point to meet their basic human needs. The situation was otherwise in some Asian cities where many individuals either did not understand why their movement had to be restricted and/or feared that unless they took care of themselves and their loved ones no one else would. Before long, the police entered the picture and were instructed to use deadly force if necessary.

Finally, there are all the ethical challenges that will greet medical workers and first responders during a pandemic. Can they be expected as a matter of duty to help flu victims even if doing so means risking their own lives or those of their families? Can they even be forced to do so? And if medical workers and first responders courageously accept the risks society wishes to impose upon them, what will society give them in return? How will society show its appreciation for people willing to put their lives on the line to serve the common good?

As a member of the NC Division of Public Health/NC Institute of Medicine Task Force on Ethics and Pandemic Influenza Planning, and in my role as one of its ethicists, I have come to the conclusion that as important as an ethics of justice will be during a flu pandemic, even more important will be an ethics of care. In the end, we human beings are a very vulnerable lot. We are radically dependent on each other for survival and we need to view ourselves as folks in a lifeboat in the middle of the ocean with no visible sign of rescue. If there aren't enough supplies to go around until help arrives, we can do several things: we can ask for volunteers to jump off the boat; we can start drawing straws for who gets pushed off the boat; we can have a majority vote about which lives are most dispensable; or we can look in each others' eyes and see ourselves—fearful, hopeful, and in need of compassion—and then we can start paddling together to get to shore, knowing that although we might not all make it, we didn't turn on each other in our panic. What we most need to weather a pandemic is an ethics of trust, reciprocity, and solidarity. If we have that, we will have the most precious health care resource of all. **NCMJ**

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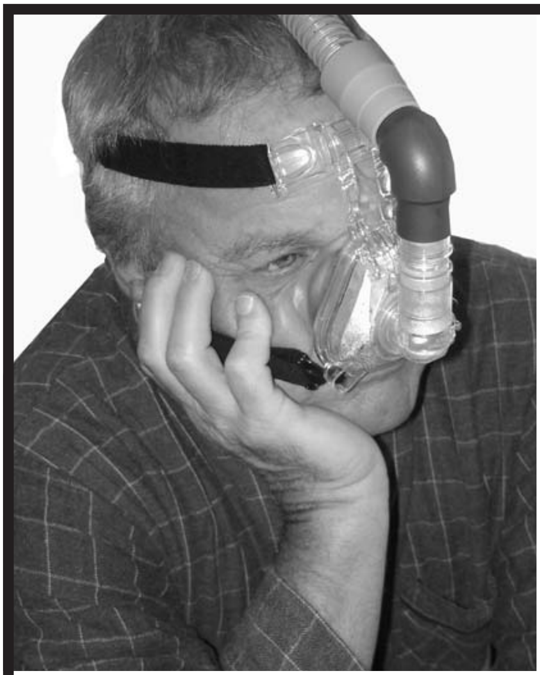

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Kent E. Moore, M.D., D.D.S. is the founding chairman of the American Association of Oral & Maxillofacial Surgeon's Clinical Interest Group on Sleep-Related Breathing Disorders and Obstructive Sleep Apnea and has served as faculty for the National Sleep Medicine Board Review Course 2002-2005 (sponsored by the American Academy of Sleep Medicine). He is immediate past president of the American Academy of Dental Sleep Medicine and founding board member of the International Society of Sleep Surgeons.

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From the State Center for Health Statistics, NC Department of Health and Human Services
http://www.schs.state.nc.us/SCHS

Influenza Surveillance

For health care providers, the start of flu season is often heralded by an increased number of patients complaining of fever, cough, and aches asking the question, "Do I have the flu?" For public health departments, the onset of flu season is often heralded by calls from health care providers asking the question, "Is flu reportable?" The answer to this question is a qualified "yes."

In North Carolina, any fatal case of influenza in a child (< 18 years of age) is reportable by health care providers to the health department. In addition, any infection with a novel influenza virus, such as the current avian influenza H5N1 strain that has caused human cases in multiple countries since 2003, is also reportable. Influenza outbreaks in closed settings such as schools or long-term care facilities are also reportable. The total number of influenza cases is not reportable and neither are fatal cases of influenza in persons 18 years of age or older (other than on a death certificate).

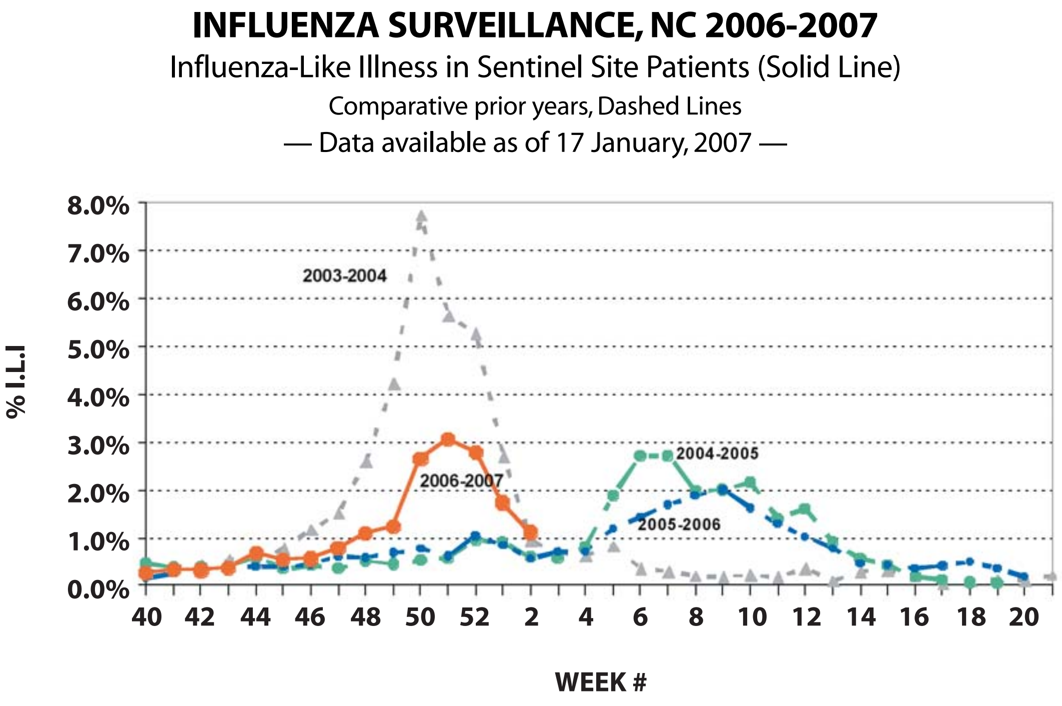
In North Carolina, routine influenza surveillance is conducted from October through May of each year. Although it does not provide a count of all influenza cases, it can be used to determine when and where influenza is circulating, the types of influenza viruses that are causing illness, and the level of influenza activity present in the state.

Disease-based surveillance is comprised of a network of voluntary providers who serve as sentinel sites for influenza activity in a variety of outpatient settings. For the 2006-2007 season, 74 providers representing 45 counties volunteered to serve as sentinel providers. Of these sentinel sites, 34 sites are private health care providers, 19 sites are county health departments, 15 sites are college and university student health centers, and 6 sites are hospital-based clinics. Sentinel providers record the number of patients they see each week with an influenza-like illness (ILI), which is defined as a fever of 100^{o} F or greater and one respiratory symptom such as cough or sore throat. Sentinel providers also submit a count of the total number of patients seen each week. This gives a proportion of visits that are attributed to ILI on a weekly basis throughout the flu season, and enables public health officials to monitor influenza activity across the state.

Figure 1 shows data on influenza activity from the sentinel provider network over several influenza seasons. The weeks of the influenza season are assigned a number, with the start of the flu season in October represented by week #40 and the end of the flu season in early May represented by week #20. The current influenza season is shown in red. For the week ending with January 12 (week #2), approximately 1.1% of all visits to the sentinel provider sites was for an ILI. This is down from a peak of 3% in week #51. Figure 1 also illustrates that every influenza season is different, both in severity as well as timing. For example, flu activity began peaking earlier (December) in the current flu season compared with the two previous seasons in which flu activity peaked in February or March (2005-2006 shown in blue and 2004-2005 shown in green).

RTN—continued on page 75

Figure 1.
Influenza Surveillance in the Sentinel Provider Network, 2003-2004 to 2006-2007



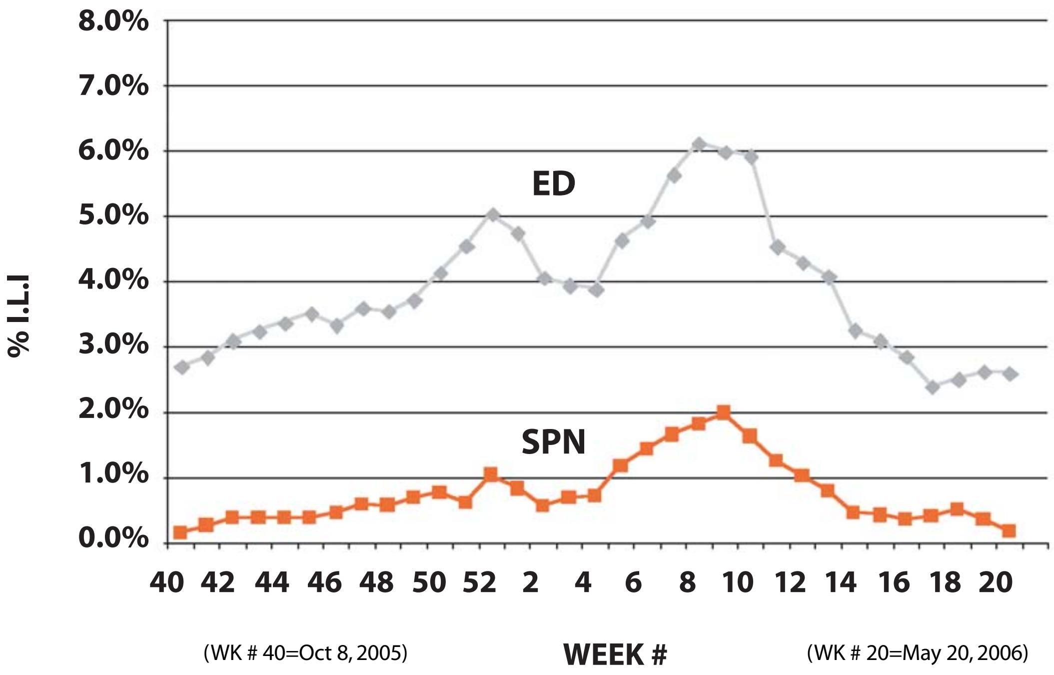
Beginning in the 2005-2006 influenza season, disease-based influenza surveillance was also conducted in hospital emergency departments (EDs) by monitoring ILI using the North Carolina Disease Event Tracking and Epidemiologic Collection Tool (NC DETECT) system. NC DETECT currently monitors real-time data from 90 hospital-based emergency departments throughout the state. The system categorizes visits into syndromes in real time in order to detect unexpected cases and outbreaks earlier in their course than traditional disease-based surveillance would allow.

The case definition for ILI in hospital EDs is broader than the ILI case definition used in the sentinel provider network. Emergency department visits are grouped into syndromes by analyzing the chief complaint and, when available, the triage notes and initial ED temperature. ILI cases must include any case with the term "flu" or "influenza" or have at least one fever term and one influenza-related symptom. The hospital ED data were compared with the sentinel provider network data for the 2005-2006 flu season (Figure 2).

RTN—continued on page 76

RTN—continued from page 75

Figure 2.
Influenza-Like Illness Surveillance in North Carolina, 2005-2006 Influenza Season. Comparative Trend between Two Surveillance Systems: Sentinel Provider Network (SPN) and Hospital Emergency Department (ED)



Although the patient populations, severity of illness, and case definitions for ILI are different in these two surveillance systems, it is important to note that the trends in ILI activity are well correlated. The use of NC DETECT as one method of monitoring ILI activity is validated by the existing sentinel provider network data. The trends for the first half of the 2006-2007 flu season are also well correlated.

In the event of an influenza pandemic, there will be significant challenges to influenza surveillance. Current systems of influenza surveillance will likely become overwhelmed, and flexibility will be essential in adapting current systems to meet the demands of tracking the pandemic across North Carolina. It is expected that the voluntary sentinel provider network will not be able to report weekly data regarding the percentage of visits for ILI because this data collection is still done the old-fashioned way: by hand. Syndromic surveillance for ILI in emergency departments, on the other hand, may be a viable option since these data are collected electronically as patients are being triaged through the emergency department. Another advantage of NC DETECT over the sentinel provider network is that it provides the opportunity for immediate surveillance of a new condition. This could apply to an outbreak of a novel strain of influenza in which the current case definition for ILI may need to be modified to capture cases. Expansion of NC DETECT to all hospitals in North Carolina with licensed acute care 24/7 emergency departments is underway.

Contributed by Kristina Simeonsson, MD, MSPH, and Lana Deyneka, MD, MPH
Epidemiology Section, North Carolina Division of Public Health

Worksites Need to Know How to Get Started.

To The Editors:

We congratulate the *NC Medical Journal* for addressing the important public health issue of worksite health promotion in the November/December 2006 issue. Many employers and policymakers are seeking solutions to the rising cost of healthcare and in so doing, turn to worksite wellness. Oftentimes, they wade into these waters without an understanding of what works, what resources exist, what to measure, what is considered a success, or how to even begin.

NC Prevention Partners has made the strategic decision to address worksite health promotion because it is an important way to significantly improve the health of North Carolinians. While the Healthy People 2010 goal is for 75% of businesses to establish a comprehensive worksite health promotion program, only 6.9% nationwide have done so. The majority of NC employers are not actively engaging in health promotion efforts because they simply do not know where to start.

Many of the tools and training opportunities developed by NC Prevention Partners focus on implementing policies and creating environments that can significantly influence the behavior of all employees, regardless of their health status. Establishing a solid foundation of supportive policies and environments can help keep healthy people healthy and can help reduce health risks in persons with existing disease conditions.

For the business community, the problem—rising healthcare costs—is clear, but the solutions are not. We recommend the following quick-start, low-cost, high-return health promotion strategies as the place to start.

- **Start with a prevention audit.**
  NC Prevention Partners has created a web-based Prevention Audit as part of the *Prevention 1st Challenge* (www.preventionfirstchallenge.com). The audit helps employers take a critical look at their policies and environments, and take steps to create healthy worksites.
- **Make it convenient to choose healthful options at work.**
  In Orange County, businesses participating in the Prevention 1st Challenge are making healthy snacks available in vending machines and starting walking groups. NC Prevention Partners established a worksite policy making healthy options like fresh fruit and spring water available onsite and more convenient than the soda and snack machines down the hall. For other strategies, visit www.eatsmartmovemorenc.com.
- **Go 100% tobacco-free campus wide.**
  Hospitals in North Carolina are making significant changes to eliminate exposure to secondhand smoke through the *Healthy Hospital Initiative*, a partnership between NC Prevention Partners, the NC Hospital Association and The Duke Endowment. With tools and support, North Carolina hospitals are leading the nation in establishing 100% tobacco-free campus wide policies. For more information on reducing secondhand smoke in the workplace, visit www.healthyhospital.org and www.fammed.unc.edu/enter/.
- **Purchase benefits that give employees access to proven preventive care.**
  A new publication, *A Purchaser's Guide to Clinical Preventive Services: Moving Science into Coverage*, from the National Business Group on Health (www.businessgrouphealth.org) and the Centers for Disease Control and Prevention is an excellent tool to help businesses purchase proven preventive benefits. In addition, NC Prevention Partners' Preventive Benefits Watch (www.ncpreventionpartners.org/preventivebenefits) is a web-based resource that provides policymakers and businesses the opportunity to learn about preventive benefits offered by North Carolina insurers. Using this tool can assure businesses that they are purchasing the best prevention coverage, which should be actively promoted to their employees.
- **Businesses can learn more at the April or November 2007 NC Prevention Institutes (www.ncpreventionpartners.org).**
  - Complete a Prevention Audit and begin to create healthy policies and environments.
  - Gain insight about what works from the National Business Group on Health and the Centers for Disease Control & Prevention.

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Executive Director
NC Prevention Partners

Jennifer Hastings, MS, MPH
Prevention & Communications Manager
NC Prevention Partners

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Spotlight on the Safety Net

A Community Collaboration

James D. Bernstein Community Health Center

In early March, local and statewide leaders gathered in Greenville, North Carolina to dedicate the James D. Bernstein Community Health Center. The center was founded on the premise that a person's health depends on much more than just access to health care. This multipurpose facility is designed to integrate professional and community educational programs, job training, and social support systems, as well as health services. These services are tailored to the unique needs of rural, low-income families.

The concept was born out of a sense of community need expressed by Pitt Partners for Health, a Healthy Carolinians partnership. Local safety net providers, agencies, and volunteer groups came together four years ago to form the Eastern Carolina Community Health Care Consortium. That group envisioned a new kind of health center to be named after Jim Bernstein, the founder of the state's and the nation's first Office of Rural Health. The land and site work was donated by E. R. Lewis Construction and the building is owned by Access East, an independent 501(c)3 organization formed by Pitt County Memorial Hospital and East Carolina University to house indigent care programs. The lease for the building is only $1 a year plus maintenance. Greene County Health Care, Inc, a federally qualified health center which has won national recognition for its innovative programs, is charged with the operation of the health component of the center including full medical and dental services. Pitt Community College is responsible for the coordination of educational programs including current courses in health information management, dental hygiene, and radiation technology. East Carolina University Brody School of Medicine operates the pharmacy, which offers 340b (lowest available costs) pricing and access to all pharmaceutical company assistance programs. The East Carolina University School of Nursing and Department of Child Development and Family Relations also provide medical and behavioral health services at the center.

Jim Bernstein, the center's namesake, was a tireless, unselfish and brilliant advocate for North Carolina's rural poor and medically underserved. His office founded the first rural health center in the state, located only twenty miles from the site of the newly dedicated Bernstein Community Health Center. That center, the Walstonburg Community Health Program, has become a part of Greene County Health Care, Inc, a network of seven clinics.

In that same spirit, those who have worked hard to bring the center into existence follow the motto by Thomas G. Irons, MD, "We will do what's right, do it well, and do it together."

Funding for capital and operational costs were generously provided by the following local, state, and national organizations: Blue Cross Blue Shield of North Carolina Foundation, Bureau of Primary Health Care Health Resources and Services Administration, The Duke Endowment, Dunn & Dalton Architects, E.R. Lewis Construction Company, Inc., Golden LEAF, Inc., Kate B. Reynolds Charitable Trust, North Carolina Office of Rural Health and Community Care, North Carolina Rural Economic Development Center, Inc., Pitt Memorial Hospital Foundation, and R.R. Miller Construction, Inc.

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For additional information contact Valerie Gilchrist, MD, Professor and Chair, Department of Family Medicine, Brody School of Medicine, East Carolina University, 600 Moye Boulevard, Brody 4N-84, Greenville, NC 27834; phone: 252-744-2592; email letchworths@ecu.edu.

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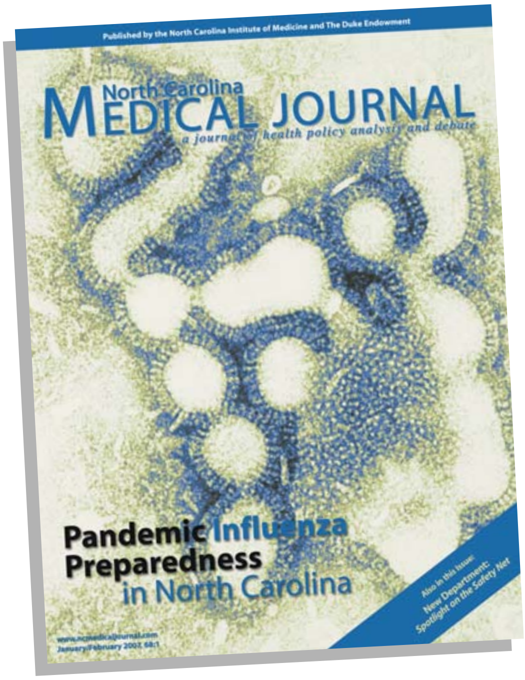

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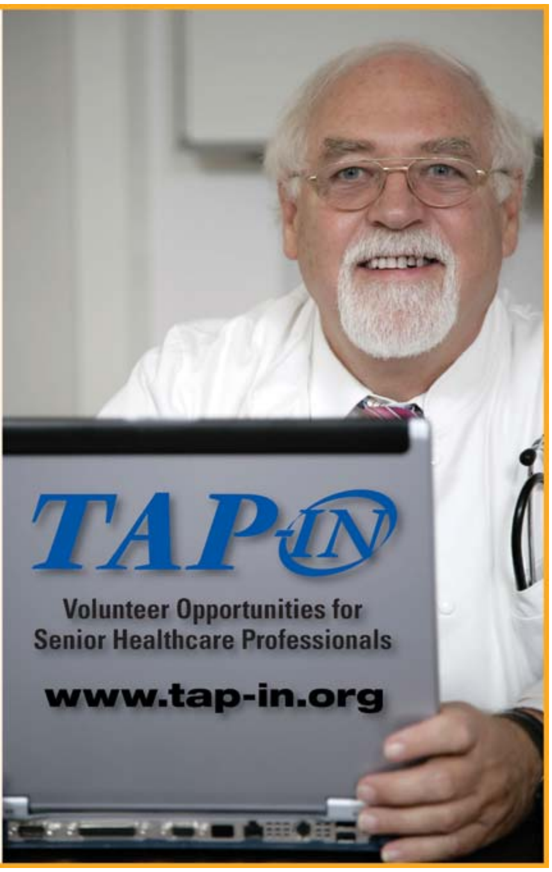

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In 1983 the North Carolina General Assembly chartered the North Carolina Institute of Medicine as an independent, nonprofit organization to serve as a nonpolitical source of analysis and advice on issues of relevance to the health of North Carolina's population. The Institute is a convenor of persons and organizations with health-relevant expertise, a provider of carefully conducted studies of complex and often controversial health and health care issues, and a source of advice regarding available options for problem solution. The principal mode of addressing such issues is through the convening of task forces consisting of some of the state's leading professionals, policy makers, and interest group representatives to undertake detailed analyses of the various dimensions of such issues and to identify a range of possible options for addressing them.

health policy
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North Carolina MEDICAL JOURNAL

a journal of health policy analysis and debate

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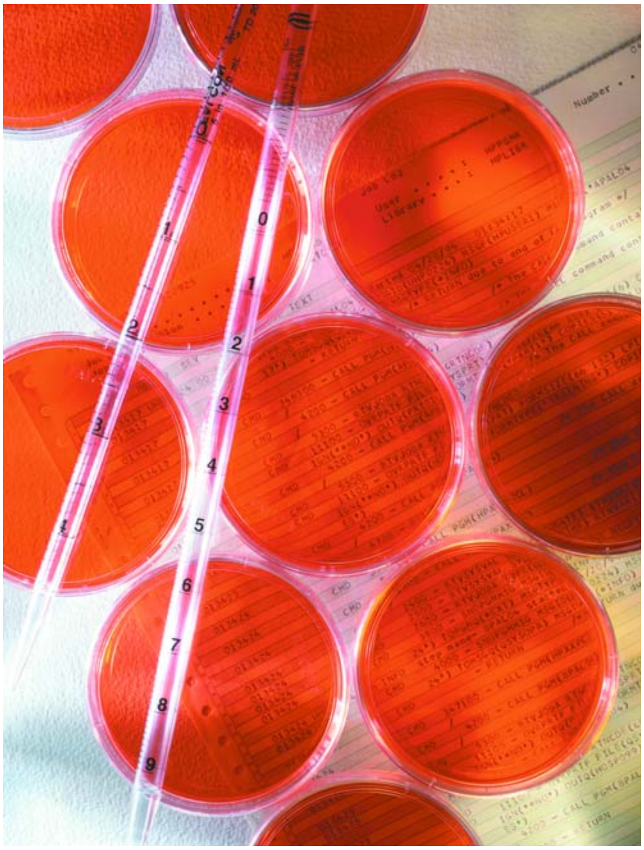

Tarheel Footprints in Health Care

Recognizing unusual and often unsung contributions of individual citizens who have made health care for North Carolinians more accessible and of higher quality

H. Neil Kirkman, MD
Kenan Professor Emeritus of Pediatrics
The University of North Carolina at Chapel Hill

H. Neil Kirkman, MD

The Newborn Screening Program of the North Carolina Division of Public Health is considered to be one of the most important public health programs today. The program screens newborns for genetic disorders and provides early diagnosis and timely treatment to those affected. As such, it mitigates the terrible outcomes of undiagnosed and untreated disorders, which may include mental retardation or even death. This screening program has both ethical and financial benefits for the state. Screening and the subsequent treatment of affected newborns is a better use of resources than the long-term care of undiagnosed and untreated children. Moreover, it reduces the emotional burden for families with affected children. Most of the states in the US started to offer this program in the 1960s and North Carolina was no exception. North Carolina started its program in 1965 with screening for a single disorder (phenylketonuria, or PKU) and has, since that time, expanded to screen for more than 30 disorders.

Dr. Kirkman came to North Carolina in 1965, only 6 months before the newborn screening for PKU began. Infants with PKU were initially treated at 2 or 3 university medical centers, but it became apparent that the management for such an uncommon disorder was most economically and effectively done at a single medical center, which became the PKU Center at the University of North Carolina at Chapel Hill (UNC Chapel Hill). Dr. Kirkman served as the Chief of the Division of Genetics and Metabolism at UNC Chapel Hill from 1965 until his retirement in 1991. During his tenure, he cared for nearly all the PKU babies in North Carolina. Along with his medical team, he talked with the parents by telephone the same day he received the word that the baby likely had PKU and made an appointment for the parents to bring the infant to the hospital immediately. He needed to confirm that all the infants who tested positive actually had PKU and that the special PKU diet would not be deadly to the child or be overly restrictive for quality of life reasons. At the hospital, he and his medical team also gave the parents a positive message about early diagnosis of PKU and provided them with an opportunity to ask questions. He continued to care for his PKU patients on a part-time basis even after his retirement. Dr. Kirkman fully retired from seeing patients in 2000. According to Dr. Dianne Frazier, Professor of Pediatrics and a longtime colleague of Dr. Kirkman, "He is loved by all his patients and their families. They still ask about him whenever they come to the clinic."

Dr. Kirkman is not only a clinician but also a laboratorian. He wrote the computer program for confirmatory test for galactosemia, which is still being used in the newborn screening laboratory. After his full retirement in 2000, he made several attempts to develop an automated galatose-1-phosphate uridyl transferase assay, traveling from Chapel Hill to Raleigh. He continues to write and publish scientific papers with his longtime research colleague Dr. Gian Gaetani. His latest project is to write the history of the North Carolina Newborn Screening Program.

Even after his retirement, Dr. Kirkman continues to serve as an active member of the NC Newborn Screening Advisory Committee and campaigns vigorously for the North Carolina Newborn Screening Program. Several years ago, he wrote to the state legislature against privatization when a for-profit commercial company tried to dismantle the state-managed Newborn Screening Program.

His tender care to his patients and his dedication to the North Carolina Newborn Screening Program have won the respect of his patients, their parents, and his colleagues. As Dr. Dianne Frazier summarizes, "He is a scholar and a gentleman, who always went about his work with deep regard for both patients and colleagues."

The Editors of the *NC Medical Journal* are pleased to recognize Dr. H. Neil Kirkman for his lifetime of work dedicated to quality patient care, development of a successful newborn screening program, and contributions to the field of laboratory science and clinical pathology.

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ARTICLE

Correlates of Intimate Partner Violence Among Female Patients at a North Carolina Emergency Department

Melissa Roche, MA; Kathryn E. Moracco, PhD, MPH; Kimberly S. Dixon, MSW; Elizabeth A. Stern, MPH; J. Michael Bowling, PhD

Abstract

Objective: *This paper identifies comorbid factors among female emergency department (ED) patients who have experienced intimate partner violence (IPV).*

Methods: *321 adult female patients completed self-administered questionnaires while in an urban North Carolina emergency department. IPV was assessed by questioning whether the patient had ever been afraid of a partner, physically hurt or threatened by a partner, or forced to have sex by a partner.*

Results: *One third of all female patients reported at least one form of IPV in their lifetimes. IPV was associated with a low self-rating of physical and mental health, frequent visits to the ED, and problems with alcohol, drugs, and mental health. In multivariate analysis, only a history of alcohol and mental health problems and a low self-rating of mental health remained significant.*

Conclusions: *The findings illustrate the need for IPV screening protocols that address mental health and substance abuse and also emphasize the importance of screening all women for IPV.*

Background

It is well established that physical, sexual, and psychological intimate partner violence (IPV) against women is both widespread and a serious threat to women's health. The National Violence Against Women Survey estimates that 25% of women are physically or sexually assaulted by intimate partners in their lifetimes.[1] Physical health consequences of IPV include fatal and nonfatal injuries, trauma-specific and generalized pain, unwanted pregnancies, sexually transmitted infections, and gynecological problems.[2,3,4,5] IPV is also associated with substance abuse and a variety of mental health problems including depression, anxiety, suicide, and post-traumatic stress disorder (PTSD).[6,7,8,9,10] Victimized women view themselves as being less healthy and report lower levels of physical and mental well-being than women who have not been victimized.[1,11,12]

The prevalence of IPV among emergency department (ED) patient populations varies widely depending on the definition of IPV, identification method, sample, and setting. Research indicates that 5% to 19% of all female ED patients have been physically or sexually abused in the previous year and 33% to 54% report a lifetime history of abuse.[13,14,15,16] Moreover, studies suggest that 2% to 7% of *all* female ED patients present with acute trauma due to abuse,[17,18,19] and 30% to 41% of the

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* This study was supported by a grant to Dr. Moracco (number R49/CCR322636-01-1) from the National Center for Injury Prevention and Control.

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Elizabeth A. Stern, MPH, is the domestic violence program coordinator at the Duke University Health System.

J. Michael Bowling, PhD, is a research associate professor at the Department of Health Behavior and Health Education at the University of North Carolina at Chapel Hill.

violence-related injuries to female ED patients are inflicted by intimate partners.[20,21] However, most battered women present in emergency departments with health problems other than injuries.[16,20]

The ED is an optimal setting for identifying and referring victims of IPV because clinicians come into contact with past, current, and future victims daily, yielding multiple opportunities to reduce morbidity and mortality caused by IPV. Accordingly, during the past two decades there has been a call for emergency departments to develop and implement IPV screening protocols for female patients. Since 1992, the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) has required that accredited emergency departments have IPV policies, procedures, and educational opportunities in place. Despite widespread efforts to train providers and institutionalize IPV protocols, research indicates that IPV screening rates in emergency departments remain low.[22,23] This is in part because health care providers feel they lack effective interventions to respond to the needs of women who disclose violence.[24]

The purpose of this paper is to identify comorbid factors among adult female ED patients who have experienced intimate partner violence. Given the high prevalence of IPV in this population, distinguishing characteristics and conditions that are associated with IPV may enable providers to respond more effectively to these patients by identifying their specific physical and mental health needs.

Methods

Data for this study come from an evaluation of a hospital-based intervention designed to increase IPV detection and provide appropriate services to IPV survivors in the emergency department of a mid-sized community hospital located in an urban, ethnically diverse county in north central North Carolina. We consecutively approached all female patients age 18 and older who visited the ED to receive care for themselves during randomly selected six-hour shifts within two three-week periods pre and postintervention. Women were excluded from the study if they showed signs of cognitive impairment (including intoxication), were in police custody, did not speak English or Spanish, or were admitted to the hospital.

Participants completed a two-page self-administered questionnaire (available in English and Spanish) that included questions about their demographic characteristics, self-assessed physical and mental health status, history of IPV, and whether they were asked about IPV during their ED visit. Respondents indicated whether they were willing to be called for a 15 to 20 minute phone interview, and if so, they were asked to provide a safe date, time, and number for project staff to call.

In order to protect patients' safety and privacy, participants were offered one of two versions of the questionnaire. Women who were unaccompanied or could complete the form alone received a full version of the questionnaire, which contained questions about adult lifetime IPV experience and IPV screening in the ED. Women who could not complete the form in privacy received an abbreviated version that did not contain questions about IPV. Those women who completed the abbreviated questionnaire and indicated willingness to participate in a phone interview were called and asked the questions about IPV. All participants received $5 in cash for completing the survey.

The Institutional Review Boards of Durham Regional Hospital, Duke University Health System, and the Pacific Institute for Research and Evaluation (PIRE) all reviewed and approved this study.

Variable Definitions

Lifetime experience with IPV was assessed via 3 items on the questionnaire that asked whether the respondent had ever been (1) afraid of a partner, (2) physically hurt or threatened by a partner, and (3) forced to have sex by a partner. For this study, we categorized women as having experienced IPV during their lifetime if they responded "yes" to any of the 3 questions.

Demographic variables included age, race, educational level, and marital status. Health-related variables included single questions about participants' self-assessment of their current physical and mental health ("Compared to women your age, would you say your physical / mental health is: excellent / very good / good / fair / poor?"), disability status ("Do you have a physical disability or health condition that limits your physical functioning?" yes / no), history of problems with mental health ("Have you ever had any mental health problems, like depression, bipolar disorder, or post-traumatic stress disorder?" yes / no), alcohol ("Have you ever had a problem with alcohol?" yes / no), and drugs ("Have you ever had a problem abusing prescription or nonprescription (recreational/illegal) drugs?" yes / no). We also asked participants a number of health care related items, including how many times they had been to the ED in the past 12 months, how most of their medical costs were covered (self pay, Medicare, Medicaid, private insurance, other), the reasons for their current visit (injury, illness, or other), and satisfaction with their current ED visit (very satisfied, somewhat satisfied, somewhat dissatisfied, very dissatisfied).

Data Analysis

We used SPSS version 11.3 (SPSS Inc, Chicago, IL) for all analyses. After examining univariate frequencies, we used Fisher's exact tests for analysis of bivariate associations with whether or not women reported IPV. We then included factors that were significantly associated with experiencing IPV in a logistic regression model and calculated adjusted odds ratios (AOR) and 95% confidence intervals (CI). A p-value of .05 was considered significant for all analyses. We assessed for multi-collinearity among the independent variables in our model and did not find any cause for concern using the criteria of variance inflation factor (VIF) = 2.5.[25]

Results

A total of 346 female patients completed the survey during a visit to the emergency department, representing 75% of eligible patients. Of those, 321 completed the full form that included questions about their personal experience with IPV and 25 completed the abbreviated form. Of the women who completed the full form, seven failed to provide information about their history of IPV. Of the 25 women who completed the abbreviated form, seven were successfully contacted by telephone and provided information about IPV. In total, 321 women (93%) provided information on their history of IPV and are thus included in the analysis. Of the sample included in this analysis, 124 women were interviewed preintervention and 197 were interviewed postintervention. Given that the intervention was designed to increase identification of IPV among female ED patients and that respondents were, in fact, more likely to have been asked about IPV by ED staff postintervention, there is a possibility that the women surveyed postintervention would be more likely to note a history of IPV on their self-administered survey. However, we found that the pre and postintervention groups did not differ significantly on any of the independent variables nor in their reporting of IPV.

Table 1 describes the characteristics of the study sample. The ages of women ranged from 18 to 74, with a mean age of 37. Two thirds of the patients were African American and more than half (56%) were not married. In addition to the current visit, most (81.2%) of the patients had made at least one other visit to an ED in the previous 12 months, with 63.9% of the sample reporting 2 or more other ED visits in the last year.

One third of women (33.3%) reported that they had experienced some form of IPV in their lifetimes. Table 2 presents the combinations of IPV reported by women who disclosed some form of IPV. As indicated in the table, most types of IPV did not occur in isolation.

Table 3 presents the results of the bivariate analyses of factors associated with reporting IPV. Factors consistently associated with all 3 forms of IPV are describing current mental health as fair or poor, a self-reported history of alcohol problems, a self-reported history of drug problems, and a self-reported history of mental health problems. Factors associated with reporting IPV, but not consistently associated with the individual forms of IPV, are Medicaid status, describing physical health as fair or poor, and two or more visits to the ED in the past year. None of the other factors analyzed were significantly associated with reporting IPV, including whether the woman was at the ED due to an injury or came accompanied by a partner.

We included the variables that were bivariately associated with IPV in a logistic regression analysis, with reporting any IPV as the outcome variable (Table 4). After controlling for age, education, race, and marital status, only a self-described history of mental health problems, history of alcohol problems, and reporting mental health as fair or poor remained significantly associated with experience of IPV. Marital status also independently predicted experience of IPV. Women who were separated or divorced were more than eight times more likely (AOR 8.47; 95% CI: 3.44-20.88) to report a history of IPV compared with single women.

Table 1.
Respondent Characteristics (n=321)

	%
RACE	
African American	66.4
White	25.5
Latina/Hispanic	2.8
Native American	2.5
Other	2.8
AGE GROUPS	
18 to 24	21.9
25 to 34	24.1
35 to 44	26.3
45 to 54	15.9
55 to 64	7.8
65 and over	4.1
EDUCATION	
Did not complete high school	23.4
Completed high school	36.8
Some college	26.2
Graduated college	13.7
MARITAL STATUS	
Single	43.9
Married	29.3
Separated	9.0
Divorced	13.4
Widowed	4.4
HOW MEDICAL COSTS ARE PAID	
Self pay	27.1
Medicare	8.8
Medicaid	32.5
Private/group insurance	27.8
Other	3.7
EXPERIENCED IPV	**33.3**
Hurt or threatened by a partner*	24.4
Forced to have sex*	16.3
Afraid of a partner*	26.5
* IPV categories are not mutually exclusive	

Discussion

Our finding that a third of female ED patients have experienced IPV in their lifetimes is consistent with the high prevalence of IPV among female patients found in other ED-based studies.[13,14,15,16] Also consistent with previous research are the findings that most women who have experienced IPV visit the ED for noninjury complaints, and that there are few discernable differences between victims and nonvictims.[13,14,15,16] The differences that remained significant, self-reported histories of alcohol and mental health problems and fair or poor self-assessed

Table 2.
Patterns of IPV Among Respondents Reporting IPV (n=107)

Type of IPV	n	%
Physically hurt or threatened only	14	13.1
Afraid only	12	11.2
Forced sex only	6	5.6
Physically hurt or threatened and afraid	29	27.1
Afraid and forced sex	11	10.3
Physically hurt or threatened and forced sex	2	1.9
All three forms of IPV	33	30.8

mental health status, indicate that ED patients who are IPV survivors may have unaddressed mental health and substance abuse needs.

The results of this study indicate that the ED is a good place to identify and assist IPV survivors, and that all women should be screened for IPV, regardless of their presentation. We recognize that there is an ongoing debate over the effectiveness of IPV screening in health care settings, including how to measure the long-term effectiveness of IPV screening.[26,27] While there certainly is an urgent need for rigorous research regarding the effectiveness of screening, universal IPV screening for female ED patients seems warranted given the high prevalence of IPV among female ED patients, support for screening by professional organizations as well as patients,[16,28,29,30] and the lack of evidence that screening is more harmful than not screening.

The fact that IPV survivors were more likely than women who had not experienced IPV to report having ever had alcohol and mental health problems, and that they were more likely to rate their current mental health status as fair or poor, suggests that women who have experienced IPV have potentially unaddressed mental health and substance abuse needs. Previous research has documented the strong association between IPV and mental health problems, particularly depression and post-traumatic stress disorder (PTSD).[6,7,8,9,10] Similarly, alcohol use or abuse has been associated with an increased risk of past or current IPV.[6,10,16,31] The etiology of mental illness and substance abuse among battered women is unclear, as the bulk of previous research cannot establish temporal sequence. Regarding the link between IPV and mental health problems, Frank and Rodowski (1999) note that mental health problems may be more common among female IPV victims "both because mentally ill women are more vulnerable to abuse and because verbal or physical abuse may precipitate or perpetuate psychiatric disorders."[32] Regardless of the exact nature of the relationship, previous research, along with this study's findings, suggest that a high proportion of IPV survivors presenting in the emergency department will have concurrent mental health needs. Referrals to services to address these needs should be part of IPV screening protocols in health care settings.

Table 3.
Bivariate Analyses of Health Status and Emergency Department Visit with Intimate Partner Violence (IPV) Among Adult Female Emergency Department Patients (n=321)

		Any IPV		Physically hurt or threatened		Forced to have sex		Afraid of a partner	
	Total (n=321)	Yes (n=107)	No (n=214)	Yes (n=78)	No (n=242)	Yes (n=52)	No (n=268)	Yes (n=85)	No (n=236)
% with medical costs covered by Medicaid	35.3	43.0*	31.4*	43.6	32.4	42.3	34.1	43.5	32.3
% who report physical health as fair or poor	21.9	29.9*	17.8*	24.4	21.2	32.7*	19.9*	27.1	20.0
% who report mental health as fair or poor	12.9	23.4**	7.6**	21.8**	10.0**	30.4**	9.4**	21.2**	9.9**
% with 2 or more visits to the ED in past year	63.9	71.8*	60.0*	72.4**	61.4**	80.0**	60.7**	72.3	60.9
% with history of alcohol problem	8.4	17.8**	3.7**	20.5**	4.5**	26.9**	4.9**	21.2**	3.8**
% with history of drug problem	4.7	11.3**	1.4**	13.0**	2.1**	17.6**	2.2**	13.1**	1.7**
% with history of mental health problem	30.8	55.7**	18.4**	61.0**	21.3**	59.6**	25.3**	53.6**	22.6**
% who came to ED for an injury	32.4	31.8	32.7	29.5	33.1	26.9	33.2	36.5	30.9
% who were accompanied by a partner to the ED	28.1	26.2	29.1	25.6	29.0	23.1	29.2	20.0	31.1

* P < .05
** P < .01

Table 4.
Logistic Regression Model of Characteristics of Health Status and Emergency Department Visit History that Predict Intimate Partner Violence (IPV) Among Female Patients, Controlling for Age, Education, Race, and Marital Status (n=301)

Referent	Adjusted OR	95% CI
History of alcohol problem	4.09	(1.27, 13.18)
History of mental health problem	2.77	(1.44, 5.34)
Reports mental health as fair or poor	2.72	(1.04, 7.16)
History of drug problem	3.94	(.75, 20.6)
Medical costs covered by Medicaid	1.77	(.94, 3.34)
2 or more visits to the ED in past year	1.61	(.84, 3.06)
Reports physical health as fair or poor	1.35	(.62, 2.92)
Marital status Ref group: Single		
Married	1.75	(.79, 3.87)
Divorced / separated	8.47	(3.44, 20.88)

C statistic = .788 (95% CI .733 - .843, p < .001)

The results of our study should be viewed within the context of its limitations. First, because the study was conducted in a single urban emergency department, it is not generalizable to all women in the state nor to all female ED patients. The study also only included women who were discharged from the ED. These women may be significantly different from women who were subsequently admitted to the hospital in terms of the severity of their illness or injury. In addition, given that the ED intervention was designed to increase identification of IPV among female ED patients and that respondents were, in fact, more likely to have been asked about IPV by ED staff postintervention, there is a possibility that postintervention respondents would be more likely to note a history of IPV on their self-administered survey. However, we found that the pre and postintervention groups did not differ significantly in the proportions reporting of IPV.

We also asked women about their lifetime experience with IPV without collecting any information about the characteristics (eg, recency, severity, frequency, duration) of those experiences. It is possible that some participants experienced only isolated incidents of IPV in the distant past. However, previous research has demonstrated that IPV has profound and long-lasting effects on women's physical and mental health,[2,3,4] and past victimization is a risk factor for current and future IPV.[33] An additional limitation to the study is potential misclassification bias that could have occurred because respondents provided self assessments for several of the key independent variables, notably their histories of substances abuse and mental health problems. All respondents may not have understood and interpreted these questions in the same way.

Finally, the cross-sectional nature of this research makes it impossible to establish temporality, and the study is subject to both recall and reporting bias.

Despite these limitations, our study provides further evidence that the emergency department is an important setting in which to identify and assist women who have experienced IPV. It also reinforces the need to screen all adult female ED patients regardless of their presenting complaint. Providers should also be cognizant of the potential concurrent mental health needs of women who have experienced or are experiencing IPV and ensure that they are equipped to provide appropriate referrals to mental health providers, substance abuse services, and intimate partner violence agencies. **NCMJ**

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ARTICLE

Providing Medical Care in State Psychiatric Hospitals

Susan Saik, MD; Brian B. Sheitman, MD; Scott Mann, MD; Walter W. Stelle, PhD;
James W. Osberg III, PhD

Abstract

Background: *Dorothea Dix State Psychiatric Hospital (DDH) was cited by regulatory agencies in 1999-2001 for serious deficiencies in providing medical care to psychiatric patients. This resulted in a change in the discipline responsible for providing medical care. We report here how clinical staff and regulatory agencies evaluated the change. In addition, we sought to determine how medical care is currently provided at other state hospitals across the nation.*

Methods: *A transition occurred whereby the responsibility for medical care (direct care and supervision of physician extenders) was changed from psychiatrists to internists. We surveyed psychiatrists and nurses about their impressions of the change and calculated the number of citations from regulators pre-and post-changeover. In addition, a survey was sent to all 212 state psychiatric hospitals.*

Results: *Response rates were: 100% for DDH psychiatrists, 42% for DDH nurses, and 67% for state hospitals. At DDH, clinicians favorably viewed the changeover with 23 (96%) of the 24 psychiatrists reporting a preference for internists having overall responsibility for medical care. There was also a marked reduction in deficiencies cited by regulatory agencies, with 10 prior to the change and only one after the change. Responses to the State Psychiatric Hospital survey revealed that psychiatrists currently provide or are responsible for at least some portion of the medical care at 69% of all facilities.*

Limitations: *DDH staff evaluated a change from a system that had not been in place for 3 years. Quality of care measures were not available. How these data generalize to other state hospitals is unknown.*

Conclusions: *Having internists responsible for medical care was well received by staff and regulatory agencies. Currently, state psychiatric facilities use different approaches to provide medical care. Further research is needed on how quality of care, and ultimately patient safety, may be impacted by these different service delivery models.*

Key words: *Inpatient psychiatry, state hospitals, medical comorbidity*

Introduction

Patients with psychiatric and/or substance abuse disorders have an increased prevalence of comorbid medical disorders compared to the general population.[1-4] A recent report on the physical health of the 1500 schizophrenia patients enrolled in the Clinical Antipsychotic Trials of Intervention Effectiveness (CATIE) study showed that over 40% had signs and symptoms consistent with the metabolic syndrome.[5] This syndrome is characterized by insulin resistance and associated with an increased risk of diabetes and cardiovascular disease. In addition, among patients hospitalized for either a medical or surgical condition, those patients with schizophrenia, when compared to those without the condition, had significantly more complications, with their average length of stay 10 days longer.[6] The reason for the increased prevalence of medical problems is less clear and likely multifactorial.[7-10] A reduced commitment/ability to maintain overall good health, side effects of prescribed psychotropic medications, an increased neuro-developmental vulnerability, increased use of tobacco products, and some combination of all

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the above have been suggested. Recent recommendations acknowledging the increased medical comorbidity among schizophrenia patients now call for mental health providers to offer physical health monitoring in primary care settings for those patients who do not routinely receive ongoing physical health monitoring.[11]

How to best provide medical care for psychiatric inpatients in state facilities or freestanding psychiatric hospitals (not affiliated with a general medical hospital) has received limited systematic investigation. Given Dorothea Dix Hospital's (DDH) history of regulatory problems directly related to the proper medical care of patients on the psychiatric units, a decision was made in 2001 to change the professional medical discipline responsible for providing and supervising all medical care from psychiatrists to internists. The purpose of this report is to describe the impressions of clinical staff (psychiatrists and nurses) and outside regulatory agencies on how they evaluated the changeover to the current system. In addition, we conducted a survey of all state psychiatric hospitals in the United States, whereby we requested information on which medical disciplines are responsible for providing medical (nonpsychiatric) care to the patients on the psychiatric units.

Methods

Part I. This study was conducted at DDH in Raleigh, North Carolina. The hospital maintains both Joint Commission on Accreditation of Hospital Organizations (JCAHO) and Centers for Medicare and Medicaid Services (CMS) certification. The hospital is the primary off-site training location for the University of North Carolina at Chapel Hill (UNC-Chapel Hill) Department of Psychiatry. Psychiatric residents and medical students rotate through the adult and adolescent admission wards. In addition, all psychiatric residents spend two months of their medicine rotation on the DDH medical unit. All of the teaching attending physicians have faculty appointments at either the UNC-Chapel Hill Departments of Psychiatry or Medicine.

DDH serves adolescent, adult, and geriatric patients. The hospital also has both a Pre-trial Evaluation Unit and a 90-bed Forensic Treatment Program. There is a separate medical unit that provides a scope of service capable of handling most acute medical problems (ie, with capabilities similar to a general hospital non-Intensive Care Unit bed). There are approximately 4500 admissions per year to the hospital and an average daily census of about 320. The hospital serves both acute patients and those requiring extended stays. The primary diagnoses among the acute admissions patients are substance abuse disorders (60%) and the major mental illnesses (40%), consisting of schizophrenia, schizoaffective disorder, and bipolar disorder. The longer stay patients are primarily diagnosed with a major mental illness.

A transition in the provision of direct medical care began toward the end of 2001. Internists were made responsible for these functions rather than psychiatrists who had previously been providing direct medical care and were also supervising the physician extenders. The change was fully implemented by the end of the year 2002.

Management believed the changeover was remarkably successful and that almost everyone was pleased with the new system. However, data was not systematically collected to verify this opinion. Therefore, in the winter of 2005, a survey was conducted of all psychiatric and nursing staff. The survey was conducted anonymously for nursing staff, but not for the psychiatrists. Conducting the survey anonymously for psychiatrists, as well, was considered but decided against due to the difficulty of achieving true anonymity given the relatively small number of psychiatrists employed (n=24).

The investigators developed the survey and designed it to be brief. The psychiatrist survey consisted of 6 questions, with 5 of the 6 questions requesting a selection of the best response out of 3 or 4 choices (ie, yes, no, not sure). The other question, "What do you like or not like about the way medical care is provided to psychiatric patients at DDH," instructs the psychiatrist to select as many of the listed responses that are applicable. There is also a space left to write in responses. The authors did not formally assess the validity of the instrument before using it. The surveys were sent directly to all psychiatrists, and their supervisor was responsible for following up to see that it was completed. Completed surveys were sent to the clinical director's office. The nursing survey consisted of 3 questions. Similar to the psychiatrists' survey, the nurses' survey included a question asking what they liked or disliked about how medical care is provided at DDH. The nursing surveys were distributed from the director of nursing to nursing supervisors, who then distributed the surveys to the individual nurses. Nursing staff were instructed to send the surveys back to the director of nursing's office. Surveys were sent one time only, though supervisors were asked to remind nurses to respond. No incentives were offered to those who responded. At the time of the survey, there were 24 staff psychiatrists at the hospital, of which 21 were diplomates of the American Board of Psychiatry and Neurology Board (ie, board certified) with the remaining 3 board eligible. Sixteen psychiatrists had worked at either DDH or another state hospital where psychiatrists were directly responsible for providing medical care. There were 155 nurses employed at the time of the survey.

Part II. The Centers for Medicare & Medicaid Services (CMS, formerly known as the Health Care Financing Administration or HCFA) facility and compliance survey records were reviewed for two 3-year periods: 1999-2001 and 2003-2005. All regulator-cited deficiencies specifically related to the medical care of patients for each period were recorded. To be counted as a deficiency, there needed to be a specific reference in the CMS record to care that did not meet either the element, standard, or condition of care as required by CMS. If the same deficiency was cited in more than one place (ie, cited as deficient on multiple elements, standards, or conditions) it was only counted one time.

Part III. Due to the impression of how successful the changeover had been at DDH and to the anecdotal stories of the many different ways medical care was provided in other state hospitals, we sought to systematically collect data on this issue. Therefore, a list of all state psychiatric hospitals (n=212), including chief executive officers (CEOs) and addresses, was obtained from the National Association of State Hospital Program Directors (NASHPD) website in 2006. A brief survey was developed by the investigators consisting of 5 questions with instructions to choose the best answer from a list provided or to write in a response if the response choices did not fit their institution. The survey was then sent to each hospital's CEO with instructions to please forward the survey to the person at the institution who could best answer questions about which disciplines were providing medical care on the psychiatric units. Questions addressed both normal business hours and off–hours coverage since many institutions use "moonlighting" providers (ie, licensed physicians either within or outside of their specialty who typically work nights or weekends, in addition to their regular jobs, to earn additional compensation). The survey was sent one time only and no incentives were provided.

Given the types of data collected, only descriptive statistics were used for all data analyses.

Results

Survey of psychiatrists and nurses at Dorothea Dix Hospital

Psychiatrists

All 24 psychiatrists responded to the survey. All except one (96%) preferred having internists provide and be responsible for the medical care of patients. One (4%) psychiatrist wasn't sure. The most common reasons sighted for this preference were:

a. Reduces my concern about missing a serious medical problem 100%
b. Gives me more time to focus on psychiatric issues 96%
c Reduces my potential medical legal risk 83%

Psychiatrists described their working relationship with the internists and the physician extenders as follows: excellent 92% (n=22), good 8% (n=2), fair and poor 0%.

Nurses

Of the 155 nurses who were sent surveys, 65 (42%) responded. All except four (94%) stated that they preferred the current approach. Forty-seven nurses had worked at DDH for more than 4 years and had experience with both service delivery systems. The most common reasons sighted for their preference were:

a. I feel more comfortable having a medical provider address medical issues.....................................88%
b. I prefer to contact the person who will specifically address the problem, rather than often being asked to make more than one call................................71%

Deficiencies Cited by CMS

During the period 1999-2001, there were 10 citations identified by regulators that were directly related to the medical care of patients. Thus, the hospital was found to be out of compliance with the "Conditions of Participation" and needed immediate plans for correction to avoid losing federal funding. During the period 2003-2005, there was one citation related to medical care. This was corrected by the time regulators visited, so there were no requirements for additional follow-up.

Survey of State Hospitals

Responses were received from 145 (67%) of the state hospitals and included the following:

1. Medical (nonpsychiatric) care during business hours was provided as follows:
   Psychiatrists 65/143 (45%), physician extenders 58/143 (41%), physicians other than psychiatrists 137/143 (96%). Note: Many hospitals reported that multiple disciplines provided coverage; therefore, the numerator does not add up to 143.
2. If physician extenders were used, who was responsible for their supervision?
   Physician extenders were used in 70/143 facilities (12 facilities reported using physician extenders as moonlighters). They were supervised by psychiatrists in 35/70 (50%) of facilities and internists in 66/70 (94%) of facilities.
3. Off-hours coverage was provided by moonlighting physicians in 68/143 (48%) of the facilities. Psychiatrists provided this coverage in 42/68 (62%) facilities, nonpsychiatric physicians in 52/68 (76%), and physician extenders in 13/68 (19%).
4. Nonpsychiatric physicians solely provided medical care in 44/143 (31%) facilities, while psychiatrists were responsible for medical care by either directly caring for patients during regular business hours, supervising physician extenders, or providing moonlighting coverage in 99/143 (69%) of the facilities.

Discussion

These data suggest that the transition from psychiatrists to internists went very well at DDH. Both psychiatrists and nurses overwhelmingly endorsed the current system with most having experience working in the previous model. Psychiatrists unanimously endorsed that the change reduced their concern about missing a serious medical problem. In addition, despite some concerns that there would be an emergence of "turf" battles between psychiatrists and nonpsychiatric physicians, relationships between the two disciplines were described as excellent by 22/24 psychiatrists and good by the other two psychiatrists. Nurses also overwhelmingly reported that they preferred having a medical provider address medical issues and preferred directly contacting the person who would address the problem. Moreover, there was a marked reduction in the number of regulator-cited deficiencies in the medical care provided to patients.

The data received from the survey of all the facilities would suggest that there is currently no consensus on which disciplines should be providing medical care to patients in state facilities. Though psychiatrists do not provide medical care at our facility, this remains the case at 69% of the facilities. Psychiatrists provide direct medical care during business hours in 45% of hospitals, are responsible for supervision of physician extenders in 50% of facilities that use them, and are responsible for medical care while moonlighting at 62% of hospitals where moonlighting occurs.

We were in favor of the change from psychiatrists to internists because we felt that staying current with the latest psychiatric advances is a full-time job, and it is unrealistic to expect psychiatrists, no matter how competent, to keep up with the internal medicine literature as well. Interestingly, the Psychiatry Board recertification exam contains no questions directly related to internal medicine. Anecdotal accounts suggest that having "split" treatment (ie, mental health care treatment by a psychiatrist and nonmental health care by a nonpsychiatrist) seems to be the way most outpatient psychiatrists operate their practice. Furthermore, the larger issue of how to best provide medical care to a patient hospitalized for a different indication is not only relevant to psychiatric inpatients. A recent publication described a project whereby a hospitalist-orthopedic team worked together in a collaborative model with orthopedic surgery patients, as opposed to the traditional consultant model used in academic medical centers.[12] They reported a reduction in minor postoperative complication rates, with no statistically significant differences in length of stay or cost. Both the nurses and surgeons strongly preferred the comanagement hospitalist model.

This report has its limitations. The survey data are comparing two different time periods and are limited to "satisfaction" with the change, not differences in specific quality of care measures. In addition, psychiatrists were not surveyed anonymously, which could have biased their opinions, and only 42% of the nurses responded. DDH also has a medical unit with a scope of service beyond what some other state hospitals may have, and it also has a strong affiliation with an academic medical center located relatively close to it. Nevertheless, we believe this is a very important topic for the medical field. Currently, state psychiatric facilities use different approaches to provide medical care for patients. These data suggest that further research is needed on how quality of care and, ultimately, patient safety may be impacted by these different service delivery models in order to eventually make best practice recommendations. **NCMJ**

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POLICY FORUM

Laboratory Medicine and Clinical Pathology: Changing Paradigms of Practice

COMMENTARIES

> *"The volume and precision of information we can gather has brought us to the threshold of a new paradigm in health care where we are changing from a system in which diagnosis and treatment prevail to one in which prognosis is joined with treatment to anticipate the effects of interventions, even to anticipate the incidence and existence of disease."*

INTRODUCTION

Policy Forum:
Current Topics in Laboratory Medicine and Clincal Pathology

Modern day medicine has become a very complex process that depends more and more on specific information about individuals. We are familiar with "tests" that assess the nature and content of our fluids, tissues, and physiological functions and recognize that these tests provide necessary information to ensure the best possible care. What we may not understand is how precise, sensitive, and complex those tests have become and how much the practice of health care has come to depend on these assays and evaluations. In fact, the volume and precision of information we can gather has brought us to the threshold of a new paradigm in health care where we are changing from a system in which diagnosis and treatment prevail to one in which prognosis is joined with treatment to anticipate the effects of interventions, even to anticipate the incidence and existence of disease.

One area of testing that has received perhaps more attention than others is genetic testing for susceptibility to disease. This line of work has evolved such that we are able to assess the overall disease susceptibility of the human genome for groups of people and for individuals in some cases. That work is controversial and raises ethical concerns for the bedside clinician, the laboratorian, and the policy makers who shape payment and information sharing rules. This issue of the *North Carolina Medical Journal* includes discussions of these consequences as well as the promise of the new technologies.

The location of testing has broadened from the hospital, clinic, or laboratory to the home or workplace. Diabetes monitoring and pregnancy testing are the most familiar in-home tests, but there are emerging tests for drug monitoring and other disease self-management. We are seeing intensive testing and screening efforts making use of health fairs, there are a range of tests available in "minute clinics" in pharmacies, health clubs and fitness centers are offering a range of tests, and shopping malls have become the location for testing centers or volunteer efforts that include taking samples. These new opportunities for testing may be seen as a "disruptive technology" that threatens the organization of medical care or as a chance to intervene more effectively in population health.

This issue of the *Journal* ventures into some quite technical areas such as nucleic acid amplification, karytotyping, mass spectromtetry in proteomics, polymerase chain reaction, and flow cytometry. These may seem to be very complex and specialized parts of the world of pathology and laboratory medicine, but they are becoming more and more the workhorse components of day-to-day health care. These techniques and approaches will likely be so ubiquitous that the material covered in this issue of the *Journal* may become part of the standard vocabulary and knowledge base for all caregivers as well as patients in the not-to-distant future

The goal of this issue of the *Journal* is to help the lay person as well as the broadest array of caregivers begin to understand how rapidly this field is developing and how it has the potential to bring even more change to clinical care and prevention of disease as we seek to give people healthier and happier lives.

Thomas C. Ricketts III, PhD, MPH
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ISSUE BRIEF

Polishing the Crystal Ball:
Emerging Trends in Contemporary Clinical Laboratory Medicine

Dana D. Copeland, MD, PhD

For clinical laboratory medicine in the 21st century nothing is so important as strong prediction. Strong in the sense of robust and specific detail of the predicted events and strong in the sense of high likelihood of predicted outcomes. For a discipline that has focused primarily on diagnosis for more than a century, this new ascendancy of prognosis in the application of clinical laboratory data represents a paradigm shift. The value of a laboratory test in the modern era is often measured by the utility of the test result in predicting a future clinical event in the patient's course. In some cases the test result will be useful in predicting relevant events that will occur in the next few minutes or hours and, in other cases, events years and even decades in the future.

> *"In the new 21st century paradigm, the role of the laboratory will increasingly be one of helping the physician answer the question: What will happen to this patient and will any of several interventions likely change what will happen in a favorable way?"*

The prevailing diagnostic applications of medical laboratory testing in the 20th century are giving way in the 21st century to prognostic implications for risk stratification, prevention, therapeutic design and timing, and ultimately even for disease definition. In the 20th century the laboratory helped the physician answer the question: Is anything wrong with the patient and if so what? This paradigm led to a generalized notion that a laboratory result was either normal or abnormal. In the new 21st century paradigm, the role of the laboratory will increasingly be one of helping the physician answer the question: What will happen to this patient and will any of several interventions likely change what will happen in a favorable way? In the new paradigm, significance for laboratory results will increasingly be measured in incremental impact on likelihood of clinically significant events and methods of prevention or mitigation.

This issue of the *North Carolina Medical Journal* examines some of the factors driving this paradigm shift and the implications of increasing prognostic utility for laboratory testing. We explore some innovations that illustrate the trend and the implications for health care providers and patients alike in commentaries that illustrate emerging technologies, evolving platforms for testing, and new ways of applying the data to shape the interaction of patient and health care provider. For contemporary clinical laboratory medicine, change occurs along 3 principal axes: what we can detect, where the analysis occurs, and how the result is applied in patient management.

What we detect in the modern clinical laboratory changes, as it has for over 150 years, through the power of advances in analytic technology. Today clinical laboratories in most modern hospitals routinely detect analytes down to a level of one part per 10 billion. Not only has the detection level of our assays been improved by several orders of magnitude, but the inventory of analytes with clinical significance has exploded as our more sensitive assays allow researchers to explore in detail the relationships between disease and body chemistry. Dozens of new markers with potential

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clinical significance are introduced every year. Advances in proteomics, nucleic acid amplification, and molecular genetic pathology promise to accelerate the introduction of new tests with clinical significance.

Where we test is undergoing a dramatic shift. The first useful clinical laboratory test was the visual, olfactory, and gustatory analysis of urine. Analysis was often performed at the patient's bedside. In the 20th century, the emergence of more sophisticated testing that required either laboratory expertise or expensive equipment led to centralized laboratories in hospitals or at reference sites. Specimens were obtained from the patient and then transported to the testing laboratory, sometimes in the same building and sometimes thousands of miles away. Most testing moved away from the patient and into the remote laboratory. Then with the introduction of semi-quantitative glucose testing with dipsticks in the early 1960s and true quantitative glucose testing with portable glucometers in the 1970s, analytical chemistry testing began to return to the near patient environment. The trend has only accelerated with the introduction over the past two decades of a variety of point-of-care testing devices that put powerful analytic capabilities into the hands of health care professionals at the bedside, require only minimal expertise for operation, and provide real-time data for clinical management and decision making.

In contemporary clinical laboratory medicine, the site of testing is determined in part by the time frame in which prognostic significance applies. If the results of the test predict clinical events or therapeutic impact that will occur within minutes, the testing is likely to occur in a setting near the patient. For tests with prognostic significance in the hour to 24-hour range, a centralized laboratory remains the most likely venue. Intense clinical management of the patient in either the inpatient or ambulatory setting favors rapid turnaround for even routine tests, and economic pressures for efficient and cost-effective care are driving dramatic changes in the centralized hospital laboratory of the early 21st century.

Already for diabetes, and in the near future for other conditions, the ease of operation and reliability of point-of-care devices will facilitate the migration of traditional laboratory testing not only away from the central laboratory but also out of the hands of health professionals and into the hands of patients. Patients so empowered will be able to participate more effectively in the management of their own disease and in triage decisions that determine if and when intervention by medical professionals will be necessary.

A third area of accelerating change, and perhaps the most intriguing, is how the data generated by clinical laboratory medicine is employed in the management of the patient. Modern medicine and the experimental laboratory were born conjoined twins in the 19th century with the discovery of causal agents for disease, especially micro-organisms. A classification of diseases based on etiology and pathogenesis is still used today and continues to evolve in large measure on the basis of discoveries in the experimental laboratory. Once a causal understanding of the disease is established in the experimental laboratory, the clinical laboratory is positioned to test for the presence of etiological agents or their biochemical or immunological footprints. For the 20th century and the latter 19th century, the role of the clinical laboratory was to support or refute a physician's diagnosis.

While advances in the clinical laboratory continue to support this diagnostic paradigm, increasingly the clinical laboratory produces data with direct prognostic implications. Molecular studies can identify patients with genetic risk for the future development of disease; proteomics offers the promise of detecting patients that are evolving toward a disease state long before the disease is clinically manifest; and immunopathological assays may identify which patients among a group with the same type of tumor will do well on one treatment regimen and which will do better on another. Polymerase chain reaction (PCR) detection of microbials offers the promise of detecting and identifying pathogens in real clinical time instead of the days or weeks required by conventional microbiological assays, and identification of human papillomavirus strains in infected patients now rivals and supplements the value of the tried and proven morphologic pap smear in predicting which patients require intervention to prevent progression to cervical cancer.

Milestones in the History of the Laboratory Medicine

A cursory outline of milestones in the development of clinical laboratory medicine is helpful in understanding the implications of the rapidly evolving discipline. Examination of urine for prognosis was advocated by Hippocrates as early as 400 BC. Kouba et al recently described the 1100 year evolution of the prognostic application of uroscopy to a diagnostic approach advocated by Theophilus.[1] The objective and systematic use of urine examination by Theophilus became a paradigm for the use of an analytic test to establish diagnosis.[1] By 900 AD, guidelines for the use of urine examination as a diagnostic aide were available, and by 1500 AD, color charts for the interpretation of urine in diagnosis were widespread.[2]

The invention of the microscope in the 17th century greatly extended the power of observation as a tool for diagnostic formulation. The microscopic analysis of urine sediment emerged as an important additional quantitative analysis in the latter half of the 18th century with J. W. Tichy's work.[2] The microscopic recognition of the cellular components of blood by Marcello Malpigihi in 1661-1665, and subsequent studies by Antony von Leewenhoek, promoted a second body fluid to importance in laboratory medicine.[3] However, throughout the 17th and 18th century, urine continued to be the sample of choice for medical analysis. The 17th century chemical analysis of blood was significantly advanced by the important work of William Hewson, who first demonstrated the presence of a coagulable substance that could be separated from the cellular component of blood. Hewson's discovery of "coagulable lymph," or fibrinogen, provided the foundation for the laboratory investigation and evaluation of coagulation and disorders of coagulation.[2]

The second century Greek physician Galen is often considered the most influential medical author of all time. Galen taught that illness was a result of imbalance in the 4 fundamental humors (phlegm, blood, yellow bile, and black bile). This view was unassailed until the mid 18th century when the work of Giovanni Battista Morgagni in the post-mortem laboratory established a systematic correlation between clinical symptoms and anatomical changes in organ structure. Morgagni's seminal work *De Sedibus et Causis Morborum (On the Sites and Causes of Diseases)* became a foundation for the development of the science of pathologic anatomy. Nevertheless, the notion that the anatomical changes were themselves reflective of some imbalance in body humors continued for another hundred years.

The emergence of the germ theory of disease in the late 19th century not only laid to rest the humoral theory of Galen but also forged a relationship between modern medicine and the laboratory that came to dominate western medicine in the 20th century.[5] Physicians and patients had long recognized that outbreaks of epidemic disease implied an element of contagion, but assumed that some ambient and nonliving substance causing an imbalance in humors led to disease. Thus in the great London cholera outbreak of 1854, "miasma," a conjectured, noxious, and airborne substance arising from the decay of organic matter, was proposed by most medical authorities of the time as the cause of the epidemic. Physician John Snow, after a careful study of the patterns of case occurrence, came to the conclusion that the disease was spread by an agent in contaminated water from a particular pump in the city.[6] Snow's work advanced public hygiene and epidemiology and stimulated the search for specific agents for epidemic disease. The work of Snow as well as Semmelweis and Lister, established that at least some diseases were the results of contagious agents and the spread of these agents could be restricted by antiseptic procedures. A search for these contagious agents culminated in the revolutionary laboratory work of Louis Pasteur and Robert Koch that demonstrated the agents to be microbes.[4] The demonstration that living organisms caused disease advanced an approach to classifying disease based on external cause, an approach that persists and dominates our modern view.

A cornerstone in the development of a causal taxonomy of disease was the introduction of Koch's postulates in 1884. The postulates provided criteria for establishing an etiological link between a microbe and a disease. The four postulates in modern form are: (1) the putative causative organism must be found in every patient with the disease, (2) the organism must be isolated from a diseased individual and grown in culture, (3) the organism must produce disease when introduced into a healthy individual (usually an experimental animal), and (4) the organism must be reisolated from the experimentally infected animal.[7] Postulates 3 and 4 fall entirely into the domain of the experimental laboratory. However, the requirements of the first 2 postulates provided great impetus to the emergence of the clinical microbiology laboratory. If Koch's postulates are satisfied and a causal link established between a microbe and a disease, then it should be necessary in a patient with symptoms of that disease to require that the causative agent be recovered from the patient and grown in culture in order to establish a definitive diagnosis. This logic provided a strong tradition for clinical laboratory measures in confirming a medical diagnosis.

By the end of the 19th century, the clinical laboratory provided the culture of microbial pathogens, hemoglobin estimation, counting of red and white blood cells, microscopic identification of some parasites, clotting time in coagulation disorders, examination of sputum in tuberculosis, simple immunological tests such as agglutination tests for typhoid fever, and the demonstration of amino aciduria in liver disease.[2]

The first half of the 20th century saw an explosion of advances in analytical techniques in clinical chemistry, immunology, and blood banking as well as microbiology. With the exception of the important therapeutic applications of blood banking, the emphasis was almost entirely on the application of the methods of the clinical laboratory in diagnosis. The first textbook of laboratory medicine was edited by James C. Todd and published in 1908 as *A Manual of Clinical Diagnosis*. Ninety-eight years and seven editors latter, the 21st edition remains the authoritative reference for clinical pathology under the title, *Henry's Clinical Diagnosis and Management by Laboratory Methods*.[8] The addition of the word management reflects the emerging importance of the laboratory in not only helping make a diagnosis but also in providing data to monitor progression of disease and therapy.

Many diagnostically useful tests in clinical chemistry were developed in the first 50 years of the 20th century: serum phosphorus (1920), serum magnesium (1921), protein electrophoresis (1926), erythrocyte sedimentation rate (1929), alkaline phosphatase (1930), lipase (1932), amylase and acid phosphatase (1938), ammonia (1939), creatinine phosphokinase (1954), lactate dehydrogenase (1955), and alanine aminotransferase (1956).[9] The tests were useful but labor intensive and required manual methods by skilled technologists using sophisticated instrumentation. They were primarily applied in patients only after a physician's thorough evaluation and examination had narrowed the differential diagnosis to a short list of possibilities.

The introduction of the first automated clinical chemistry analyzer by Technicon Corporation in 1959 was a watershed in the application of these clinical analyses.[10] The Technicon Auto-Analyzer and the subsequent development of ever more powerful automated analyzers ushered in an era in which large batteries of laboratory tests could be performed quickly and economically. The ease and economy of performing multiple clinical chemistry tests presented for the first time in laboratory medicine the potential of screening healthy populations with batteries of tests to detect disease early, before pathological damage could occur. In the case of screening neonates for inborn errors of metabolism this strategy has worked exceedingly well. In 2006, the North Carolina Laboratory of Public Health screened 127 175 newborns for 41 genetic disorders. In the well adult population the results have been less satisfactory. For a period of time in the 1970s and 1980s, annual physicals might include batteries of 40 or more laboratory tests; but this approach led to little measurable improvement in outcomes. For most of the analytes in these batteries, there is overlap between values encountered in healthy and diseased populations. The more tests performed, the greater the likelihood that one or

Prediction and Accuracy

Galen and Gambino and subsequent researchers[a,b] have applied mathematical tools to medical decision making to quantify the justifiable level of confidence a particular test result can offer physicians and patients in predicting the presence or absence of disease. A full understanding of the subject is challenging for many health professionals and formidable for the lay public, however, some generalizations are possible. The overlap in the distribution of values for analytes in diseased and healthy populations means no one test can perfectly discriminate between diseased and healthy individuals.

The *sensitivity* of a test is the probability of getting a positive test result in a diseased patient. The *specificity* of a test is the probability of getting a negative result in a person without the disease. For any given test we can adjust the limit of the reference range to improve sensitivity and capture a greater portion of the diseased population, but in doing so we also increase the number of healthy patients in the test positive group *(false positive)*. If we make an adjustment in the reference limit in the other direction, we can exclude more healthy individuals from the test positive population, but we also exclude some diseased individuals *(false negatives)*. Tests that have both higher sensitivity and specificity for a certain disease are preferred. We can compare tests by plotting the true positive rate against the false positive rate at all cutoff points for reference range. This curve, called the *receiver operating characteristic curve* (ROC curve), provides a measure of the accuracy of the test for that disease. The test with the bend in the curve that is closest to the upper left hand corner of the graph is the more accurate test.[b]

The clinical laboratory strives to develop tests with optimal sensitivity and specificity. Clinician and patients are most interested in the interpretation of a particular test result for a given patient: the *predictive value*. The *positive predictive value* of a test gives the probability of a disease given a positive test result, whereas the *negative predictive value* gives the probability of no disease given a negative test result. A counter-intuitive concept it that the predictive value of a test depends not only on the accuracy of the test, but also on the prevalence of disease in the population tested.[a] Therefore, the same test can have different predictive values when applied to different populations with different prevalence of the same disease.

Consider this example. We have a test that returns a positive result 99% of the time in diseased individuals and only 1% of the time in healthy individuals (false positive rate). We apply the test to a group of 200 000 individuals with a disease prevalence of 50%. The test will return a true positive finding in 99 000 of the 100 000 individuals with disease and a false positive finding in 1000 of the 100 000 individuals without the disease. Accordingly, any one individual with a positive test will have a 99% chance of having the disease.

Now we apply the same test to a population in which the prevalence of the disease is only 0.1%. Only 200 patients out of 200 000 have the disease and 198 (99%) will test positive. Of the 199 800 individuals without disease, 1% or 1998 will test positive. We now have 2196 individuals with a positive test result and only 198 with the disease: a predictive value of 9%. Therefore, in different populations the same test has an entirely different significance for a positive result. This is the reason that some tests may be excellent at confirming a suspicion on the part of the physician that a disease is present, but not very good for screening healthy populations with low disease prevalence. By evaluating relevant medical history, symptoms, and risk factors and then choosing tests for diseases that might fit these findings, the physician effectively creates a test population with a much higher prevalence of disease than the general population. Confirmation by laboratory testing will have much greater positive predictive value in such prescreened populations. It is also the reason that screening healthy individuals with large batteries of laboratory tests in the 1970s and 1980s generated so many false positive results.

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more test results will fall outside the reference range, not because the patient has a disease, but simply because of variation in the distribution of values for that analyte in the healthy population. The problem of getting abnormal laboratory results in normal patients led to important advances in the mathematical quantification of predictive value for test results in Galen and Gambino's publication of the landmark 1975 monograph, *Beyond Normality: the Predictive Value and Efficiency of Medical Diagnosis*.[11] Advances in analytical technology have only accelerated at the end of the 20th century with the development of radioimmunoassay (1950), immunoelectrophoresis (1952), high-performance liquid chromatography (1969), enzymatic immunoassay (1972), and the laser cell sorter (1975).[12]

At the start of the modern medical era, Louis Pasteur advocated for the advancement and expansion of the medical laboratory.[13] By the end of the 20th century western medicine was dominated by this diagnostic laboratory paradigm: in the experimental laboratory, understanding the etiology and pathogenesis of the disease and, in the clinical laboratory, identifying the etiologic agent or the footprints of the pathogenic process to confirm the diagnosis. Then, from the diagnosis, formulate a prognosis and, if necessary, propose a treatment. The dominance of this paradigm was summarized by Andrew Cunningham and Perry Williams in the opening paragraph of their 1992 monograph, *The Laboratory Revolution in Medicine*.

> If you feel unwell and go to see a doctor or are admitted to hospital, the chances are that the physicians will take a sample of your body – generally blood, tissue or urine – and send it away to another place for testing; in such cases the decision as to whether you are ill or not, and if you are, what disease you have, will be primarily taken not by you and not by your doctor but by a laboratory test. If you require treatment, this will probably involve the administration of medicinal substances prepared not by you or your doctor but in a highly specialised factory-like laboratory. If you decide to become a doctor yourself, your formal professional training will begin not with general practice, nor with hospital work, but with study of the medical sciences, in lecture rooms, libraries and laboratories.[5]

Now, at the start of a new century, this diagnostic laboratory paradigm may be undergoing a new revolution.

The Case of Cardiac Troponin

Cardiovascular disease is the leading cause of death in the United States and has been every year since 1900 except for the pandemic flu year of 1918.[14] More Americans die of cardiovascular disease than of the next 4 leading causes of death combined.[14] Coronary artery disease leading to myocardial ischemia accounts for more than half of deaths due to cardiovascular disease.[14] Despite the importance of this disease, laboratory tests for the diagnosis of myocardial injury due to ischemia lagged the development of tests to detect disease in other organs until the discovery of transaminase elevations following myocardial infarction (MI) in the 1950s.[15] Because glutamate-oxaloacetate transaminase (now aspartate transaminase) and alanine transaminase are also released by damage to other organs such as liver and skeletal muscle, elevations of the transaminases were poor discriminators for injury to cardiac muscle versus other tissue.

A significant advance in the laboratory detection of myocardial injury was the introduction of creatine kinase isoenzyme assay.[16] Creatine kinase (CK) exists in 3 isoforms. One of the isoenzymes, CK-MB, is present in greater concentration in heart muscle than in skeletal muscle. While massive increases of CK can be seen in injury to skeletal muscle, a CK increase with a greater ratio of CK-MB to the other isoforms suggests injury of cardiac muscle. The clinical utility of the assay was initially limited by the need to perform electrophoretic separation of the isoenzymes, so assays could only be performed about once a day. At a time when patients were being admitted to hospitals for several days just to exclude MI, that limitation was acceptable.

With the advent of efficacious therapies for treatment and prevention of MI, the need for rapid laboratory confirmation of MI increased. Direct immunometric assay for CK-MB[17] (CK-MB mass) significantly reduced the time required to perform the test, making stat assays in an hour or less possible. CK-MB mass assay greatly facilitated the laboratory confirmation of a diagnosis of MI. However, since CK-MB is not specific for myocardium, the assay still suffered from low sensitivity for small infarcts and low specificity in the setting of skeletal muscle injury. The initial detection of CK increase in the setting of MI had been possible because of the enzymatic properties of CK.[18] The technology of immunometric assay made possible the detection at low levels of protein markers without enzymatic activity. A search for a protein specific to cardiac muscle culminated in the identification of cardiac troponin subunits I and T (cTnI and cTnT), which are specific to cardiac muscle. Cardiac troponins are released into the circulation following necrosis of myocardial fibers. In the absence of irreversible myocardial damage, the level of cardiac troponin is so low that it is undetectable by most assays. Following myocardial injury, cardiac troponin is released from damaged myocardial fibers and becomes detectable 2 to 4 hours after ischemic onset. Troponin levels rise and peak 24 to 48 hours after the infarct. Elevations of cTnI persist for 5 to 10 days after the infarct.[19]

Because cardiac troponin is only present in heart muscle, its presence in blood is a very sensitive and specific marker for cardiac injury. CK-MB was a significant advance over previous enzyme methods and reached sensitivity levels of 80%. With the most current cTn, assays sensitivity for myocardial injury is 96% to 98%.[19] Because of the greater sensitivity cTn is the preferred marker for detecting and ruling out MI.[19,20,21] The rise in cardiac troponin and CK-MB occurs only 2 to 4 hours after ischemic injury, so samples taken within the first 2 to 3 hours after symptoms may not demonstrate an elevation.[19] Cardiac troponin assay in serial samples taken 1 to 2 hours apart provides the most sensitive means for both detecting and excluding MI. Acute MI can be excluded in those patients with chest pain who, 4 to 6 hours after onset of symptoms, still have nonrising serial cTn levels below the 99% reference cutoff for the assay utilized.[22]

The diagnostic power of current cardiac markers is so strong that in 2000 the American College of Cardiology and the European Society of Cardiology issued a consensus statement redefining MI based on changes in sensitive and specific biomarkers such as cTn and CK-MB. The new clinical definition provides that MI is diagnosed when there is a typical rise and fall of biochemical markers of myocardial necrosis and one of the following: ischemic symptoms, development of pathologic Q waves on the ECG, ECG changes indicative of ischemia (ST segment elevation or depression), or coronary artery intervention (eg, coronary angioplasty).[23] The one finding that has to be present is the temporal change in a sensitive and specific marker for cardiac necrosis such as cTn or CK-MB.

The troponin story to this point is just another illustration of how a clinical laboratory test can be a powerful aid to diagnosis. The prognostic power of cTn emerged when patients with low or borderline elevations of cTn were studied. The pathologic definition of MI is the irreversible damage of cardiac muscle due to ischemia. While diagnosing and treating MI is important, it's better to prevent it. When cTn assays were first introduced, many physicians complained that the tests were too sensitive because some patients had elevated levels of troponin but did not have clinical evidence of MI. However, when followed, these patients had a much higher incidence of significant cardiac events and sudden death after discharge than did patients with no cTn elevation.[24] Multiple studies have demonstrated that patients with stable or unstable angina or acute coronary syndrome all have significantly worse prognosis if cTn is elevated.[25,26,27] Moreover, the increase in mortality risk in patients with acute coronary syndrome with increased cTn levels is proportional to the increase in cTn.[26] The prognostic significance of small elevations of cTn, less than the cut-off level for diagnosis, has proven to be so prognostically significant that troponin elevation is a key criterion in the risk stratification and clinical management of patients with unstable angina and acute coronary syndrome.[23,28]

Cardiac troponin has proven to be an exquisitely sensitive marker for myocardiac injury arising from any source. Elevations can be seen in cardiotoxicity from drugs, hypothyroidism, sepsis, inflammatory myocarditis, heart failure, and cardiac trauma among others. In these cases the cTn elevation reflects real damage to cardiac fibers. In chronic conditions the cTn tends to be stable and clinical interpretation is necessary to distinguish cTn elevation due to ischemia from elevations due to myocardial injury from other causes. Even in those patients without symptoms or other evidence of cardiac disease, cTn retains prognostic significance. Patients with sepsis, noncardiac patients on critical care units, and emergency department patients without cardiac illness all have increased risk of short-term mortality if cTn is elevated compared to similar patients with normal cTn.[29]

The Emerging Paradigm

Cardiac troponin is just one of many laboratory assays with strong prognostic significance. Cardiac troponin elevation predicts increased risk for patients with infarction, angina, and acute coronary syndrome, but some patients without elevated cTn still experience significant cardiac events including infarction and sudden cardiac death in the the 60 days following a cTn assay.[19] A search is underway for biomarkers that can predict ischemic events in asymptomatic patients without cTn elevation. No marker with prognostic significance comparable to cTn for this group of patients has yet been identified but several candidates, including C-reactive protein (CRP), sCD40 ligand, matrix metalloproteinases, myeloperoxidase, and ischemia-modified albumin, are being intensely studied.[19] For all of these analytes, prognostic significance is the desired characteristic.

In the case of heart failure, brain-type natriuretic peptide (BNP) is released by myocardium in response to stretch. BNP and its pro peptide NT-proBNP are increased in heart failure and have proved useful in diagnostic triage of patients with dyspnea.[30] High levels of BNP and NT-proBNP indicate poor prognosis in both heart failure patients and patients with acute coronary syndrome.[31,32]

Biomarkers with prognostic significance for disorders other than cardiovascular disease are also proliferating. Molecular genetics already has wide implications in the diagnosis, prognosis, and therapeutic management of neoplasia.[33] There are currently 17 588 disorders, variations, or protein structural alterations demonstrated to have a genetic basis in humans. While the majority of these are rare or cause minor changes of no clinical significance, some have increased risk of subsequent development of disease ranging from amyotrophic lateral sclerosis to hereditary breast cancer.[33] For many common diseases, genetic predisposition may depend on complex interactions of multiple alleles. The possibility of widespread screening using DNA microarray technology for genetic combinations that predispose to disease has attracted wide commentary.[34] Identifying those at increased risk has the potential to benefit the individual by interventions or lifestyle modifications that prevent or delay the onset of the disease. Identifying those at risk also entails significant ethical and social issues and has the potential to stigmatize and harm individuals.

Not everyone who has a demonstrated genetic predisposition for a certain disease will develop the disease. The relative risk factor may vary substantially and most diseases for which a genetic basis has been demonstrated entail complex interactions between several genes and often environmental agents as well. For diabetes mellitus[35] and some other autoimmune diseases[36] there is promise that autoantibodies that appear years before the onset of the symptoms may help predict which patients will go on to develop the disease. In the case of type 1 diabetes, autoantibodies to insulin, glutamic acid decarboxylase, and islet antigen-2 may appear as early as 10 years before onset of the disease. When one antibody is present a person has a 10% chance of developing type 1 diabetes within 5 years. When 2 antibodies are present the risk increases to 50%, and when all 3 antibodies are present the risk exceeds 60%.[35] Similarly in rheumatoid arthritis an autoantibody to citrulline may appear as early as 10 years before onset of the disease and the appearance of the autoantibody increases the risk of onset of rheumatoid arthritis 15 fold.[36] Finally, mathematical techniques will be increasingly used to predict future clinical events based on combinations of biomarkers independent of a patient's specific diagnosis. In a recent report, Gruenewald used recursive partitioning techniques to identify combinations of 13 biomarkers that conveyed higher risk of mortality in a 12-year study of older adults.[37]

In the 21st century, emphasis in clinical laboratory medicine has shifted from diagnosis to prognosis, risk stratification, treatment selection, and monitoring. If the medical paradigm of the 20th century was: first diagnosis then prognosis and treatment; then the paradigm for this century may be: first assess risk, then suggest risk modification or intervention; next monitor for early predictors of progression and, if detected, intervene; if symptoms appear, stratify for selected treatment based on prognostic tests.

Rocket Science or Stamp Collecting?

This is an exciting time for clinical laboratory medicine. Rapid advances in science and technology are expanding the role and utility of clinical testing in the central laboratory, at the patient bedside, and in patients' homes. New and more sensitive assays provide valuable information for clinical decision making in real time. It's also an intriguing time as research in scientific laboratories identifies a host of markers that provide, for many patients and healthy individuals alike, powerful predictions of clinical events in the near and distant future. These technologies herald a paradigm shift in the relationship between medicine and the clinical laboratory from diagnosis to greater emphasis on prognosis, prevention and management, and from binary decisions about the patient as "diseased or well" to incremental prediction of risk and potential therapeutic benefit.

There is a significant difference in the predictive power of those sciences in which progress in knowledge is manifest by ever more powerful and elegant mathematical formulas and those descriptive sciences in which progress in knowledge is expressed by ever more complex and arcane taxonomies. The distinction was famously articulated by the early 20th century physicist and Nobel prize winner Ernest Rutherford who quipped, "all science is either physics or stamp collecting."[38] Collectors are students and illustrators of the taxonomies created to describe the objects they collect. In the early 20th century when Rutherford made his remark, many sciences including botany, zoology, geology, and medicine were primarily concerned with classification. From Rutherford's perspective, physicists calculated the formulas that orchestrated the universe, whereas other scientists simply classified. The relationship between the laboratory and medicine throughout the 20th century has been based on a taxonomic approach to disease. We have, from Rutherford's perspective, primarily been stamp collectors.

Despite the disdain in Rutherford's remark, we should not underestimate the important advances made through diagnostic taxonomy. Since the mid-19th century a classification of disease has evolved based on scientific understanding of the dysfunctions in anatomy, physiology, and chemistry that cause illness. This understanding is often founded upon, and evolves through, investigations in the experimental laboratory. The critical first step in the approach to an ill patient is to diagnose or classify the patient's disorder. Once the classification or diagnosis is established, the physician can answer the patient's question, "Is something wrong with me, and if so, what will happen to me?" Armed with a diagnosis, the physician can make predictions about the patient's likely clinical course. If the course is unfavorable, intervention can be considered and selected.

Making a diagnosis has prognostic and therapeutic significance because we have studied the natural course and response to therapy of other patients that have been assigned to the same diagnostic category. Of course, we know that the patients assigned to these disease categories are never exactly alike, and natural course and response to therapy will vary among patients with the same diagnosis. So our predictions for outcome, response to therapy, and side effects based upon the classification of the patient's disease are too often couched in terms of probabilities that leave the patient and family confused and dissatisfied. For all the progress scientific medicine and the laboratory have made together, we are humbled when we consider the rocket scientist who, armed with the calculus of physics, can hurl an object into space and predict with stunning accuracy when and where the probe will rendezvous with a speeding comet, millions of miles away and months or even years in the future. Beside the predictive power of scientists who calculate, the prognostic skill of the scientist who classifies seems feeble indeed.

The clinical laboratory has been and will continue to be a powerful source of data for classification and diagnosis. The promise of the clinical laboratory in the 21st century will be to increasingly provide data with which the physician can calculate as well as classify. In some cases the calculation will have clinical significance for the patient well before pathologic changes that permit a diagnosis have occurred. In other cases the data may support calculation of a prognosis that is much more specific than could be rendered on the basis of diagnosis alone. There is much speculation that the future of medicine will entail a highly personalized approach to prevention, treatment, and disease management in each patient. With the help of the clinical laboratory, the physician may well be moving toward a fuller implementation of the dictum "treat the patient and not the disease" and in doing so becoming a little more of a rocket scientist and a little less of a stamp collector. **NCMJ**

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Public Policy Recommendations for Oversight of Molecular Laboratory Tests

Margaret L. Gulley, MD

Laboratory tests have long been used to help diagnose and classify disease. Increasingly, these assays are used to predict disease in healthy individuals or to predict outcomes in response to a specific therapy (See Table 1). The subspecialty of molecular genetic pathology (MGP) has recently emerged to promote and recognize physician expertise in DNA- and RNA-based testing. In fact, the University of North Carolina at Chapel Hill has the nation's first accredited MGP fellowship training program to graduate a physician who subsequently became board-certified.

Table 1.
Clinical Utility of Molecular Assays

Clinical Application	Diagnosis	Screening	Monitoring	Prediction
Heritable trait or disease	Detect germline mutation causing inherited disease	Determine carrier status		Predict disease presymptomatically, predict drug toxicity or optimal dose
Oncology	Help diagnose tumor based on acquired genetic defects	Screen high-risk individuals for cancer	Measure tumor burden, detect early recurrence	Predict drug efficacy, resistance, or toxicity
HLA typing & identity testing	Help diagnose HLA-linked disease	Match potential organ donors to recipients	Measure engraftment of transplanted hematopoietic stem cells	Predict organ rejection or graft versus host disease
Infectious disease	Detect pathogen based on unique DNA or RNA sequence	Screen blood donor for transfusable pathogen	Measure viral load during therapy	Predict drug resistance

The public should be reassured that molecular genetic tests are analytically valid. All clinical laboratories in the United States (with the exception of certain government laboratories) are subject to regulatory oversight by the Centers for Medicare and Medicaid Services (CMS) involving, among other things, demonstration of accuracy and precision, periodic revalidation of assay performance, laboratory inspections, and biennial recertification.[1] Proficiency surveys offered by the College of American Pathologists are voluntarily used by many testing laboratories to further check the quality of various DNA- or RNA-based assays. Indeed, laboratorians are widely recognized as leaders among health care practitioners in terms of measuring the quality of our clinical services.

Although demonstration of "clinical utility" for tests is not mandated by law, the vast majority of laboratory tests are known to be clinically useful even if they have not been reviewed by the Food and Drug Administration (FDA). The physician consultant in every testing laboratory has an ethical duty to look out for the best interests of the patients whose samples are being tested, and the laboratory physician assumes the risk of legal action if harm ensues. There are abuses: A recent report from the Government Accountability Office warned that certain genetic tests being marketed directly to the public (via the internet) seem to have no clinical value.[2] These tests may not directly harm the health of a consumer, but they are likely to harm their pocketbook.

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Most people are surprised to learn that many genetic tests are not FDA approved. Achieving FDA approval is costly to those who prepare and submit a completed application (estimated at hundreds of thousands of dollars),[3,4] and that money may be better spent on higher priority efforts such as improving access to health care. Furthermore, the FDA lacks the manpower required to review validation data for all genetic tests. Overcoming this shortage would be burdensome to the FDA and would likely have the unintended consequence of delaying and impeding the availability of testing for patients. Finally, there is no demonstrated evidence that the quality of laboratory testing would substantially improve if FDA clearance were achieved. In this regard, it appears that existing governmental oversight of laboratory testing is adequate.

The Pathologist as a Resource for Clinicians

It is estimated that at least 60% of medical decision making is based on laboratory test results, implying that the pathologist is among the most important members of the health care team.[5] Clinicians are encouraged to consult pathologist colleagues for advice on which laboratory test(s) to order, optimal specimen collection and handling, interpretation of test results, and implications for patient management. Pathologists, in turn, may formally document each consultation in the patient's medical record (using, for example, procedure codes 80500 or 80502) so that their expert advice and any links to additional resources are recorded in a way that may be accessed immediately by the requesting clinician and later by other members of the health care team.

Clinicians face tough challenges as they are bombarded with massive amounts of medical information, including both patient-specific data and never-ending piles of published literature.[6,7] The amount of medical information is estimated to double every five years, and the pace of progress seems even faster in the realm of molecular pathology where new technologies are now available to inform translational research and clinical practice. These new tools for analyzing DNA or downstream RNA transcripts and proteins encoded by the human genome (or by human pathogen genomes) have resulted in many new opportunities to diagnose and classify disease and to predict outcome in response to various alternative therapies. Every medical journal now seems to deal with novel genotype-phenotype associations or proposed targeted therapy based on analysis of the biochemical pathways that are altered in disease.

> *"At least 60% of medical decision making is based on laboratory test results, making the pathologist among the most important members of the health care team."*

Pathologists are well positioned to keep up with the medical literature on the tests that their laboratory offers, as well as guiding use of esoteric tests available from outside laboratories. An increasingly important role is understanding and conveying useful genetic information to clinicians. This consultative role extends to surgical pathologists since molecular assays are increasingly applicable to a wide variety of sample types including formalin-fixed, paraffin-embedded tissues, thus helping to reunite the two major subdisciplines of pathology—anatomic pathology (dealing mainly with biopsy tissues) and clinical pathology (dealing with blood and other body fluids). Furthermore, quantitative DNA amplification assays are being used to monitor disease levels (eg, tumor burden or viral load) so as to inform how a given therapy is working. The exquisite sensitivity of molecular assays can allow us to predict early on (before complete drug resistance develops) that the therapeutic regimen should be altered.[8,9]

Predicting Drug Efficacy, Optimal Dose, or Toxicity

Pathologists have traditionally been involved in diagnosis of disease, whereas clinicians select therapy. But novel laboratory assays are increasingly informative with regard to optimizing therapy, making it all the more important that each laboratory physician is well versed in validating, interpreting, and assuring quality of test results. An excellent example of the drive for quality improvement is a recent guideline jointly issued by the American Society of Clinical Oncology and College of American Pathologists on the performance of ERRB1 (Her2) assays for predicting trastuzumab (Herceptin) efficacy in breast cancer patients.[10] Some of the early work developing molecular assays for Her2 was done at the University of North Carolina at Chapel Hill.[11] Another pharmacogenetic test with local ties targets the VKORC1 gene and predicts (at least in part) optimal dose and toxicity of warfarin (eg, Coumadin) therapy. The VKORC1 gene was first characterized in 2004 at the University of North Carolina in Chapel Hill by Darryl Stafford and colleagues.[12] The clinical importance of this discovery was quickly recognized so that, within two years, molecular tests for alterations in VKORC1 were being correlated with clinical outcome in response to warfarin therapy.[13]

Progress through Clinical Research

New molecular tests further expand our ability to predict as well as detect disease. This creates new challenges for policy makers who will be asked to support the costs of these tests as well as fund the new knowledge necessary to optimally apply them. More backing for translational research is needed to support clinical trials that will ultimately define algorithms for managing patients based on molecular test results. The utility of our powerful new molecular tools is only just beginning to be understood, but already their promise is quite evident. **NCMJ**

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COMMENTARY

The Ethics of Genetic Testing:
Is More Always Better?

Nancy M. P. King, JD

The recent explosion of interest in prognostic genetic testing raises a host of ethical issues for patients, research subjects, physicians, investigators, policymakers, and the public. None of these issues is really new, but all of them have gained new significance as the science of gene finding accelerates and new genetic tests become more widely available.

Public expectations are high regarding the potential value of genetic information. This confidence extends to the information obtained from new genetic tests, especially those identifying genes associated with common complex disorders. After all, nearly everyone knows someone with diabetes, heart disease, depression, asthma, attention deficit hyperactivity disorder, osteoarthritis, cancer, or any of the other common multifactorial disorders that mark the human condition, and the promise of the Human Genome Project[a] has always been both to explain the human condition and to ameliorate it.

> *"Is it meaningful to base clinical recommendations, health behavior change, or public policy on predictive genetic testing?"*

Today, science is increasingly able to assign precise percentages to at least some of the genetic contribution to an individual's chance of developing a common complex condition. This quantification of risk is a seductive enterprise. Simply knowing that many people develop emphysema later in life does not seem to mean as much as knowing that individuals with a particular genetic test result are a specified percentage more likely to develop emphysema than those whose test is negative. But are we right to think this? Does more precision mean more accuracy, or more truth? Is it meaningful to base clinical recommendations, health behavior change, or public policy on predictive genetic testing?

Ethical questions arise in the process of research, development, and marketing of predictive genetic tests; in their use and interpretation by physicians and patients; and in the utilization of predictive genetic test results in public health and other policy contexts. The issues to consider include understanding probabilistic and uncertain information, informed decision making, the medicalization of nondisease states, stigmatization of individuals and groups, genetic essentialism and fatalism, and the potential for genetic discrimination.

Logically, first among issues are those surrounding gene finding. To identify genetic associations of interest requires large-sample gene discovery research and biospecimen collection, "biobanking," and specimen sharing. Long-standing questions exist about the scope of consent to biospecimen research and sharing, how biobanks should be established and overseen, and how research results should be reported and interpreted.[1,2] It is far from clear, for example, that everyone who provides a biospecimen for genetic research into one disorder (eg, Tourette syndrome) would agree to share that specimen with investigators seeking genes associated with a different disorder (eg, colon cancer or

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[a] The US Human Genome Project was begun in 1990 by the US Department of Energy and the National Institutes of Health to identify all the genes in human DNA, determine the sequences of the base pairs that make up human DNA, store this information in databases, improve tools for data analysis, transfer related technologies to the private sector, and address the ethical, legal, and social issues that may arise from the project. (US Department of Energy Office of Science. Human Genome Project Information. Available at: http://www.ornl.gov/sci/techresources/Human_Genome/home.shtml. Accessed March 21, 2007.)

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cystic acne). Should they be asked? Or should consent forms simply inform specimen providers that their DNA could be shared and studied for any scientific purpose? And is such a broad consent really consent at all?

Once research is underway, questions arise about its results. There is considerable uncertainty about the significance of genetic associations in common complex disorders and gene-environment interactions. Even though knowledge is expanding rapidly in genetics, it is simply not yet known how the interplay of multiple genetic and environmental factors affects the likelihood of developing a disorder or its probable severity.[3] Thus, associating a gene with a disorder is only a small piece of a rather large puzzle. How, then, should researchers and clinicians describe that single piece? Moreover, as is already well recognized, population-based research results are difficult to translate into individual application. Although the espoused goal of genetic research is "personalized medicine" (ie, prediction at the individual level), at present, genetic associations are usually reported in broad general categories of questionable meaning. Most notably, genetic research results are grouped by race and ethnicity (eg, "X gene, associated with Y disease, is three times as common in African-Americans as in whites."). Although genetic research has definitively shown that racial categories have no biological meaning, such racialized characterizations remain all too common.[4,5] Ironically, these categories help to wrongly reify race as genetically significant. Not incidentally, reporting about research in this way is often highly stigmatizing to members of the racial and ethnic groups thus identified (eg, "Another 'Jewish gene' has been identified by researchers.").[6]

The process of translating such imperfect data into a genetic test used predictively in individuals is similarly fraught with ethical challenges. Standards for the development and marketing of genetic tests are at present nearly nonexistent. Whether and how to regulate these tests is the subject of major policy debate.[7,8] What counts as a valid and reliable test? How are commercial genetic tests advertised to practitioners and consumers? Even when these questions have been answered satisfactorily, others loom regarding the best uses of such tests. Should children be tested for genetic predispositions to adult-onset disorders?[9,10] Does it matter whether the test results are used to monitor the child's health, to initiate a prophylactic regimen, or to help the child's parents make decisions about future reproduction?

How should doctors decide whether to base recommendations to their patients on genetic test results? It has long been known that health care providers may themselves have difficulty understanding and explaining probabilities to patients. Making use of probabilistic information in the context of risk reduction, which is how predictive genetic test results will be used, is even more complex than applying probabilities to treatment choices. This difficulty is compounded in genetic testing by the temptation to view genes as deterministic and, thus, to overestimate their importance—especially in common complex disorders.[11] Since the beginning of the Human Genome Project, much attention has been given to providing genetic education to primary care providers and the general public. However, the available information changes so quickly that it's necessary to run very fast to keep up—and it's all too easy to fall behind. As a result, much decision making about genetic testing is likely to be based on poor information and poor understanding. Not surprisingly, poor information and poor understanding make for imperfect decisions about whether to test, how to interpret the results, and what to do with them.

What should be done with the information that predictive genetic testing provides? It is essential to acknowledge that even with perfect information, there is a substantial gap between gene identification and effective prophylaxis (let alone treatment).[12] Just consider the decision making challenges faced by women who learn they have a breast cancer (BRCA) gene: intensive monitoring? prophylactic drug regimens? radical surgery? or only standard exams and mammography, since having a BRCA gene is far from a guarantee of developing breast or ovarian cancer?[13] Now multiply that range of options by every new genetic association identified by prognostic testing, such as other cancers, type II diabetes, cardiac disease, obesity, psychiatric and behavioral disorders, asthma and allergies, and lots more we probably haven't even thought of as disorders—yet.[14]

One issue of principal concern has not materialized as a significant reality, but profoundly affects public perceptions about genetic testing information. The risk of genetic discrimination can deter testing, even when test results are well characterized and prophylaxis can make a difference. There is little evidence to date of discrimination in the cost or availability of health insurance, or in employment, on the basis of genetic predisposition information, although discrimination on the basis of existing disease is common, and troubling.[15,16] However, many states—North Carolina included[17]—have legislation in place prohibiting genetic discrimination, and federal legislation (the Genetic Information Nondiscrimination Act, "GINA"[18]) stands an increasingly good chance in Congress.

Another kind of discrimination by health insurers, in the name of health promotion, is actually somewhat more likely. Many health insurers are beginning to offer incentives to their insured members to change their behavior in an effort to reduce health care costs. Could an insurer require members to undergo predictive genetic testing and use the results to adjust premium rates? Could an insurer base those adjustments not solely on the test results, but on whether members with certain test results make use of certain preventive or health maintenance services (eg, stop smoking, successfully lower cholesterol or blood pressure levels, or maintain a certain weight) because their genetic profiles make them more likely to develop associated disorders? This may make good fiscal sense, or even good public health sense, but it can be quite intrusive on personal privacy. In most cases it makes little sense to distinguish between those with and without incriminating genetic profiles for disorders that are common in the general population.

Will the future bring us to more precise information and the truly personalized genome? Perhaps, in awhile; but what we do until we get there matters a great deal. If we can encourage both health care providers and patients to learn more about the meaning of genetic information, ask lots of questions about genetic information, and examine each use of genetic information carefully and comprehensively, then it may be possible to make both scientific and moral progress.[19]

There are, unfortunately, no easy answers. The best way to address these ethical issues is the hard way: taking great care in how we think about, talk about, understand, and use genetic information. We are not just our genes. For every genetic test that informs us of a susceptibility to a common complex disorder, there are many ways to alter the environmental influences that we know are also implicated, both at the individual level and as matters of public health and social policy. We already have ample reason to change habits of diet and exercise, improve the availability of healthy food choices in shops and schools, reduce environmental pollutants and hazards in the workplace, and make safe physical activity possible in all communities. The discovery of genetic associations adds scant momentum, if any, to these efforts and could be detrimental if poorly understood.[20]

More information isn't always better; only good information is better. It may be time to say no to the genetic testing explosion —at least until we know what is hype and what is not. **NCMJ**

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COMMENTARY

Molecular Diagnosis of Infectious Diseases

Melissa B. Miller, PhD

During the past 10 to 15 years, we have seen expansive growth of the use of molecular technology in the clinical laboratory for diagnosing infectious diseases. As a result, many laboratories are able to offer more sensitive testing, faster turnaround times, and ultimately improved patient care. The gold standard in bacteriology largely remains culture, primarily due to cost accounting and the potential complex nature of associated infections (ie, urine, wound, and respiratory cultures). However, in circumstances in which there may be minute quantities of a specific pathogen present, the patient may have received antibiotics prior to specimen collection, or the etiologic agent may require unusual culture conditions, molecular detection offers a great advantage to culture techniques. In many virology laboratories, molecular detection has supplanted cell culture techniques for the identification of several viral pathogens and in many cases has become the new gold standard. Though molecular techniques can offer an abundance of added benefits when used to augment current gold standards such as culture and/or serology, the optimal use of molecular methodologies in microbiology resides with specimens in which a limited number of pathogenic organisms are sought and in cases where the enhanced sensitivity and faster turnaround time of molecular methods far outweighs the increased cost.

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Applications in Bacteriology

A classic example of successful nucleic acid amplification (NAA) testing in microbiology is the detection of *Chlamydia trachomatis* (CT) and *Neisseria gonorrhoeae* (NG) from vaginal, cervical, urethral, and first-void urine specimens. Sexually transmitted infections such as those caused by CT and NG can be rapidly and accurately identified using NAA, thus improving treatment and transmission prevention. Implementation of routine screening for CT has lowered the prevalence rates of CT and associated pelvic inflammatory disease.[1] The increased sensitivity offered by NAA detection of CT and NG is important not only for the diagnosis of symptomatic patients, but also for the asymptomatic individuals that account for more than 70% of positive cases. Until implementation of NAA testing for CT and NG, culture was the gold standard, although it has subsequently been shown to have only 60% to 75% sensitivity compared to NAA.[2] A further disadvantage of culture is that organism viability must be preserved during transport. The implementation of routine confirmatory testing should be considered when using NAA for a low prevalence population that results in a positive predictive value below 90%.[2]

Another prime example of NAA results positively impacting patient care is the laboratory diagnosis of tuberculosis. Using

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direct detection of *Mycobacterium tuberculosis* (MTB) from respiratory samples, tuberculosis can be confirmed in less than 24 hours as opposed to 6 to 8 weeks. The sensitivity of NAA detection of MTB in smear-positive respiratory specimens is 96.9%, and the specificity is 100%, whereas the sensitivity and specificity in smear-negative specimens is 72.0% and 99.3%, respectively.[3] It should be noted that NAA of MTB does not replace the need for routine mycobacterial culture and susceptibility testing. In addition to the direct detection of MTB, techniques such as probe-based technology and sequence analysis can be applied to cultured isolates to decrease the time to identification over routine biochemical analysis. Rapid identification of MTB impacts not only patient care, but also infection control. Due to the increasing frequency of isolation of mycobacterial species associated with immunocompromised hosts and the increased incidence of multi-drug resistant MTB, it has become imperative to offer accurate yet rapid diagnostic tools for the detection and identification of mycobacteria.

A debate exists regarding the gold standard for the laboratory diagnosis of *Bordetella pertussis*. Historically, culture plates collected at the patient's bedside (ie, cough plates) have been considered the reference method. Although culture is very specific, its sensitivity suffers partially due to the organism's fastidious nature, but primarily because the highest sensitivity for culture occurs before patients are symptomatic. NAA remains positive for longer after therapy than culture, and NAA is also positive for a longer period after onset of symptoms.[4] Therefore, NAA is useful for patients presenting later in their illness. NAA testing allows for same-day results and since erythromycin-resistant *B. pertussis* is still rare, a cultured isolate is rarely needed for antimicrobial susceptibility testing. Multiple studies have demonstrated significant increased detection of *B. pertussis* when comparing NAA to culture: reported PCR-positive, culture-negative samples range from 13% to 88%.[5] However, due to potential false positive and false negative results with *B. pertussis* NAA procedures, it is strongly recommended that results be considered in the context of patient clinical presentation, and clinically inconsistent results should be confirmed by a second method.

NAA is also being used in bacteriology to detect antimicrobial resistance. Since antimicrobial resistance can be multi-factorial, this practice is limited to organisms in which the results can be interpreted with confidence in regard to the genotypic relationship to clinical treatment and/or infection control precautions. Such examples are direct detection of vancomycin-resistant *Enterococcus* (VRE) and methicillin-resistant *Staphylococcus aureus* (MRSA) from rectal and nares surveillance cultures, respectively. Screening patients for VRE and MRSA carriage is a key strategy for preventing the spread of these organisms in health care settings. NAA technology reportedly increases VRE detection by up to 120%.[6] In addition, enterococci that confer low-level intrinsic resistance, and thus not considered "true" VRE, are accurately ruled out preventing unnecessary contact precautions and contributing to hospital savings.[6] NAA detection of MRSA has been shown to be equal in sensitivity to culture-based methods, but has the advantage of offering a faster turnaround time, thus impacting hospital cost savings.[6] However, it should be noted that direct specimen testing for MRSA comes with limitations, often including a lower positive predictive value than conventional methods.[7,8] More recently, new strains of MRSA have appeared that are associated with skin and soft tissue infections in outpatients and are called community-associated MRSA (CA-MRSA).[9] The increasing incidence of CA-MRSA is causing overall rates of MRSA to rise. Therefore, it has become even more important to quickly and accurately identify resistant isolates.

Applications in Virology

Monitoring the viral load (quantified determinations of virus using NAA) in patients infected with human immunodeficiency virus (HIV), hepatitis C virus (HCV), or hepatitis B virus (HBV) is useful for tracking therapeutic response to antivirals and potential antiviral resistance. In addition, viral load monitoring for cytomegalovirus (CMV) in transplant recipients has allowed clinicians the benefits of identifying patients most at risk for developing clinical CMV disease, monitoring antiviral therapy response, and optimizing pre-emptive treatment.[10] Analogously, Epstein-Barr virus (EBV) viral loads can be monitored in the posttransplant setting to identify patients at risk for developing posttransplant lymphoproliferative disorder.

Molecular detection of viruses has extended beyond the standard therapeutic monitoring of viral loads in specific patient populations. For example, NAA testing for the laboratory diagnosis of herpes simplex virus (HSV) encephalitis and enterovirus (EV) meningitis has become the standard of care. Cell culture techniques are insensitive due to the low viral burden typically found associated with encephalitis and perhaps also the presence of host neutralizing antibodies.

HSV is the most common cause of nonepidemic encephalitis in the US, accounting for up to 20% of cases. CSF culture for HSV detects less than 2% of clinically determined adult HSV encephalitis cases and 40% of neonatal central nervous system (CNS) disease.[11] In contrast, HSV NAA is positive in most adult cases resulting in sensitivity and specificity > 95%[11] and is 75% sensitive and 100% specific for neonatal meningitis.[12] The rapid diagnosis of HSV encephalitis can prevent a brain biopsy and rapidly determine the need for acyclovir therapy.

Enterovirus is the most common cause of aseptic meningitis in the summer and fall months in temperate climates and accounts for 10% to 20% of encephalitis cases. A wide array of cell lines must be utilized to recover the majority of EV types by culture, and culture sensitivity still remains approximately 70%.[13] The sensitivity and specificity of CSF NAA for EV are estimated to both be > 95%.[12]

Nucleic acid amplification has also been successfully applied to other etiologies of viral CNS disease, such as CMV and varicella-zoster virus (VZV), but these assays have not been implemented as broadly as those for HSV and EV, so are still transitioning to becoming the method of choice. It should be noted that not all encephalitis viruses are readily detected by NAA. For example, due to the short period of viremia in many

"With the use of molecular technology to detect potential etiologic agents of disease, we need to remember Koch's postulates."

arboviral infections (ie, West Nile Virus), CSF NAA has low sensitivity, and the gold standard remains serology.[14] CSF NAA false negative results can occur due to collection of CSF very early or very late in illness, rapid viral clearance in immunocompetent hosts, and NAA inhibitors.[12] False positive CSF NAA results also occur primarily due to lack of data to suggest the detection of certain viral nucleic acids correlates with clinical CNS disease, but can also be caused by the presence of peripheral blood in the CSF.[12] While CSF NAA is considered by many the diagnostic standard of care as discussed above, the lack of standardized FDA-approved assays has made implementation of CSF NAA difficult in nonacademic settings. While most laboratories offering CSF NAA use qualitative methods, data indicate a role for quantitative CSF NAA in differentiating nonspecific presence of virus and virus-associated disease, to aid in prognosis for improved patient management, and in monitoring antiviral therapy.[14]

Challenges and Opportunities

The field of molecular infectious disease testing has grown so rapidly that the diagnostic industry has not kept up. To fill this void, independent investigators have turned to the development of user-defined, or "homebrew," molecular detection methods in the clinical laboratory. The implementation of user-defined NAA testing has revolutionized clinical molecular infectious disease testing. In addition, commercially-available non-FDA-approved NAA assays are increasingly becoming available as analyte specific reagents (ASRs). Though all reagents necessary for the amplification reaction can be purchased commercially, assay development and verification studies must be performed by individual laboratories. In many cases, there are no comparative studies between user-defined NAA procedures, including ASRs, limiting the comparative value of assays between institutions (particularly in viral load monitoring) and restricting the application of such procedures to more experienced laboratories.

It is not without considerable cost that a molecular infectious disease diagnostic lab is developed. It represents an institutional commitment because the costs may only be offset when analysis of hospital-wide cost savings is employed (ie, shorter hospital stays, decreased use of unncecessary antibiotics). The costs incurred not only stem from instrumentation purchases, but also from the dedicated, expert staff required for such testing. Since many academic medical centers have resorted to implementing user-defined assays, verification and validation studies are substantial and require extensive resources, including time, staff, and expertise. These studies are crucial to defining the performance of the assay and determining appropriate clinical utilization. Most laboratory directors view the implementation of user-defined assays and ASRs as a temporary fix until FDA-approved assays are available. However, many diagnostic companies are opting not to seek FDA-clearance to replace current ASRs or "research use only" tests. The FDA, diagnostic companies, and major molecular infectious disease laboratories need to work together to resolve the poor standardization that exists between laboratories using user-defined assays or ASRs. Further, in the absence of FDA-approved tests, many nonacademic medical centers will not have the opportunity to enter the field of molecular infectious disease diagnostics.

Conclusion

The applications of molecular technology in clinical microbiology are endless, but challenges also abound. We are still learning what many NAA results mean in terms of infectious etiology. With the use of molecular technology to detect potential etiologic agents of disease, we need to remember Koch's postulates.[15] Is the mere presence of an organism's nucleic acid convincing evidence of disease causation? Undoubtedly, additional clinical scientific evidence is needed to make such a claim, and such evidence or lack thereof should be considered when interpreting molecular infectious disease results. Though there is still much to be learned regarding the appropriate application and interpretation of molecular infectious disease testing, there are numerous exciting opportunities on the horizon. User-defined assays and ASRs have allowed experienced laboratories to offer critical diagnostic services that have yet to become available with FDA clearance. As investigators refine molecular applications for infectious disease testing, diagnostic companies market such applications, quality control and government organizations standardize results, and as costs associated with implementation decrease and reimbursement increases, molecular infectious disease testing will not only be available in academic medical centers and reference laboratories, but will also transition to community hospitals, thus more globally impacting patient care. **NCMJ**

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COMMENTARY

New Developments in Proteomics

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Genes are relatively static instruction sets for protein manufacturing processes in the cell. Fundamental genetic components (encoding regions) are linked, modified, and combined to create a wide variety of unique protein products. The total number of human protein-encoding genes has been estimated by the Human Genome Sequencing Consortium to be 20 000 to 25 000 genes.[1] The size of the proteome, the complete set of proteins expressed from the genome, is far larger and may exceed 100 000 proteins in humans.[2] Proteomics, the study of the proteome, is the next great challenge in biology and medicine and may rival genomics in complexity, costs, and benefits.

Legacy protein chemistry techniques such as chromatography, electrophoresis, and affinity columns have been used for decades and are an effective means to identify and characterize individual proteins. Proteomics is distinguished from protein chemistry in that proteomics tends to focus on patterns and systems of protein expression rather than on single components.[3] Proteomic techniques are capable of simultaneously examining the expression of thousands of proteins to identify unique patterns associated with phenotypes, tissues, disease states, and responses to environmental or therapeutic exposures.[4] Clinical proteomics encompasses an understanding of protein systems in pathologic processes leading to new diagnostic and prognostic tests, the discovery of protein targets for new pharmacologic therapies, and the identification of patients most likely to benefit from these therapies.[5]

"New and emerging technologies in the application of mass spectrometry to the field of proteomics offer clinicians a means to rapidly identify markers of disease leading to new diagnostic tests and treatments."

The central problem in clinical proteomics is to distinguish and identify multiple proteins related to a disease or condition, even when these proteins are initially unknown. The underlying assumption is that a given disease or condition is manifested by a pattern of protein expression that is unique and identifiable. Proteomic methods compare protein expression in patients with and without a given condition to identify unique patterns or profiles of protein expression related specifically to that condition. Once a condition-specific protein expression pattern is discovered, its constituent proteins are identified

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as potential biomakers for diagnosis and prognosis and as targets for treatment.

Mass spectrometry (MS) has become a promising technique in proteomics following advances supporting the processing of large molecules.[4] Mass spectrometry enables the separation and characterization of proteins in a complex tissue sample based on their different physical and chemical properties. The 2002 Nobel Prize in chemistry was awarded to John Fenn and Koichi Tanaka for their pioneering work in this area. Tanaka's approach utilized laser induced protein ionization and led to the development of matrix-assisted laser desorption/ionization mass spectrometry (MALDI-MS) in the 1980s and to surface-enhanced laser desorption/ionization mass spectrometry (SELDI-MS) during the 1990s.[6-8]

In practice, these MS techniques are carried out in a series of steps. First, proteins are extracted from tissues by disruption of cellular structures and removal of nonprotein components. Next, protein solutions are cocrystallized with a matrix substance on specially developed chemically inert (in the case of MALDI-MS) or chemically active (in the case of SELDI-MS) surfaces. The matrix facilitates ionization of proteins when excited by laser energy.

Mass spectrometry devices identify patterns of protein expression by measuring the abundance of proteins at different molecular weights with a technique known as time-of-flight (TOF) detection. Figure 1 illustrates the basic concept of TOF detection. Proteins are ionized when struck by laser light and "fly" (ie, leave the surface). Ionized proteins are then captured by a high voltage electrical field and are accelerated in a vacuum chamber. During this acceleration period, or "flight," proteins become separated based on their charge and mass, arriving at a detector at different times. The more massive the protein, the less it is accelerated and the later it arrives at the detector.

Proteins striking a detector after TOF separation create a signal with an intensity related to the number of molecules arriving at the detector. The greater the abundance of molecules, the greater is the amplitude of the signal. Proteins with similar masses and charges arrive at the detector at approximately the same time creating a high amplitude spectral "peak" (Figure 1). The pattern of peaks in a complex sample creates a spectrum—a unique fingerprint characterizing protein expression in a given tissue (Figure 2).

The MS spectrum graphically relates a protein's mass and charge (X-axis) to its abundance as measured by its signal intensity (Y-axis). Spectra from different tissue samples can be compared and common patterns of expression identified. Expression pattern differences can be mapped and analyzed. Peaks at similar mass-to-charge ratios (clusters) are identified across spectra (Figure 2) and relative signal amplitude differences are compared using sophisticated pattern recognition software to identify expression patterns that uniquely characterize specific diseases or conditions.

Recent developments in MS proteomics incorporate the use of chemically active surfaces on commercially available arrays known as protein chips.[9,10] Chemically active surfaces allow for on-chip selective extraction of proteins based on chemical properties to simplify processing of complex clinical samples.

Despite the promise of this new technology, a number of

Figure 1.
Basic Components of a Laser Desorption-ionization Mass Spectrometry System Used in Clinical Proteomics.

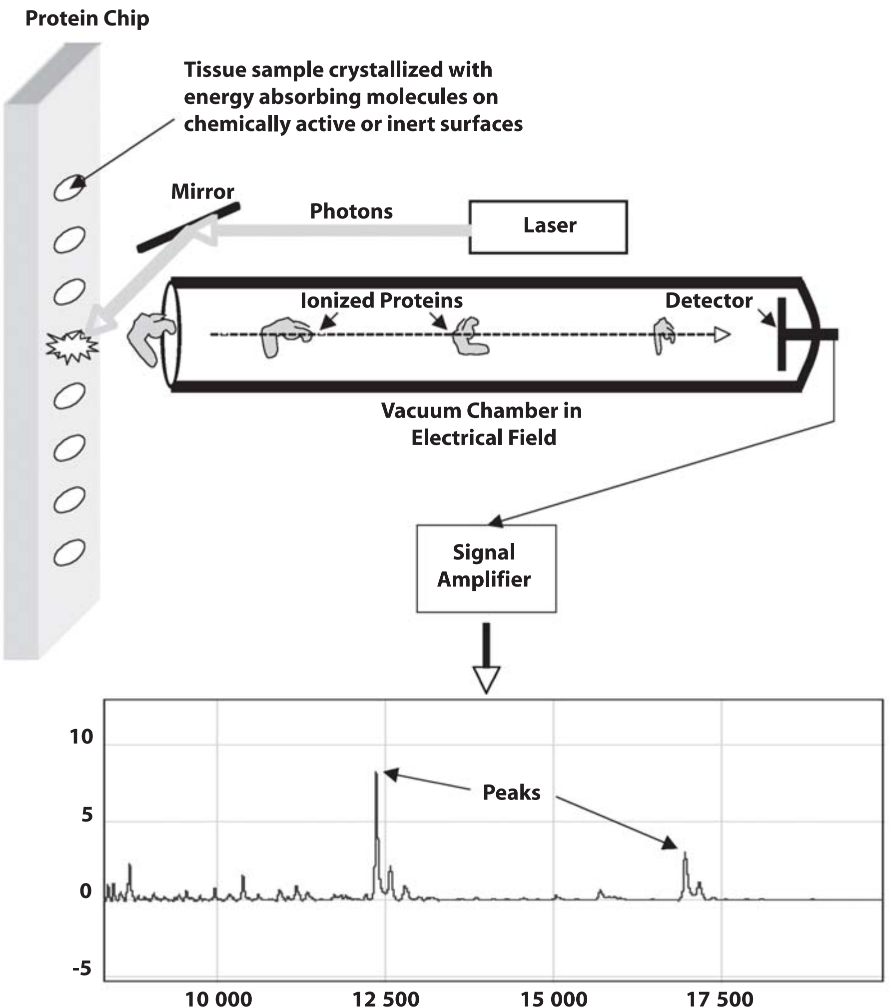
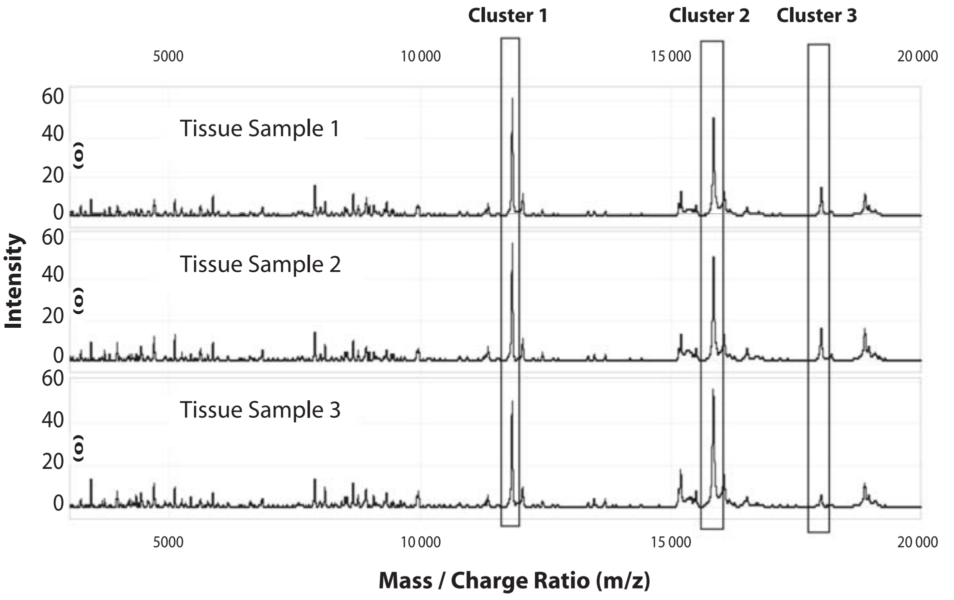


Figure 2.
Spectra from Three Samples of Rat Quadriceps Muscle Showing Three Signal Peaks Sharing Mass-to-Charge Ratio Values (Clusters).



technical obstacles impede its rapid adoption. Often the most difficult issue is defining and obtaining clinical samples suitable for proteomic analyses. Variations in patients, sample handling, and collection protocols constitute substantial challenges. The first step in any proteomics experiment is to obtain and prepare the tissue sample for processing. Tissue preparation is frequently the most resource intensive activity.

Investigators are currently developing and refining SELDI-MS protocols to process a variety of tissue types including serum/plasma, brain, cerebrospinal fluid, urine, tears, saliva, cells from washes and biopsies, and muscle. The earliest efforts at biomarker discovery with SELDI-MS focused on markers associated with various cancers, especially those remaining asymptomatic until late stages such as ovarian[11] and pancreatic[12] cancers. Diagnostic and prognostic tests for these diseases were desirable and tissue preparation protocols for blood were developed early and have been refined considerably over the years.[13]

An issue of critical importance for proteomics analysis of complex biological and clinical samples for discovery of biomarkers is the need for reduction of tissue sample complexity prior to MS analysis. Most tissue samples contain far too many proteins to be evaluated on a single protein chip. These complex samples are broken down into a series of less complex fractions based on the chemical properties of constituent proteins. Conventional methods such as fractionation of complex clinical samples by ionic exchange chromatography and new methods such as enriching low abundant proteins by affinity capture with a combinatorial library of ligands[14] provide much needed tools for processing complex biological and clinical samples for proteomics research.

Another major concern is ensuring that tissue preparation and subsequent processing is standardized and does not vary between samples within experiments. Tissue samples from different individuals are never uniform. Even if gross tissue mass is identical, differences in connective tissue, vascularization, and fat content may result in differences in tissue protein expression patterns.

In examining the entire proteome, it is frequently the case that multiple protein expression differences are found when comparing tissues from different sources or time frames. A challenging problem in proteomics is the identification of patterns of expression associated with a given condition of interest using voluminous experimental data.[15] Mass spectrometry analysis of the proteome can generate an intimidating amount of data. A single clinical tissue sample could generate many thousands of data points describing protein expression patterns. Even small experiments generate too much data to be processed manually. A variety of different approaches, frequently borrowed from genomics, have been used including decision tree analyses, genetic algorithms, and neural networks.[16-18] Development of standardized and universally accepted approaches to analyze protein expression patterns is a goal that has yet to be realized.

It is hard to overstate the potential clinical relevance of the application of MS to the field of proteomics. New and emerging technologies offer clinicians a means to rapidly identify markers of disease leading to new diagnostic tests and treatments. Objective screening tests for conditions such as psychiatric illness based on proteomic techniques could revolutionize the care of patients and lead to better treatments. However, it is important to temper our enthusiasm with an understanding of the challenges that await us as nascent proteomics technologies mature. Sound experimental protocols and analytic methods must keep pace with the rapid development of proteomics tools and hardware. A rush to process experiments without considering common standards and potential pitfalls could generate misleading results and wasted effort. With this caveat in mind, the upcoming era of proteomics should complement genomics and provide a direct clinical relevance not possible by genomics alone. **NCMJ**

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Specialized Testing in Hematopoietic Disorders Aids Diagnosis and Prognosis

Matthew J. Snyder, MD

Introduction

The classification of hematopoietic, or bone marrow and lymph node, disorders (eg, leukemia, lymphoma, myelodysplastic syndrome, myeloproliferative syndrome) has changed significantly over the last 10 to 15 years. Historically, leukemias and lymphomas had been categorized largely by morphology (microscopic appearance). The resulting broad categories gave some prognostic and therapeutic guidance, but the heterogeneous nature of disease entities within each group limited the accuracy of the information.

The tide started turning in the early 1970s with the discovery of the so-called Philadelphia chromosome in patients with chronic myelogenous leukemia,[1] a blood disorder in which the bone marrow typically produces too many white blood cells, which have impaired function. The Philadelphia chromosome is a result of a chromosomal translocation that juxtaposes the gene *ABL* on chromosome 9 to the gene *BCR* on chromosome 22. This results in the production of an abnormal protein that causes the unregulated growth of bone marrow cells. This monumental discovery added focus to the genetic basis of many disorders, especially hematopoietic ones.

There are many methods in the clinical pathology laboratory to examine chromosomes and their respective genes. Karyotyping involves microscopic examination of the chromosome structure itself. It offers an overview of all the chromosomes and can detect some abnormalities. This method remains very useful, despite being time-consuming and requiring cells to divide in culture, a potential technical challenge. If a known, specific genetic abnormality is being sought, fluorescence *in-situ* hybridization (FISH) can be used to detect translocations, gene deletions, monosomies (loss of an entire chromosome), trisomies (gain of an entire chromosome), and other abnormalities. The most sensitive method for detecting targeted chromosomal abnormalities is the polymerase chain reaction (PCR). However, this is used on a somewhat more limited basis due to the technically demanding nature of the test and the general requirement of an unfixed specimen in some circumstances, although recent advances in PCR automation are making its use more widespread.

While the science of cytogenetics has been evolving, another technology called flow cytometry has found a vital niche in the categorization of leukemias and lymphomas. The power of this technology lies in its ability to help classify these disorders based on the pattern of expression of certain cell surface molecules and to detect a very tiny population of abnormal cells among predominantly normal ones.

> *"Karyotype, FISH, PCR, and flow cytometry are being used currently in everyday practice to aid diagnosis and prognostication of hematopoietic disorders and to guide therapy. While each test can add an important level of understanding to a patient's disease, none of them should be used in isolation or without regard to other clinical information."*

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All of these technological advances are used in the clinical pathology laboratory, and data from these tests, in conjunction with morphologic features, form the foundation of the most recent classification scheme for disorders of the hematopoietic system from the World Health Organization (WHO).[2] This scheme is widely accepted by health care professionals around the world because it is based largely on genetic characteristics that have direct impact on treatment and prognosis. Elucidation of mechanisms by which these genetic abnormalities produce disease has led to the discovery of targeted therapies with dramatic clinical success. One example is imatinib mesylate (Gleevec® from Novartis Pharmaceuticals), which has proved a great therapeutic success for patients with chronic myelogenous leukemia.

Although targeted therapies are not available for many hematopoietic disorders, the genetic and flow cytometric characteristics of a hematopoietic disease can play an enormous role in evaluating an individual's prognosis and choosing the most appropriate therapy. These methodologies will be explained in greater detail as they relate to the new classification scheme of hematopoietic disorders, and examples of how the technologies are used for diagnostic, therapeutic, and prognostic purposes will be given.

Karyotype

Karyotyping, the standardized arrangement and morphologic analysis of cell chromosomes, has long been used to diagnose congenital genetic abnormalities, and its significance in evaluating hematopoietic diseases is now well entrenched. Since karyotyping requires cells to divide, this technique is useful in the evaluation of primary bone marrow diseases such as myelodysplastic syndrome, myeloproliferative disease, and acute leukemia. Diseases producing more mature cells, such as many types of lymphoma, are difficult to study using this method because they do not divide readily in culture. Multiple, well-documented cytogenetic abnormalities have been described in patients with myelodysplastic syndrome (MDS). These include abnormalities involving chromosomes 5 and 7 and trisomy 8.[2] In conjunction with morphology, detection of these abnormalities is used to help make the diagnosis of MDS and to track the progression of disease. For example, as some patients with MDS progress toward acute leukemia, additional cytogenetic abnormalities are acquired and serial karyotype analyses can detect this evolution. These changes help predict which patients will persist with a relatively indolent disease versus those who are at a greater risk of developing acute leukemia. Also, there is a particular type of MDS, known has 5q minus syndrome, in which a unique set of clinical and morphologic findings exist. The loss of the genetic material on the long arm of chromosome 5 confers a good prognosis with a very low risk of progression to acute leukemia.[3]

There are several acute leukemias that are now classified primarily based on cytogenetic findings that directly affect treatment and prognosis (Table 1). One example is acute promyelocytic leukemia (APML), which is characterized typically by a translocation of the *PML* gene on chromosome 15 next to the *RARα* gene on chromosome 17. The translocation results in the overproduction of the retinoic acid receptor, making retinoic acid an essential component of the therapy by inducing maturation of the abnormal promyelocytes.[4] The cytogenetic

Table 1.
Examples of Genetic Findings Used for Prognosis

Disease based on WHO classification	Prognosis	Characteristic flow cytometric or morphologic findings
Myelodysplastic syndrome		
Multiple chromosomal abnormalities or complex karyotypes	Poor	
5q minus	Good	X
Acute myeloid leukemia		
Translocation (8;21)	Good	X
Inversion 16	Good	X
Translocation (15;17)	Good	X
Abnormalities of 11q23	Intermediate	
Acute lymphoid leukemia		
Hyperdiploid (>50 chromosomes)	Good	
Translocation (12;21)	Good	X
Translocation (9;22)	Poor	
Abnormalities of 11q23	Poor	X
Translocation (1;19)	Poor	
Hypodiploid	Poor	
Chronic lymphocytic leukemia/Small lymphocytic lymphoma		
Trisomy 12	Poor	
Deletion 13q14	Good	
Deletion 17p13	Poor	
Deletion 11q22-23	Poor	
Multiple myeloma		
Deletion 13q14	Poor	
Translocation (11;14)	Good	
Deletion 17p13	Poor	

finding is important to recognize due to this unique therapy. It also predicts a good prognosis, and bone marrow transplantation is often not considered as a treatment option. This is in contradistinction to many other types of acute leukemia for which it occasionally offers the only chance for extended remission.

Fluorescence *In-situ* Hybridization (FISH)

This technology offers similar information to a karyotype but generally detects abnormalities on a much more targeted part of the genome. However, FISH has the advantage of not requiring dividing cells and, hence, can be performed much more quickly and on a wider variety of specimens than a karyotype. Cells are incubated with fluorescently-labeled primers (manufactured segments of DNA) that bind, or hybridize, to a specific DNA sequence within the cell. The cells are then viewed under fluorescent microscopy and the fluorescent signals analyzed. The relatively rapid turnaround time is important in certain situations, such as in APML. If certain features present in an acute leukemia raise the suspicion of APML, FISH for the translocation can confirm the diagnosis and appropriate therapy can begin promptly. This is vital in this setting because conventional chemotherapy can actually be harmful for patients with APML. Another instance where FISH plays a role in rapid confirmation of a diagnosis is Burkitt lymphoma. This lymphoma grows very rapidly due to overreplication of the *c-MYC* gene on chromosome 8 that causes the cells to remain in a near constant state of division. The confirmation of Burkitt lymphoma is important because treatment typically begins very soon after diagnosis, and it is treated more aggressively than other types of lymphoma.[5]

FISH plays a crucial role in prognostication of diseases that have historically been difficult to characterize by karyotype because they do not divide readily in culture. Chronic lymphocytic leukemia/small lymphocytic lymphoma (CLL/SLL) and multiple myeloma are two notable examples. (See Table 1.) A panel of FISH studies is typically performed on these to arrive at a genetic profile of an individual's disease. This information is then integrated with clinical parameters to arrive at an overall prognosis that guides treatment options. Consequently, some patients are treated with a "watch and wait" approach because of a very low risk of significant progression, whereas others are treated very aggressively at initial diagnosis because of a significant risk of rapid progression. Prior to these genetic advances, the outcome of patients with CLL/SLL and multiple myeloma was quite variable, and there were only limited ways to predict how an individual's disease would behave.

Polymerase Chain Reaction (PCR)

Polymerase chain reaction is an exquisitely sensitive method of genetic investigation and has many applications. Relevant to this discussion, PCR is used to detect genetic abnormalities and, in some instances, to measure the quantity of the abnormality. Although advances in automation are currently available, PCR remains time consuming and requires relatively high technical expertise due to the sensitivity of the method to contamination. The test can use an unfixed sample or, for some PCR primers, a fixed sample. A series of tightly controlled steps amplify, by making many copies, and then detect a genetic target. A practical application of PCR in evaluating lymphomas is the detection of clonality in B and T cell lymphomas. Detecting monoclonality can confirm malignancy, but it is generally not used as the sole determining factor. Furthermore, the PCR characteristics of an individual's lymphoma are often unique and can be used to determine if a subsequent tumor is a recurrence of the former lymphoma or a new primary. This distinction is often of prognostic and therapeutic importance.

Quantitative analysis precisely measures the amount of PCR product, and this can be of value in some settings. Quantitation of the gene fusion product resulting from translocation between chromosomes 9 and 22 that characterizes chronic myelogenous leukemia (CML) can be followed over time to assess the response to imatinib mesylate, the targeted therapy for CML. A negative or decreasing quantitative PCR test is reassurance that the current treatment regimen is controlling the disease, whereas an increasing amount of PCR product could trigger an increase in the dose of imatinib mesylate or consideration of other treatment, such as bone marrow transplant.

Flow Cytometry

Flow cytometry is a technology that detects the presence and quantity of certain molecules that exist on cell surfaces or in the cytoplasm. By examining the pattern of expression (presence) of these molecules, cells from peripheral blood, bone marrow, or a lymph node are grouped into populations of similar cells. Flow cytometry is used primarily as a diagnostic aide in the classification of lymphoma and leukemia, and, as mentioned, the diagnostic categories in the WHO classification[2] carry therapeutic and prognostic significance. One practical application of flow cytometry allows classification of acute leukemia into two major categories, myeloid and lymphoid. Lymphoid tumors can be further subcategorized into B and T lymphoblastic types. These categories of acute leukemias are treated differently and carry different prognoses, especially when correlated with genetic findings. (See Table 1.) Some acute leukemias express molecules that are not characteristic of a particular cell line, known as aberrant expression. These aberrant markers can be unique to an individual's disease and offer a useful way to detect minimal residual disease by easily separating the abnormal cell population from primarily normal cells.

The molecules that are detected by flow cytometry can serve as a surrogate marker for some of the genetic findings described earlier. (See Table 1.) For example, APML has a distinctive profile by flow cytometry in that it lacks expression of HLA-DR and CD34, two molecules that are very frequently present on other types of acute leukemia.[6] Along with morphology, these findings prompt the pathologist to investigate for the characteristic translocation.

The Future

The methods of molecular and genetic evaluation discussed so far originated as research tools, and their utility in the clinical pathology laboratory has evolved quickly. Another type of test that might make this transition is gene microarray technology, sometimes called "gene chip." The results of this test, on a research basis, have been shown to be a very powerful tool to further evaluate how hematopoietic diseases relate to each other and, in some instances, offer an even clearer understanding of the mechanism of disease, prognosis, and optimal therapy.[7] Researchers hope that the identification of specific gene expression in these diseases will lead to effective gene-targeted therapies. This assay entails extracting DNA from tissue and simultaneously analyzing for the overexpression or underexpression of thousands of genes to create a gene expression profile. At present, the gene microarray chips are generally too expensive for routine clinical testing, and the amount of data generated can take many hours to analyze using today's fastest computers. Moreover, storage of these massive amounts of data presents another challenge. Great advances in automation of this test have been made recently, and the cost has also decreased substantially in just a few years. As all of these technological and economic aspects improve, this test will very likely play some role in the evaluation of hematopoietic disorders and may subsequently alter the classification of these diseases.

Table 2.
Examples of Genetic Findings Used for Diagnosis

Genetic Abnormality	WHO Classification Diagnosis
Translocation involving 8q24	Burkitt lymphoma
Translocation (14;18)	Follicular lymphoma
Translocation (11;14)*	Mantle cell lymphoma
Translocation (11;18)	Extranodal marginal zone lymphoma
Translocation (2;5)	Anaplastic large cell lymphoma

* This translocation defines mantle cell lymphoma but has also been reported in some cases of multiple myeloma.[2] These diseases can be differentiated by morphology and flow cytometry.

Conclusion

Karyotype, FISH, PCR, and flow cytometry are being used currently in everyday practice to aid diagnosis (Table 2) and prognostication of hematopoietic disorders and to guide therapy. While each test can add an important level of understanding to a patient's disease, none of them should be used in isolation or without regard to other clinical information. The pathologist plays a critical role in this process by correlating the microscopic morphology with these data from specialized tests and making an overall assessment. Pathologists oversee the performance of these tests, interpret the results in light of the clinical context, and communicate this information to oncologists, radiation oncologists, surgeons, and other treating physicians. This invaluable information about an individual patient's disease has a direct, and often dramatic, impact on the type and duration of therapy and offers an indication of the individual patient's prognosis. **NCMJ**

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COMMENTARY

Human Papillomavirus Testing for Precancerous Lesions of the Cervix

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Introduction

Human papillomavirus (HPV) infection is the most common sexually transmitted viral infection. An estimated 20 million Americans are currently infected with HPV and approximately 6 million new cases develop each year with the majority occurring in the adolescent age group.[1] The annual burden of cervical HPV-related diseases in the United States is estimated to cost between $2.25 billion and $4.6 billion, and the annual burden of cervical cancer is approximately $181.5 million to $393 million.[2] Persistent HPV infection is the most important risk factor for the development of cervical cancer and constitutes the basis for screening. The incidence of cervical cancer has decreased in every country that instituted mass screening for the disease.

> *"The annual burden of cervical HPV-related diseases in the United States is estimated to cost between $2.25 billion and $4.6 billion."*

Until recently, screening for cervical cancer was predominantly cytology based, relying on the detection of dysplasia, or cellular abnormalities, which are a precursor to cervical cancer. Screening with conventional smears has a sensitivity ranging from 50% to 60%. Despite this poor sensitivity, it was responsible for a 75% reduction in the incidence of cervical cancer in the United States since its introduction as a screening test in 1949.[3] With the advent of liquid-based cytology, where the sample is suspended in a fixative solution instead of smeared on a slide, cytologic screening is not only more sensitive, but also more versatile. Liquid-based cytology enables cytotechnologists to perform further tests on the specimen in solution, such as HPV DNA testing, which cannot be performed on the slide. Recent well-controlled clinical trials with verification of positive and some negative results have found sensitivities of 70% to 80% for conventional cervical cytology and 85% to 95% for liquid-based cytology.[4,5] Despite this, even the liquid-based methods can miss between 15% and 35% of high-grade dysplasia or cancer.[6] Unfortunately, given the current health care dollars spent on HPV infections, even small imperfections in the screening process can have significant financial implications.

Computer-Assisted Screening Technology

Liquid-based screening was first introduced over a decade ago. It is now the preferred method of screening, and its versatility has paved the way for other advancements in cervical cancer screening. The specimen in suspension can be filtered and sprayed evenly on a slide, allowing for less artifact and a more consistent specimen to evaluate, which results in fewer false negatives. The uniformity and clarity also enable the use of computer-assisted screening using an automated microscope to further decrease false negative results and increase the ability to identify the truly abnormal Pap test. There are currently 2 Food and Drug Administration (FDA) approved automated systems: the Focal PointTM Slide Profiler (FPSP) and the ThinPrep® Imaging System (TPIS).[7,8] They both use the principle of morphometry, the appearance and size of the cells, and both use slides created with the liquid-based technology. However, the FPSP is also approved for screening conventional Pap test slides.

The FPSP system is only approved for screening specimens from a defined low-risk population of patients. The slides are evaluated using FPSP image analysis software and assigned to

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one of following groups: (1) *negative for intraepithelial lesion or malignancy*, needing no further review; (2) *review*, requiring manual review by a cytotechnologist; (3) *quality control*, requiring manual review of slides with the highest probability of having an abnormality; and (4) *process review*, requiring manual review of slides that cannot be successfully processed by the FPSP system. This system limits the amount of manual review by a cytotechnologist and focuses him/her on the slides of concern. It can use any of the currently available liquid-based systems.

The TPIS system can only evaluate slides that use the liquid-based thin layer technology, but it can be used in both low- and defined high-risk patient populations. It scans every slide and identifies cells of interest and the 22 fields that contain them. The cytotechnologist reviews these fields using an automated microscope and assigns them as no intraepithelial lesions if all fields are judged to be normal or, if any cell is suspicious, the entire slide is reviewed and abnormal cells are evaluated by a pathologist. With this technology, all slides are reviewed, but the computer directs the cytotechnologist to the areas of concern.

HPV Testing

The ability to detect HPV DNA in the liquid-based Pap vial has led to a paradigm shift in cervical cancer screening. Instead of just looking for cellular abnormalities, the current technology allows for the assessment of the causative agent, HPV. However, there are over 100 different types of HPV and each has a different oncogenic risk. For clinical simplicity, they are usually stratified into two groups: low and high risk for the development of cervical cancer. In 2001, the results of the landmark *Atypical Squamous Cells of Undetermined Significance/Low-Grade Squamous Intraepithelial Lesions Triage Study (ALTS)* were published.[6] They compared three different methods of triaging patients with equivocal Pap testing results, atypical cells of uncertain significance (ASCUS). The results indicated that women with an ASCUS Pap test can undergo high-risk HPV DNA testing from the same liquid-based Pap test vial to evaluate for the presence of high-risk DNA. If high-risk DNA is present they should undergo further diagnostic evaluation. But, if a woman was high-risk HPV DNA negative, she had less than a 1% chance of developing a high-grade lesion within the year and could undergo routine screening the following year. The reported sensitivity of this combination of tests was 96%. As a result, fewer women were referred for costly diagnostic tests and reflex high-risk HPV DNA testing became the recommended management for women with ASCUS Pap test results.

As a result of numerous studies confirming the low prevalence of HPV in women over the age of 30, high-risk HPV DNA testing can be offered to women in addition to the liquid-based Pap test.[9] This is different than reflex testing because it is done in conjunction with, rather than as a result of, the liquid-based Pap test. If both Pap test and HPV test are negative, the woman can be rescreened in three years because she is at very low risk of developing a high-grade lesion during this time. Unfortunately, this is only cost effective in the 30 and older age group because the prevalence of HPV in the younger age group is so high.

HPV Vaccine

In June of 2006, the FDA approved the first HPV vaccine, Gardasil®, a quadrivalent vaccine against HPV 6 and 11, the low-risk types associated with 90% of anogentital warts and low-grade lesions, as well as HPV 16 and 18, the high-risk types responsible for 70% of high-grade lesions and cervical cancer.[3] Cervarix®, a vaccine against HPV 16 and 18, was also developed, but is not yet approved by the FDA. Both vaccines approach 100% efficacy in the prevention of HPV 16 and 18 associated high-grade lesions in the patients that received vaccination before contact with either virus. Gardasil® is also effective at preventing the low-grade lesions and anogentital warts associated with HPV types 6 and 11.[10] Based on available data, the Centers for Disease Control and Prevention (CDC) Advisory Committee on Immunization Practices suggested routine vaccination for girls as young as 9 years of age.[11] Several other groups such as the American College of Obstetricians and Gynecologists have also supported these recommendations.[12] Patients that are HPV naïve (ie, women who have never been exposed to the virus) will be best served by this vaccine because they have the most to gain. Although its utility in males is still not proven, if efficacy is shown, vaccination for males may be recommended as well. The true impact of the HPV won't be realized for several years, but its impact on the low-grade lesions may be apparent sooner.

Summary

As new technologies are introduced that increase the sensitivity of detecting patients at risk and the incidence of cervical cancer continues to decrease in the US, annual screening for this disease may actually be overscreening. It has been shown that the screening interval can safely be increased to every 2 years if liquid-based testing is performed with reflex HPV testing in patients under 30 and can be increased to every three years in patients over the age of 30 if they are done together and both are negative.[13,14] As we move into the age of risk stratification as a screening tool with HPV testing and liquid-based screening, it is imperative that the aforementioned recommendations are followed in order to keep the costs of screening at a minimum. Unfortunately, despite data confirming its safety and efficacy, many patients are unconvinced.[15] The overwhelming respondents in one series would still seek to obtain annual screening. In order to complete the paradigm shift in the screening for cervical cancer using the current technologies, more education will be required of the public and health care community to understand and accept the differences, most notably the increased screening interval. The true effects of the HPV vaccine will not be known for some time. Therefore, appropriate screening is still imperative even for those vaccinated because it does not offer complete protection from other strains of the HPV virus. **NCMJ**

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COMMENTARY

Automation in the Clinical Pathology Laboratory

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A large proportion of hospital pathology laboratories in the US were built or renovated in the 1960s or 1970s, and prevailing medical practice and the medical economics of the time led to common design themes. The forces felt by laboratory directors and managers today are considerably different from those that shaped the labs of the earlier era. A widening gap between what is desired from many laboratories and what they are physically capable of delivering is becoming increasingly apparent. The requirement for timely, accurate, well-communicated laboratory results is crucial. Approximately 70% to 80% of major clinical decisions are based, at least in part, upon information coming from the pathology laboratory.[1,2] Thus, the impact of a successful laboratory on the efficiency and quality of care is far-reaching. Current pressures for design and process change include cost, turnaround time, the tightening technologist market, and reduction in clerical and preanalytical errors.

Cost

The advent of diagnosis-related group-based reimbursement for inpatients shifted hospital laboratories from revenue generators to cost centers. Since then, the requirement to reduce the cost of testing has been relentless.

Turnaround Time

The desire to reduce turnaround times stems from both the impact of rapid delivery of data-based therapy on outcomes in some circumstances (eg, chest pain and stroke protocols) and the drive to reduce hospital lengths of stay.

Tightening Technologist Labor Market

The average age of medical technologists is continuing to increase and, in some markets, as many as 84% of laboratories report that finding and hiring medical technologists is either difficult or extremely difficult.[3]

Reduction in Clerical and Preanalytical Errors

Recent years have seen increasing national awareness that a significant number of poor outcomes for hospitalized patients are avoidable. Clerical and identification errors are responsible for a large fraction of such outcomes, and as many as 40% of errors occur during the preanalytical phase of testing. Reduction of human involvement in this process can result in improved patient safety, with fewer errors due to sample misidentification. Automation can also reduce sample processing time.

While our primary intention is to discuss automation in the clinical pathology laboratory, it must be emphasized that, ideally, implementation of automation should be coupled with process review. Automation often allows optimization of processes in ways that are not possible in a manual laboratory, and implementation of automation without thorough assessment of current laboratory processes is likely to result in missed

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opportunities. The flow of specimens and information and the activities of laboratory personnel should be examined with fresh eyes. Although this reevaluation may be difficult, it represents a crucial responsibility of the laboratory leadership, and everything should be put on the table. In particular, all preanalytical processing steps should be optimized to gain the full benefit afforded by automation. Container selection, specimen collection, specimen labeling, identification, receiving, and accessioning, and, ultimately, specimen tracking through the laboratory should be reevaluated. Autoverification of results, reporting methods, specimen retrieval for add-on testing, and ease of result interpretation are also vital considerations as processes are examined. Merely recapitulating the manual laboratory with machinery is not likely to reap the greatest possible benefits in efficiency and service improvement from the expenditure of resources.

Laboratory automation reduces the number of steps in testing requiring human intervention. When suitably implemented, automation reduces turnaround times for many tests. Automated systems do not reduce turnaround times by virtue of an ability to perform any individual step faster than a skilled technician does. Instead, these systems operate at or near maximum throughput up to capacity and do not suffer from potential lapses of attention. They allow a smaller number of skilled medical technologists to operate the instruments in a large laboratory. A specific example is the automated location and retrieval of specimens stored in a refrigerated stockyard for add-on testing. This does not require any human intervention, saves time, and avoids human error. With automation, the technologists expend a greater fraction of their time and energy on judgment tasks, making assessments and decisions that require their training and intelligence. Thus, the affect of the tightening labor market can be blunted.

The combination of automation and computerized interfaces has the potential to reduce the risk of clerical and identification errors. Primary sources of such errors are the preanalytical phase, the postanalytical phase, and, less commonly, any point in the analytical phase in which there is a hand-off from one person to another. Positive patient identification entails unique bar coding of the patient armband. Corresponding unique bar codes are printed at the bedside on specimen labels, which allow each specimen to be tracked during its travel through the automated system. Results are unerringly associated with the proper patient. In combination with a robust laboratory information system, this has the potential to drastically reduce errors, especially in the preanalytical phase of testing.

It is not clear a priori that the capital expenditure required to purchase the equipment to automate any individual laboratory will eventuate in an overall cost reduction. Moreover, the physical layout of some laboratories may not be amenable to large-scale automation. Thus, careful financial analysis must take into account current and projected specimen volumes, personnel costs based upon efficient management of laboratory staff, and the cost of the automation equipment and any required renovations of the laboratory space. Another factor that should be considered is that consistently short turnaround times may obviate a clinically relevant need for some types of point-of-care testing, which is usually manifoldly more expensive than testing within the laboratory.

In summary, the circumstances in which pathology laboratories now find themselves are very different from those that drove the design of a great fraction of laboratories decades ago. Laboratory automation can be a powerful tool to help many laboratories meet the challenges of the current environment and pressures. **NCMJ**

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COMMENTARY

Point-of-Care Testing:
Guidelines and Challenges

Robert L. Sautter, PhD, HCLD (ABB), Edward H. Lipford, MD

Laboratory diagnostics play an important role in managing patients. With the pressures to reduce hospital length of stay and with newer therapy options, the laboratory has been asked to decrease the turnaround time from sample to result. Therefore, point-of-care testing (POCT), testing near the patient or bedside, was developed to generate quicker results. The goal of POCT is to provide the clinician with rapid results, which can improve patient outcomes and quickly supply therapeutic interventions as compared to those results obtained from the core laboratory.[1] Laboratory point-of-care testing is not new; however, it experienced a veritable explosion in manufacturing, clinical oversight, and regulations following the "waived provision" of the Clinical Laboratory Improvement Amendments (CLIA) of 1988.[1,2,3] The number of laboratories holding a Certificate of Waiver increased from 67 294 in 1993 to 105 138 in 2004.[3] In addition, the number of Medicare Part B waived tests performed increased from 14 million to over 23 million between the years 2000 and 2004.[3] (See Table 1.) Inherent with POCT growth come challenges in performing high quality accurate testing. Decreasing laboratory errors and improving patient safety must also be considered as POCT increases.

The Centers for Medicare and Medicaid Services (CMS) regulates laboratory testing on humans through CLIA to ensure quality testing. CLIA classifies tests as "waived complexity," "moderate complexity,"[a] and "high complexity" based upon criteria developed by the federal Department of Health and Human Services. Waived complexity tests are simple laboratory examinations that are approved for home use and which employ methodologies that are simple and accurate. They render the likelihood of erroneous results negligible or pose no risk of harm to the patient if the test is performed incorrectly. Quality standards for moderately and highly complex tests are designated for proficiency testing, patient test management, quality control, personnel qualifications, quality assurance, and quality control.[2] The more complex the test, the more stringent the testing requirements. A complete listing of the tests by classification can be found on the website of the Center for Devices and Radiological Health of the US Food and Drug Administration.[4]

> *"When considering that millions of laboratory tests are performed at the point-of-care each year, it is imperative that we, as health care providers, do everything we can to dispense quality laboratory care for all patients."*

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[a] An additional subcategory classification under moderate complexity is "provider-performed microscopy." It was developed as a special consideration to allow laboratories that are otherwise classified as "waived" to perform moderately complex tests utilizing microscopic analysis.[3]

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Table 1.
Increases in Waived Analytes and Test Systems, Certificate of Waiver Laboratories, and Medicare Part B Reimbursed Waived Testing, 1993–2004

Waived testing measurement parameter	1993	1998	2000	2003	2004
No. of analytes for which waived test systems are available	9	40	53	74	76
No. of waived test systems*	203	608	832	1495	1638
No. of laboratories with a Certificate of Waiver	67 294	78 825	85 944	102 123	105 138
Percentage of laboratories with a Certificate of Waiver†	44%	50%	52%	57%	58%
No. of Medicare Part B reimbursed waived tests	§	§	14 663 751	20 781 297	23 041 693
Percentage of Medicare Part B reimbursed laboratory testing that is waived	§	§	6.5%	7.8%	8.1%
Medicare Part B payment amount for waived tests	§	§	$69,765,453	$112,247,706	$128,169,398

* Numbers reflect multiple names under which individual tests are marketed and might include waived tests no longer sold.

† Does not include Clinical Laboratory Improvement Amendments (CLIA) exempt laboratories in New York and Washington

§ Not available

Source: Centers for Disease Control and Prevention. Good laboratory practices for waived testing sites, survey findings from testing sites holding a certificate of waiver under the clinical laboratory improvement amendments of 1988 and recommendations for promoting quality testing. Recommendations and reports. *MMWR*. 2005;54(RR-13):1-23.

Several regulatory bodies are primarily involved in inspections for the POCT laboratory. Point-of-care testing occurs on floors of hospitals, nursing homes, clinics, physician offices, radiology suites, and any other location where testing is classified as a regulated laboratory test. Laboratories may apply for a Certificate of Waiver, Certificate of Compliance, or a Certificate of Accreditation.[b,3] Those that are accredited are usually accredited by private peer organizations such as the College of American Pathologists (CAP) and the Joint Commission on Accreditation of Healthcare Organizations (JCAHO). These two organizations have been inspecting hospital laboratories inside health systems for quite some time. Recently, both the CAP and JCAHO have been granted "deemed status" to inspect laboratories for CMS.[5] Laboratories are inspected in regard to directorship, quality assurance, quality control, testing personnel (training and competency), reporting, and verification of testing procedures. Accredited laboratories are inspected on a two-year cycle. All inspections are now performed on an unannounced basis. However, those laboratories that obtained a certificate of compliance or certificate of waiver have not been inspected on a regular basis in the past due to a lack of resources available to inspect the thousands of laboratories doing this testing.

Two state pilot inspection programs of physician office laboratories (POL) with certificates of waiver showed that a significant number of laboratories had serious deficiencies with regard to their compliance with regulations.[3] Testing without employee training, failure to document procedures, or failure to follow manufacturer's packaged instructions were among the most concerning deficiencies identified. Subsequent inspections of more than 1000 laboratories confirmed these problems nationwide. CMS plans to inspect only 2% of the waived laboratories yearly. Inspection results in several states have shown improvement; however, without oversight overall improvement may be difficult to achieve. The executive summary of the waived laboratory project from CMS included this review of compliance with manufacturer's instructions for performance of tests:

> *Expanded pilot studies by the Centers for Medicare and Medicaid Services (CMS), formerly the Health Care Financing Administration (HCFA), of laboratories issued a certificate of waiver (COW) and provider performed microscopy procedures (PPMP) laboratories demonstrate that 50% of laboratories performing waived tests do not follow the manufacturer's instructions or do not have manufacturer's instructions. The only CLIA requirement for COW laboratories is to follow the manufacturer's test instructions. These findings mirror those of previous pilots conducted by Colorado, Ohio, New York and most recently, the Office of the Inspector General (OIG). If these percentages are nationally representative, as many as 60,000 laboratories may not be following manufacturer's instructions and may be performing tests incorrectly to potentially harm patients.*[6]

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[b] A Certificate of Waiver is issued to a laboratory that only performs waived tests. A Certificate of Compliance is issued to a laboratory following inspection by the state department of health that determines the laboratory is compliant with CLIA requirements. A Certificate of Accreditation is issued to a laboratory based on accreditation.

Tests designed to be performed in the point-of-care setting are manufactured to be relatively fast and easy to operate. The results should be made available while the patient is present or so that the provider can respond to him during the visit. Many point-of-care tests offer these advantages and ideally result in better outcomes for the patient.[7] Pressures to see more patients in the office or to free space in an emergency department have stimulated a real need for faster results. However, faster is not always better if the result's timeliness has little or no impact on the outcome of care.[8] Unfortunately, there are few studies available showing that patient outcomes improve with tests performed at point-of-care location over those performed in the clinical laboratory. Therefore, more research is needed in this area.[7]

When considering that millions of laboratory tests are performed at the point of care each year, it is imperative that we, as health care providers, do everything we can to dispense quality laboratory care for all patients. Some problems in achieving this goal include the lack of adequate accessibility of laboratory data by those in charge of oversight, poor training and low competency of testing personnel, and lack of evidence-based studies linked to patient outcomes.

Evidence-based guidelines for point-of-care testing have been developed by the National Academy of Clinical Biochemistry (NACB) in cooperation with the College of American Pathologists and the American Society for Microbiology.[8] The guidelines cover subjects in POCT ranging from management to technical areas such as critical care, coagulation, cardiac markers for diagnosing acute coronary syndromes, infectious diseases, and renal function tests.[9] The monograph answers critical clinical and managerial questions using literature searches and grading outcome-generated studies into various categories of recommendations based upon the available literature. A key component in performing POCT at any site is managing the program. The monograph divides the management of POCT into quality control, technical oversight, data management, training and education of operators, and continuous quality improvement with quality indicators.[10]

Multidisciplinary approaches to POCT are necessary to implement a successful program.[10] Administration can supply the appropriate resources to achieve this goal along with technical expertise from physicians, nursing, and the laboratory. Each health care professional must realize his/her responsibility to achieve this goal. Decisions made by the group need to be based upon factual data or observations. These data must include a balance between sensitivity, specificity, positive and negative predictive values of the tests evaluated, and the clinical need for the results. Cost for disseminating the results is also an important consideration.

Handling laboratory data electronically clearly offers an advantage over manual systems in tracking quality care issues, following patient test results, and assuring compliance with regulations.[10,11] Remote monitoring allows technically skilled individuals to monitor performance and evaluate problems with instrumentation and suggest corrective action. A universal connectivity information system is imperative to be able to manage the many manufacturer options in POCT. Until recently, manufacturers were reluctant to connect test systems from companies not in business relationships with each other. There are now systems that allow such a connectivity to be instituted for a fee.[10,11,12] The performance of quality assurance and quality control is an expensive and time-consuming portion of laboratory medicine. In order to improve the quality of POCT, the NACB recommends developing a formal process of risk management and reducing medical errors by using an interdisciplinary committee to manage POCT, instituting POCT training programs, implementing data management systems, and instituting continuous quality improvement with quality indicators.[9]

It has been shown that 25% to 40% of laboratory tests are unnecessary.[13] Furthermore, there is potential for over utilization of point-of-care testing and the potential to do harm with results.[9,13] This makes it extremely important to make sure that all laboratory testing is warranted and that the results affect the outcome of patient management. In the critical care arena, few well-controlled outcome studies have been performed to show the benefit for POCT.[14] One positive study in sepsis patients demonstrated a decrease in mortality from 47% to 31% when early directed therapy to point-of-care arterial blood gases (including direct response to pH, oxygen saturation, and lactate) was instituted rapidly. Therefore, the Laboratory Medicine Practice Guidelines (LMPG) state there is fair evidence that arterial blood gases in the point of care should be performed for intensive care unit patients.[14] The evidence for other POCT is absent or less convincing.

For example, the detection of *Trichomonas vaginalis* in the physician office laboratory is usually made by performing microscopic examination of a wet preparation (WP). Unfortunately, the sensitivity of this testing is between 49% and 89%.[15] Although the use of POCT is recommended by the LMPG, outcomes based upon a wet mount for *T. vaginalis* do not link this agent with premature rupture of membranes.[15] The lack of sensitivity of WP necessitates a need for more sensitive tests. When tests with increased sensitivity are used in the point-of-care or core laboratory, *T. vaginalis* may in fact be associated with premature rupture of membranes.[15]

Point-of-care testing has the ability to improve outcomes and result in decreased mortality when performed correctly and following laboratory guidelines.[1,14] Using good laboratory practices, POCT will be beneficial at any patient site.[3] Some example benefits of POCT include faster decision making for cardiac patients, quicker optimization of treatment for anticoagulation, and increased patient satisfaction. Point-of-care testing will only increase in numbers and diversity of methods in coming years. The advent of complete electronic medical records including home health testing with regional databases will undoubtedly make more data available to the clinician. **NCMJ**

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COMMENTARY

The Feasibility of Home or Patient Self-Testing

Thomas E. Wall, MBA

In contemporary society, the most prevalent and the most demanding forms of illness are chronic diseases. These can involve daily regimens of care and self-management, usually for a lifetime, and often require significant modifications in the lifestyles and activity patterns of those affected. Recent year estimates suggest that as much as 75% of total health care costs can be attributed to the treatment of persons with chronic illnesses and their associated comorbidities and acute care episodes.[1] In decades past, the predominant concerns of health and medical care were largely related to the burden of illness associated with communicable and infectious diseases. However, today, our focus has shifted to the prevention and long-term management of chronic diseases.

Over many years, the emphasis in chronic illness care has been on the protocols for disease management and attempts to increase patient adherence to specific regimens of care. Health care technology applications have sought better methods for the detection and monitoring of disease indicators and the collection and analysis of trends in these indicators as part of overall strategies for patient care management. Despite the efforts of many, there continue to be widespread feelings of frustration and disappointment in the health care professions over the inability to achieve high levels of control of hypertension, diabetes, asthma, and other chronic conditions where patterns of personal health-related decisions and behaviors can affect these critical indicators of chronic disease self-management.

If satisfactorily controlling these vital health indicators among chronic disease patients were easy, it would not have required the efforts of so many over such a long period of time, with so few examples of successful and sustained outcomes. The good news is that there are now promising new forms of computer-assisted technology that offer the possibility of bringing the best knowledge in fields like health behavior and health education, clinical medicine, and information technology together to achieve a much more effective interventional mode of long-term management of chronic diseases. Effective disease management care can significantly improve quality of life for those with these diseases, lead to a more effective outcome of medical therapies, and decrease overall costs of care.

New Technologies Available for Chronic Disease Self-Management

There are a number of exciting and promising developments in the field of chronic disease self-management that take advantage of existing technologies and integrate them in new ways to achieve greater efficiency and more effective self-management. For a number of years physicians and other health care professionals have used telephones to give patients the opportunity to dial in to report or upload recent readings of key clinical indicators and to contact them for reinforcement of medical advice and counseling. To date, many of these telehealth solutions have been tethered to the patient's home telephone line. They provided solutions for the critically ill, but were not ideal for the large population living a mobile lifestyle while trying to manage a chronic disease. The emergence of the cellular phone and its

> *"The emergence of technology for data signal transmission to and from cellular telephones has opened up an entirely new dimension of communicating basic clinical information to and from a central site."*

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growing ubiquity and enhanced capabilities have provided a mobile platform to support chronic disease management in this on-the-go community.

The emergence of technology for data signal transmission to and from cellular telephones has opened up an entirely new dimension of communicating basic clinical information to and from a central site. Now it is possible, with the development of home medical devices recording biomedical indicators, to digitally transmit this information using Bluetooth® communications protocol to a cellular telephone and then to a file server. The file server can then interpret this information, comparing it to other measures taken over time, and send encouraging or instructional messages back to the patient to motivate positive health actions related to the chronic health condition. Simultaneously, a summary of this same information can be sent to the physician or other health care professional involved in the care of the patient. All of the data are accessible through a secure internet portal to the health care professional and the patient. These measurements can be taken, transmitted, interpreted, and commented upon within a few seconds, thus making it possible for both patient and health care provider to communicate about the ongoing management of one's chronic condition in near real-time.

Figure 1 depicts the way in which this new communication linkage can work with a telehealth software application installed on an off-the-shelf cell phone. Recent feasibility (acceptance) trials for Type 1 and 2 diabetes and congestive heart failure have shown that patients and their health care providers find this system an easily usable tool.

What are the Implications of These Technologies for Chronic Disease Care?

To be successful in managing chronic diseases the individual must take ownership of his/her disease. By using new mobile technology to provide a link to the doctor and to reinforce positive behaviors, the individual becomes empowered. The linkage enhances the physician-patient relationship and, through automatic notifications, keeps patients and providers updated on key aspects of the patient's treatment plan.

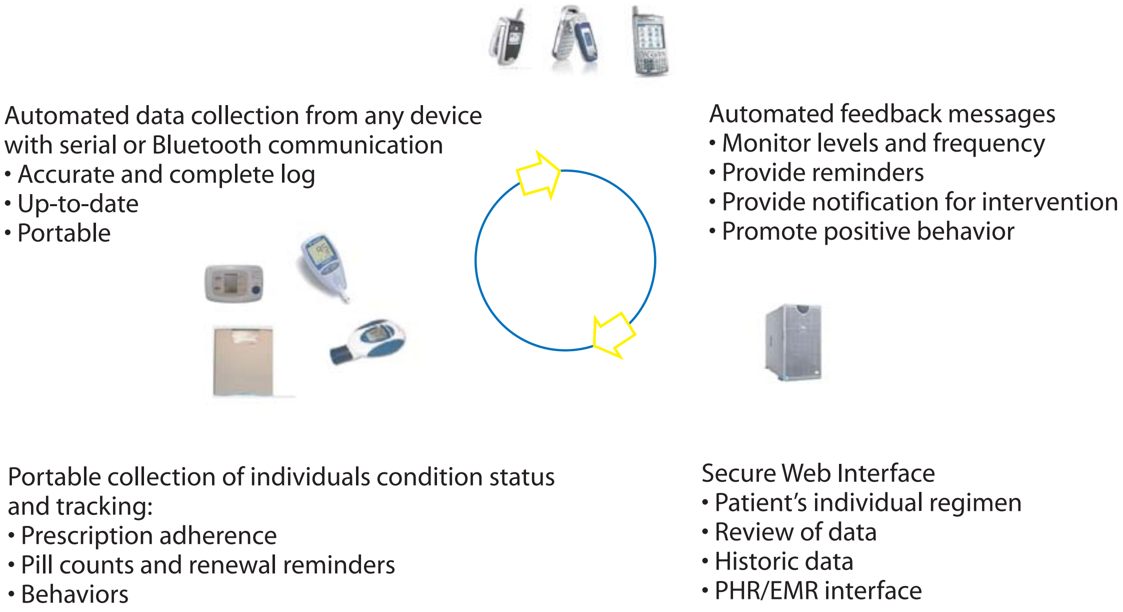
From a payer's perspective, good chronic disease management is good business. This new mobile telehealth tool has proven effective in early product trials with diabetes patients. It produced improved outcomes including more frequent testing, better glucose control, and lower HbA1cs. In addition to better short-term outcomes that translate to fewer emergency room visits, improving self-management and education is proven to reduce long-term complications and costs of care.

Other chronic diseases that require home medical device testing bear many of the same self-management issues and can benefit from this technology tool. For instance, by using an electronic weight scale, a cell phone-based weight management application can be used to promote positive behaviors in the individual's home. A protocol of self-reported symptoms and peak flow/spirometer readings can support improved asthma management. Patient reporting of prescription adherence, coupled with reminders and real-time biometric data, can be valuable to the patient as well as the provider.

In order for this or any tool to be successful in improving

Figure 1.

Cell Phone Telehealth Applications for Diabetes, Obesity, Asthma and Other Chronic Diseases Can Be Run on Many Mobile Devices



chronic disease self-management, it must be easy to use, nonintrusive, and be perceived to add value to the user. Using the cell phone, which is becoming an integral part of daily life, greatly reduces the complexity barrier and allows for the strengthened connection to the provider to become part of the user's daily routine. **NCMJ**

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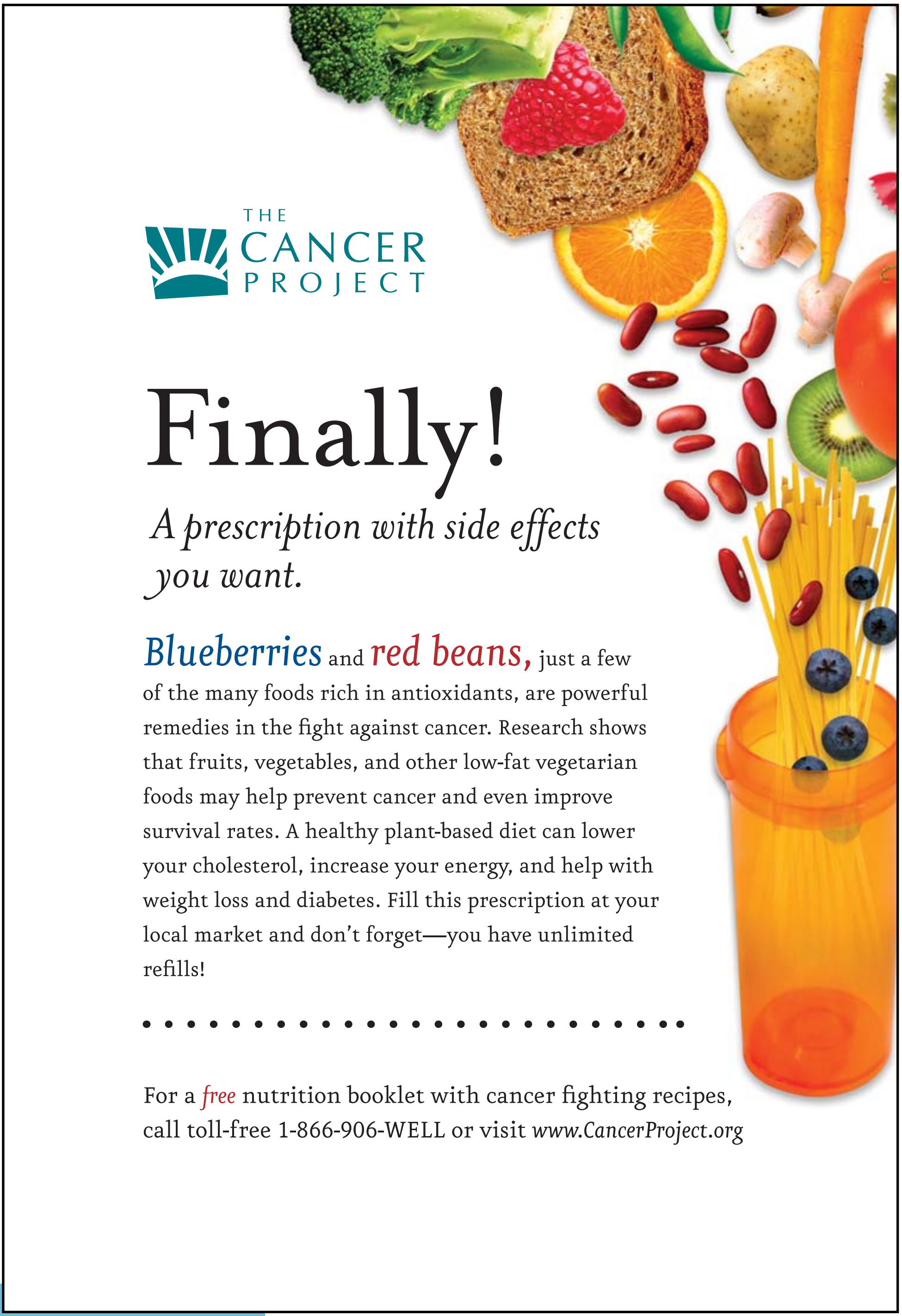

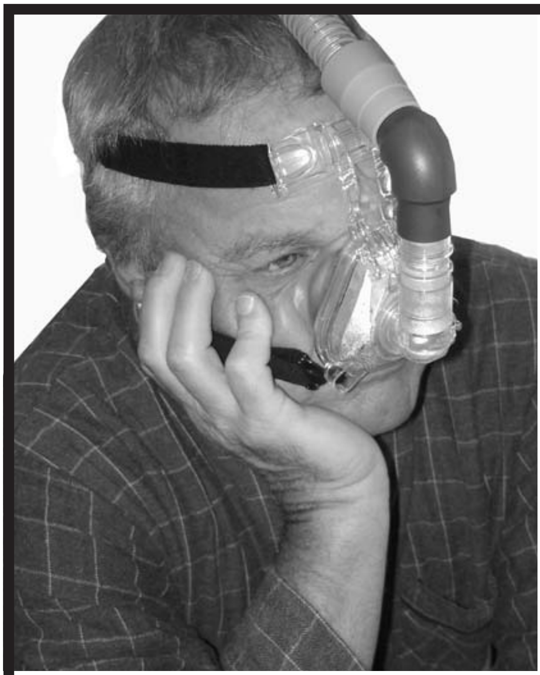

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Readers' Forum

To the Editor:

The November/December 2006 issue of The *North Carolina Medical Journal* offered a comprehensive discussion on the issue of worksite wellness and health promotion, providing both the most current research and field-based insights into what can work and how to implement those successful components. Employers have been faced with increasing employee health care costs for several years and many have considered worksite wellness as an option to address cost containment. At issue has been the true definition and scope of successful worksite wellness.

At Blue Cross Blue Shield of North Carolina we have been developing our employee health promotion program over the past several years. Among others, we sought the insight of several of the contributors to the recent issue. In part, as a result of that consultation and subsequent implementation of several initiatives, we have realized a significant increase in the proportion of members participating actively in our health and wellness programs.

In addition, we recently held our annual Health Care Symposium, which was attended by approximately 150 human resources and benefits managers from our business customers. This year's program focused on the topic of worksite and employee wellness. As a takeaway from the conference, we presented each attendee with a copy of your November/December issue as a resource to them as they further develop their own worksite wellness solutions.

Our ultimate goal is not only to successfully offer the type of worksite wellness programming highlighted in the last issue but also to continue to demonstrate objective improvements in employee health, productivity, and retention. As we accumulate more experience and develop or revise programs, we will share our experiences and success with our partnering employer groups and interested audiences across the state and nation.

Thank you for defining the issues, presenting achievable strategies, and setting the bar for the direction of worksite wellness in North Carolina.

Sincerely,
Don Bradley, MD
Chief Medical Officer
Blue Cross and Blue Shield of North Carolina

To the Editor:

Primum non nocere, first do no harm. While many consider this maxim dated and irrelevant in our techno modern world of medicine, no concept applies better in the debate of physician participation in capital punishment. The American Medical Association and North Carolina Medical Society have firmly stated that even physician presence at an execution is unethical and unacceptable. While the North Carolina Medical Board has officially stated that physician presence will not be sanctioned (in deference to North Carolina state law that requires physician presence), active participation is strictly forbidden, which includes monitoring of vital signs, levels of consciousness, etc.

Primum non nocere. As physicians, our duty is to always advocate for our patients. To always acts in their best interests. To eschew all other interests but those that best serve our patients. So how is it that a physician is brought into the realm of a state-sponsored execution to ensure proper sedation and level of consciousness so that a lethal combination of drugs will lead to an individual's demise? This was the requirement that was imposed upon the state to allow executions to continue, so that the United States constitutional requirement that prohibits cruel and unusual punishment is satisfied. But that policy conflicts with our basic tenants and ethics. How can we sedate and anesthetize, only to allow lethal drugs to be administered?

Primum non nocere. State sponsorship, state sanctioning, legislative approval, popular vote do nothing to remove physicians from their sacred duty to always act in the best interests of their patients. And our patients are anyone who we touch, treat, review, or opine. To act otherwise undermines our profession and our raison d'etre (ie, reason for existence).

Primum non nocere. We physicians must resist any action, by anybody, for any reason, that attempts to move us to violate our ethics, our tenants, and our sacred profession.

Primum non nocere.
Douglas K. Holmes, MD

Spotlight on the Safety Net

A Community Collaboration
Kimberly M. Alexander-Bratcher, MPH

Community Health Network of Henderson County

In the southwestern corner of North Carolina, local health and social service providers have joined into the Community Health Network of Henderson County (CHN). Community Health Network is a network of providers who access a shared client information system (Case Management Information System – CMIS). That system was adapted by Partnership for Health, Inc (PFH), 5 Rivers Systems, the NC Foundation for Advanced Health Programs, and the Office of Rural Health and Community Care to meet the network's needs. The CMIS electronically links health care providers and human services agencies in a 3-county area in western North Carolina to share client protected information to better serve clients, reduce duplication of efforts and services among various social service agencies and health care providers, and decrease gaps in access to services for low-income people in the Hendersonville-Brevard-Saluda area. The CMIS shared electronic database provides access to resource information used to quickly assist low-income people in finding health care, medications, and other basic human needs.

The collaboration began in 1997 when a post graduate resident physician in the Mountain Area Health Education Center (MAHEC)-sponsored Hendersonville Family Medicine Residency Program started a free clinic for homeless clients at the Henderson Rescue Mission. In 1998, MAHEC provided a licensed physician as the medical director for the Henderson County Health Department. This forged a unique relationship between the two organizations. As they encountered difficulties with mental health reform and expanded coordination with a local community health center, more stakeholders began working collaboratively. A Healthy Communities Access Program (HCAP) grant from the Health Resources and Service Administration (HRSA) was applied for and received to fund the CHN program under the umbrella of Partnership for Health (PFH), a Healthy Carolinians Partnership.

From its simple beginnings, CHN now includes more than thirty partners and is a model of community collaboration. Of 2157 applicants to the network program, 1929 have been enrolled in the network at the 15 enrollment sites. Although CHN does not provide direct services, the member organizations offer a variety of services in 9 primary care sites and 5 integrated behavioral health care sites. More that 4000 prescriptions valued at $400,741 have been filled for 742 patients. The target conditions of the program are diabetes, depression, and asthma, and more than 40% of the over 1900 CHN enrollees are affected by one of the 3 conditions. The full list of CHN members are listed in the table to the right.

When asked to describe the Community Health Network of Henderson County, medical advisor Steve Crane, MD, shared these thoughts, "Over the years there has been an extraordinary degree and breadth of cooperation between agencies and individuals in our community who care about access and quality of our health system. Each success has fostered a new project or collaboration resulting in today's multi-faceted approach. I trace the kernel of these efforts back to Jim Bernstein, who encouraged and mentored many of us to move in this direction."

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North Carolina Medical Journal

a look at:

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Brody School of Medicine at East Carolina University
Greenville, NC 27834

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North Carolina
MEDICAL JOURNAL

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For additional information contact Valerie Gilchrist, MD, Professor and Chair, Department of Family Medicine, Brody School of Medicine, East Carolina University, 600 Moye Boulevard, Brody 4N-84, Greenville, NC 27834; phone: 252-744-2592; email letchworths@ecu.edu.

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health policy
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SCIENTIFIC ARTICLES

POLICY FORUM

North Carolina's Primary Care and Specialty Workforce

COMMENTARIES

DEPARTMENTS

About the Cover:
Pressures on supply mean that North Carolina's practitioners will have to step outside their current roles and disciplinary structures to meet the needs of the state, especially in rural and underserved areas.

Tarheel Footprints in Health Care

Recognizing unusual and often unsung contributions of individual citizens who have made health care for North Carolinians more accessible and of higher quality

Recognizing Daniel Stroup, MD Hayesville, NC


Daniel Stroup, MD

When the National Health Service Corps was established in 1968, its goal was to recruit enthusiastic physicians to practice in remote and underserved areas. The expectation was that they would find their missions in these rural places and remain there as community doctors. That ideal outcome was not often achieved but there is at least one example of an ideal outcome in western North Carolina in the hills above Lake Chatuge.

In 1982 Dan Stroup came to North Carolina as a National Health Service Corps scholar. He had just finished his family medicine residency in Waukesha, Wisconsin and was recruited by the North Carolina Office of Rural Health to a practice in Hayesville in Clay County. Twenty-five years later Dr. Stroup is still there but he's much more than the "town doc." He is the leader of a progressive and modern medical practice of 3 physicians, a nurse practitioner, and a physician assistant serving the local hospital, a nursing home, and the citizens of Clay and Cherokee counties.

The Chatuge Family Practice, which has offices in Hayesville in Clay County and Murphy in Cherokee County, is known for its progressive outlook and early adoption of quality-enhancing technology. The practice has an electronic medical record system that links into the PPRNET quality management system, a regional system of disease management and care coordination. This dedication to keep up with the latest in medical care is one of the characteristics of Dr. Stroup who combines old-fashioned community care with the best and latest medical information and the mechanisms to apply that information to care.

Dr. Stroup supports the local schools and their sports teams in both Clay and Cherokee counties as well as taking care of patients in the local nursing home, acting as medical director of the office, and taking call for the hospital in Murphy. He also has served an 11-year stint as county medical examiner and currently is on the Murphy Hospital Authority Board. These supporting roles are done to enhance the scope and quality of the primary care practice and are done on a voluntary basis. Even with all this, Dr. Stroup still finds time for kayaking the Ocoee River in nearby Tennessee.

The people who work with Dr. Stroup see him as a "firm but fair" leader who treats everyone equally—patients and staff alike. He acts as the supervising physician for a nurse practitioner, Judith Wikstrom, who has been with the practice for 12 years and a physician assistant, John Tucker, who joined the practice in 2004. Dr. Stroup was instrumental in recruiting his physician colleagues to the community. Dr. Theresa Heavner came in 1990 and Dr. Matthew Molison, another National Health Service Corps scholar, arrived in 1997. Both have found a permanent home in Cherokee County.

Dan Stroup is a model for how the National Health Services Corps can work. But it requires special people with dedication and the drive to build up as well as just "fill-in" a place. It also requires the support and assistance of organizations like the NC Office of Rural Health and Community Care which brought Dr. Stroup together with the people of Hayesville as well as the support of colleagues and patients to make rural primary care in the North Carolina mountains a leader in quality.

The editors of the *North Carolina Medical Journal* are pleased to recognize Dr. Daniel Stroup for his service and dedication to provide access to quality health care in rural North Carolina.

ARTICLE

Physician Reported Communication About Depression and Psychosocial Issues During Postpartum Visits

Betsy Lynn Sleath, PhD; Naveen Thomas, MD, MHP; Elizabeth Jackson, PhD; Suzanne L. West, PhD; Bradley N. Gaynes, MD, MPH

Abstract

Objective: *Postpartum depression occurs in 13% of women after delivery, making it one of the most common puerperial complications. The purpose of the study was to examine: (1) the extent to which obstetricians/gynecologists and family physicians report discussing depression and other psychosocial issues during postpartum visits and (2) how physician specialty and gender are related to whether physicians report discussing depression and other psychosocial issues with patients during postpartum visits.*

Methods: *A survey was sent to a random sample of 600 obstetricians/gynecologists and 600 family practitioners in North Carolina.*

Principal Findings: *The overall response rate was 42%. Forty-six percent of the responding physicians (N=228) reported that they had seen women for postpartum visits during the past 3 months. Of physicians conducting postpartum visits within this time period, 43% of physicians were almost certain to ask whether the woman felt down, depressed, or hopeless and 27% were almost certain to ask about the woman's interest in her usual activities. Seventy-nine percent of physicians stated that they were unlikely to use a formal screen for depression. Obstetricians/gynecologists were less likely to ask about a woman's social support network (OR=0.33, 95% CI=0.14, 0.75), to ask about her relationship with her partner (OR=0.40, 95% CI=0.18, 0.87), and to use a formal depression screen (OR=0.16, 95% CI=0.04, 0.57) than family practitioners.*

Limitations: *The study only examined physician self-report of the extent to which they communicated about different issues with women during postpartum visits.*

Conclusions: *Communication about depression and related psychosocial issues during postpartum visits is substantially limited, likely contributing to the underdiagnosis of this common disorder.*

Background

The most recent estimates suggest that 13% of women have postpartum depression after delivery.[1] Yet it is only during the routine postpartum visit that occurs approximately 4 to 6 weeks after delivery when postpartum depression can be detected. Women may not readily discuss depression with their providers. Therefore, detection depends on whether the health care provider asks about the woman's emotional and psychological well-being to elicit indicators of postpartum depression. Very little is known about the interaction of providers and patients during postpartum visits, especially with regard to emotional or social support content. In a recent study of obstetrician-patient interactions during the prenatal period, Roter and colleagues[2] noted that most of the communication was predominantly biomedical with little psychosocial or social discussion.

Betsy Lynn Sleath, PhD, is an associate professor in the School of Pharmacy and a research associate at the Cecil G. Sheps Center for Health Services Research at the University of North Carolina at Chapel Hill. She can be reached at Betsy_Sleath@unc.edu or CB 7590, Chapel Hill, NC 27599-7590.

Naveen Thomas, MD, MHP, is a medical officer, specialist scale, at Hutt Hospital in Lower Hutt, New Zealand.

Elizabeth Jackson, PhD, was a research associate at the time this research was conducted at the Cecil G. Sheps Center for Health Services Research at the University of North Carolina at Chapel Hill.

Suzanne L. West, PhD, is a research associate professor and director of research for the Center for Women's Health Research at the Cecil G. Sheps Center for Health Services Research at the University of North Carolina at Chapel Hill.

Bradley N. Gaynes, MD, MPH, is an associate professor in the Department of Psychiatry at the School of Medicine at the University of North Carolina at Chapel Hill.

One of the only studies that assessed general practitioners' beliefs about what should be discussed during postpartum visits was conducted in Australia.[3] Seven hundred and fifteen general practitioners responded (70% response rate) to a survey that asked about physical symptoms such as urination and back problems rather than psychosocial ones. Despite the focus on physical problems, 88% of practitioners believed that the mother's feelings should be discussed during postpartum visits and 49% believed that the woman's relationship with her partner should be discussed. The researchers did not specifically ask whether the providers felt the woman's social support network should be discussed, whether they discussed depression or anhedonia (loss of interest in usual activities), or whether they used a depression screener during postpartum visits.

Previous studies have found that the following psychosocial factors are related to whether women develop postpartum depression: (a) lack of adequate social support,[4-6] (b) being a single parent,[7-9] (c) marital instability,[6,10,11] and (d) stressful life events.[6,8,12,13] If physicians took the time to ask women about these areas and about the women's emotions and feelings during postpartum visits, they could potentially identify and help those women who already have or are at risk of developing postpartum depression.

To our knowledge, no prior study conducted in the United States has examined the extent to which either family practitioners or obstetricians/gynecologists report discussing psychosocial issues with women during postpartum visits. Examining whether there are differences in communication about psychosocial issues during postpartum visits by physician specialty could help target efforts to where they are most needed. Furthermore, examining whether there are differences in communication about psychosocial issues during postpartum visits by physician gender could also help tailor efforts. Gunn et al[3,14] surveyed 1104 Australian general practitioners and found that female general practitioners were 3.7 times more likely to provide postpartum care than male general practitioners. Roter et al[2] examined communication between obstetricians and their patients, and they did not find gender differences in physician discussion of social and emotional adjustment during prenatal visits. However, the researchers did not specifically examine whether depression or other specific psychosocial issues (eg, relationship with partner, social support network) were discussed. The researchers found that only 8.6% of male physicians and 7.3% of female physicians discussed social adjustment, and 3.4% of male and 1.7% of female physicians talked about emotional adjustment.

Therefore, the purpose of the current study was to examine: (1) the extent to which obstetricians/gynecologists and family physicians report discussing depression and other psychosocial issues during postpartum visits and (2) how physician specialty and gender are related to whether physicians report discussing depression and other psychosocial issues with patients during postpartum visits.

Methods

We developed a data collection instrument using information derived from a literature search focusing on surveying physicians about depression or postpartum depression and communication about depression or postpartum depression.[2,3,15,16] The survey was targeted toward determining physician attitudes and experiences in providing postpartum care.[3,15,16] Some questions were modified from other studies and new questions were added. After obtaining IRB approval, the survey was pretested on 7 physicians (3 family practitioners and 4 obstetricians/gynecologists), and their suggestions were used to develop a final version of the survey.

The survey was sent to a random sample of obstetricians/gynecologists and family practitioners licensed in the state of North Carolina. They were identified from the 2002 North Carolina Physicians Database (NCPD) which is maintained by the North Carolina Medical Board. Information for a random sample of 600 obstetricians/gynecologists and 600 family practitioners was obtained from the NCPD, including physician name, address, specialty, practice setting, birth date, date of medical school graduation, and demographic information. A second mailing of the survey was sent to nonresponders approximately 3 weeks after the first mailing was sent. All identifiers were destroyed after the second mailing.

The first question of the survey asked whether the physicians had seen women for postpartum visits during the last 3 months. If physicians answered no, they were asked to stop and return the survey at that point.

Measurement

There were two sources of variables used in this study, the NCPD and the survey. Physician specialty (family practice or obstetrics/gynecology), gender, age, years of experience, and race were obtained from the NCPD. Physician gender and specialty were measured as dichotomous variables. Physician age and years of experience were measured as continuous variables. Physician race was originally measured as a categorical variable (white, Hispanic, African American, American Indian/Alaskan native, Asian/Pacific Islander, other) but was recoded into a dichotomous variable (white, nonwhite) because the majority of physicians were white. As physician age and years in practice were highly related (Pearson correlation coefficient = 0.96, $p<.001$), only physician age was included in the analyses.

The variables that examined physician likelihood of discussing psychosocial and other issues with women during postpartum visits were obtained from the survey. We asked about psychosocial and nonpsychosocial issues so that the physicians would not know that our main focus was communication about psychosocial issues. The physicians were asked on a 4-point Likert scale how likely (unlikely, somewhat likely, very likely, almost certain) they were to discuss 11 different areas with women during postpartum visits. The 11 areas were: (a) breastfeeding, (b) interest in her usual activities (anhedonia), (c) exercise patterns, (d) diet, (e) feeling down, depressed, or hopeless, (f) relationship with her partner, (g) social support network, (h) sleeping patterns, (i) job/work,

(j) using a formal tool to screen for depression, and (k) sexual functioning. Of note, either anhedonia (b) or depressed mood (e) is a required core element of a postpartum depression diagnosis. For analysis purposes, the 11 variables were recoded into dichotomous variables (unlikely or somewhat likely versus very likely or almost certain).

Analysis

Descriptive statistics were calculated for physician characteristics. We compared responding and nonresponding physicians by gender, age, race, and specialty using chi-square or t-tests. We then compared physicians who did see women for postpartum visits during the last 3 months to those who did not by gender, age, race, and specialty using chi-square or t-tests. Our remaining analyses included only those physicians who reported seeing women for postpartum visits during the last 3 months. Descriptive statistics were calculated for physician reports of how likely they were to communicate about certain issues during postpartum visits. Next, the bivariate relationships between the variables were examined using t-tests, chi-square statistics, and Fisher's exact tests. Multivariable logistic regression techniques were run to predict how physician gender, age, race, and specialty influenced whether physicians reported being almost certain or very likely to ask about depression, anhedonia, a woman's social support network, the woman's relationship with her partner, job/work, and sleeping patterns and whether physicians used a formal screening instrument to assess for depression. All analyses were conducted by the first author (Betsy Lynn Sleath).

Results

A total of 1200 physicians were sent surveys with postage-paid return envelopes. Sixteen were returned as undeliverable (2 obstetricians/gynecologists and 14 family practitioners). The response rate for obstetricians/gynecologists was 43% compared to 40% for family practitioners. The overall response rate for both specialties was 42% (N = 491). Responding and nonresponding physicians did not differ significantly by gender, age, or race.

A total of 228 of the 491 (46%) responding physicians reported that they had seen women for postpartum visits during the past 3 months. Female physicians were significantly more likely to report seeing women for postpartum visits during the past 3 months than male physicians (56% versus 42%; Pearson chi-square = 8.55, p = 0.003). Obstetricians/gynecologists were significantly more likely to report seeing women for postpartum visits during the past 3 months than family practitioners (74% versus 16%; Pearson chi-square = 168.56, p < 0.000). Female physicians who responded to our survey were not significantly more likely to be obstetricians/gynecologists than male physicians. Younger physicians were significantly more likely to report seeing women for postpartum visits during the last 3 months than older physicians (t-test = 6.08, p <0.000). Table 1 presents the characteristics of the physicians who reported seeing women for postpartum visits during the past 3 months.

Table 1.
Characteristics of Responding Physicians Who Treated Women for Postpartum Visits During the Past Three Months

	Percentage (N)
Age	
26 - 41	53.9 (123)
42 - 56	40.0 (91)
57 - 71	6.1 (14)
Sex	
Female	37.3 (85)
Male	62.7 (143)
Race	
White	82.9 (189)
Nonwhite	17.1 (39)
Practice type	
Obstetrics	84.2 (192)
Family practice	15.8 (36)
Sample Demographics (N = 228)	

Table 2 illustrates how likely these physicians were to communicate about depression and psychosocial and other issues during postpartum visits. Forty-three percent of physicians were almost certain to ask about the woman feeling down, depressed, or hopeless and 27% were almost certain to ask about the woman's interest in her usual activities. Twenty percent of physicians were almost certain to ask the woman about her relationship with her partner and 16% of physicians were almost certain to ask the woman about her social support network. Seventy-nine percent of physicians stated they were unlikely to use a formal screen for depression.

We found no differences by physician race, gender, age, or specialty in whether physicians were very likely or almost certain to ask versus somewhat likely or unlikely to ask the woman about feeling down, depressed, or hopeless or whether they were to ask about her interest in her usual activities (results not shown).

Table 3 presents the multivariable logistic regression results. Obstetricians/gynecologists (46%) were significantly less likely to be almost certain or very likely to ask about a woman's social support network than family practitioners (75%; OR=0.33, 95% CI=0.14, 0.75). Obstetricians/gynecologists (49%) were significantly less likely to be almost certain or very likely to ask about the woman's relationship with her partner than family practitioners (68%; OR=0.40, 95% CI=0.18, 0.87). Obstetricians/gynecologists (4%) were significantly less likely to be almost certain or very likely to use a formal tool to screen for depression than family practitioners (14%; OR=0.16, 95% CI=0.04, 0.57).

Table 2.
Physician Reports of How Likely They Were to Communicate About Depression and Psychosocial and Other Issues During Postpartum Visits (N=228)[a]

	Unlikely Percent (N)	Somewhat likely Percent (N)	Very likely Percent (N)	Almost certain Percent (N)
Ask the woman about…				
Breastfeeding	0 (0)	2.6 (6)	12.7 (29)	84.2 (192)
Feeling down, depressed, or hopeless	4.4 (10)	20.2 (46)	31.6 (72)	43.4 (99)
Job/work	10.5 (24)	14.5 (33)	35.1 (80)	39.0 (89)
Sleeping patterns	11.8 (27)	23.7 (54)	32.5 (74)	32.0 (73)
Interest in her usual activities	14.5 (33)	30.3 (69)	27.6 (63)	27.2 (62)
Sexual functioning	12.7 (29)	28.9 (66)	34.2 (78)	23.7 (54)
Relationship with her partner	12.7 (29)	36.0 (82)	31.6 (72)	19.7 (45)
Exercise patterns	10.1 (23)	37.3 (85)	32.9 (75)	19.3 (44)
Diet	16.2 (37)	34.6 (79)	31.6 (72)	17.1 (39)
Social support network	18.4 (42)	30.3 (69)	34.6 (79)	15.8 (36)
Use a formal tool to screen for depression	79.4 (181)	14.9 (34)	2.2 (5)	3.1 (7)

aEach row does not add to 228 due to missing data for certain items

Table 3.
Multivariable Logistic Regression Results Predicting Whether Physicians Were Almost Certain or Very Likely to Ask About Social Support, Relationship with Partner, Job/Work, Sleeping Patterns, and Use of a Formal Depression Screen (N=228)

Variable	Social support OR, 95%CI	Partner OR, 95%CI	Job/work OR, 95%CI	Sleep OR, 95%CI	Depression screen OR, 95%CI
Physician age	0.99 (0.95, 1.01)	1.01 (0.98, 1.04)	0.98 (0.95, 1.02)	0.97 (0.94, 1.00)	1.02 (0.95, 1.10)
Physician gender-male	0.57 (0.31, 1.06)	0.84 (0.46, 1.55)	0.38 (0.17, 0.85)*	0.77 (0.40, 1.47)	4.21 (0.78, 22.83)
Specialty-obstetrics/gynecology	0.33 (0.14, 0.75)**	0.40 (0.18, .87)*	0.36 (0.12, 1.13)	1.46 (0.68, 3.13)	0.16 (0.04, 0.57)**
Physician race-nonwhite	0.86 (0.41, 1.81)	0.74 (0.36, 1.51)	0.28 (0.12, 0.62)**	0.38 (0.18, 0.79)**	1.07 (0.20, 5.74)

* p<0.05, ** P<0.01

When examining nonpsychosocial issues, we found that male physicians (68%) were significantly less likely to be almost certain or very likely to ask about a woman's job/work than female physicians (86%; OR=0.38, 95% CI=0.17, 0.85). Nonwhite physicians (59%) were significantly less likely to be almost certain or very likely to ask about a woman's job/work than white physicians (78%; OR=0.28, 95% CI=0.12, 0.62). Nonwhite physicians (49%) were significantly less likely to be almost certain or very likely to ask about a woman's sleep patterns than white physicians (68 %) (OR=0.38; 95% CI=0.18, 0.79).

Discussion

Postpartum depression occurs in more than 1 out of every 10 women who have a baby. It is an important problem that can have effects on both the baby and the mother. One of the key places where postpartum depression can be recognized and diagnosed by a health care professional is during a woman's routine postpartum visit. We found that 43% of physicians stated that they were almost certain to ask about the woman feeling down, depressed, or hopeless and just 27% were almost certain to ask about the woman's interest in her usual activities. These are two of the core symptoms of depression, at least one of which is required for the diagnosis of major depressive disorder. Assessing women for depression is an essential part of postpartum care.

Less than 6% of physicians stated that they were very likely or almost certain to use a formal depression screening instrument during postpartum visits. Physicians might consider using a brief depression screen among women during postpartum visits so that problems are identified early and treatment initiated if appropriate. For example, the 9-item Patient Health Questionnaire is an easy to use depression screening instrument that has been successfully used in primary care and obstetrical settings; the Edinburgh postnatal depression scale[17,18] is another option.

In addition to screening for depression, it is also important that women who screen positive for depression have access to appropriate systems to receive treatment. This may include practices referring women to mental health professionals in their area if they do not have a mental health specialist as part of their practice. Future research should examine the extent to which practices have systems in place to treat women with postpartum depression.

Physician demographics were not significantly related to whether physicians reported being very likely to almost certain to ask about depression or anhedonia. However, there were some interesting differences by specialty. Family practitioners were more likely than obstetricians/ gynecologists to report asking women about social support and their relationships with their partners and they were more likely to report using a depression screener. Perhaps this is due to differences in educational training or differences in the amount of time spent with patients. Future work should explore why there might be differences between family practitioners and obstetricians/gynecologists in discussing psychosocial issues.

The study was limited in that we only examined physician self-report of the extent to which they communicated about different issues with women during postpartum visits. Future research should compare physician self-reported communication to actual care, as documented through audio tapes or other research methods. The study was also limited in that only 42% of physicians responded and responding physicians might have been more interested in these issues. Another limitation is that social desirability bias may have led to overestimates of physician self-report practices.

Despite the limitations, the study provided new information on the extent to which physicians report discussing different psychosocial issues with women during postpartum visits. Postpartum visits are one of the key places where postpartum depression can be recognized and treated. Providers should consider asking all patients at their postpartum visits about depression, anhedonia (loss of interest in usual activities), and risk factors for postpartum depression (social support, relationship with partner). Providers should also consider using a brief depression screen during postpartum visits so that problems are identified early and treatment is initiated if appropriate. **NCMJ**

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POLICY FORUM

North Carolina's Primary Care and Specialty Workforce

> *"By 2030, under almost any realistic scenario, North Carolina is likely to experience significant practitioner shortages absent any changes in supply or productivity."*

INTRODUCTION

Policy Forum:
Primary Care and Specialty Supply in North Carolina

Many of us have had the experience of wanting to see a doctor or a primary care practitioner as soon as possible but are told we have to wait for an appointment. Sometimes that wait is many days, even weeks. The ability to see a health care practitioner "on demand" is as much a function of their local availability as it is a problem with the overall supply of practitioners in the state. For individuals seeking care of a certain type or in a certain geographic region of the state, getting to see the doctor or any health care professional for a nonurgent problem can be even more difficult. These delays can have consequences for an individual's health.

North Carolina, along with the rest of the nation, is beginning to experience a situation where the availability of practitioners is becoming tighter. Some parts of the state have had a chronic undersupply of physicians and other primary care professionals, and there is evidence that we will soon experience regional shortages for some specialists. The good news is that North Carolina, as a whole, currently has what most would consider a sufficient number of practitioners on a population basis. However, there are a few exceptions, specifically in the areas of child psychiatry and in some rural and low-income communities. These conditions exist in places not too distant from cities with some of the highest concentrations of physicians in the entire nation.

What has become apparent, given the lack of any appreciable growth in the number of doctors trained in the United States, is the fact that we will not be bringing in as many physicians as we have in the past. This pattern is especially problematic because our population continues to grow, age, and face a higher incidence of chronic disease. North Carolina is one of the fastest growing states in the nation. However, the supply of practitioners is not expected to increase at the same rate. We also expect that demand for services will grow very quickly as the baby-boom generation reaches the age when need for care rises rapidly. The physician population also is aging, and many practitioners will be preparing to retire in the next two decades.

In response to these trends that have emerged over the past 3 years, a group of North Carolina health policy experts, government officials, health care providers, and businesses formed a task force to evaluate strategies for ensuring the state's ability to meet our health care needs under these conditions. The nature of the problem itself presents a challenge. Practitioners are working more efficiently and they can be even more efficient with the advent of new technology and the expansion and sharing of roles and skills within and across disciplines and professions. Thus, the issue may not be one of simply supply and demand or need for practitioners, but of organization and policy. This issue of the *North Carolina Medical Journal* highlights the perspectives of a number of individuals who participated in the North Carolina Institute of Medicine's Task Force on Primary Care and Specialty Supply.

The commentaries in this issue highlight a range of opportunities for improving future access to care. Some of the strategies include increasing the supply of underrepresented minority practitioners, expanding clinical rotation and residency opportunities for medical and health professional students, developing new models of care, and targeting funding to programs that support putting practitioners in underserved areas of the state or in shortage specialties.

We hope these commentaries illuminate the primary care and specialty supply challenges facing North Carolina and present tangible strategies for improvement. Clearly, no single strategy will sufficiently address our future concerns. However, if we implement a number of different strategies and take action now, we have the opportunity to make a difference in reducing future shortages. We should encourage our policy makers to heed the warning signals and support policy changes that could greatly benefit the future health of North Carolinians.

Thomas C. Ricketts III, PhD, MPH
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ISSUE BRIEF

Weathering the Practitioner Workforce Shortage

Pam Silberman, JD, DrPH; E. Harvey Estes Jr., MD; Kristen L. Dubay, MPP; Mark Holmes, PhD

Publisher's note: The print version of this article inadvertently omitted reference to the central role the Kate B. Reynolds Charitable Trust played in the formation and deliberation of the North Carolina Institute of Medicine Task Force on Primary Care and Specialty Supply. This oversight is corrected within the text.

Growth in the overall population, and particularly growth among older adult populations, will have significant implications for North Carolina's health care system. The state's population is expected to grow by 39% over the next 25 years (July 2005-2029). The population of older adults age 65 or older is expected to grow more quickly, by 107% during the same time period, and the cohort of adults age 75 or older will grow by 100%.[1] On average, people make approximately 3 visits per year to a physician's office or clinic. However, visit rates vary by age: in 2003, 25-34 year olds made 2.3 annual visits to a physician's office or clinic, whereas 65-74 year olds made 6.2 visits and 75-84 year olds made 7.3 visits.[2] In addition to rapid growth among older adult populations, North Carolina is experiencing growth in the number of people with chronic illnesses.[a,3] These 3 factors—growth of the overall population, aging of the population, and increased prevalence of chronic illnesses—will create increased demand on the health care system. Within 25 years, the confluence of these factors will create a perfect storm of health care need. Absent any meaningful change in production or retention, the supply of health care practitioners will not grow sufficiently to meet this need.

Physicians, physician assistants (PAs), nurse practitioners (NPs), and certified nurse midwives (CNMs) comprise the health care workforce needed to diagnose and treat individual patients. Having access to these practitioners contributes to the overall well-being of our population. While the exact relationship of overall practitioner supply to population health measures is disputed,[4] specific contributions of physicians, PAs, NPs, and CNMs to individual health is not in doubt. The consequences of not being able to see health care practitioners when needed are clear.

> *"These 3 factors—growth of the overall population, aging of the population, and increased prevalence of chronic illnesses—will create increased demand on the health care system."*

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[a] Between 1987 and 2002, there was a significant increase in the treated disease prevalence of certain chronic diseases such as cerebrovascular diseases (161% increase); kidney problems (99% increase); pulmonary conditions (90% increase); diabetes (64% increase); the presence of abnormal or elevated lipids (fatty molecules) in the blood (437% increase) with cholesterol being most common; and certain back problems (78%).

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Studies have shown people with less access to medical care live shorter lives, with more disability and lower productivity.[5]

No one currently knows the optimal number of or type of practitioners needed to optimize population health. Yet, by most measures, North Carolina has neither too many nor too few physicians. North Carolina had 20.7 physicians to every 10 000 people in 2005, which is slightly less than the national average. If nothing is done to change the supply of practitioners in North Carolina, the ratio of physicians-to-population is expected to decline by 8% by 2020 and by 21% by 2030. The ratio of all practitioners-to-population, including PAs, NPs, and CNMs, is expected to drop between 2% and 13% by 2030.

The practitioner workforce shortage is not only a problem North Carolina will face in the future; practitioner shortages currently exist in many areas of the state. Many counties have experienced a decline over the last 5 years in primary care practitioners, psychiatrists, general surgeons, and practitioners delivering babies. In addition, the state has far fewer minorities in these health professions than their representation in the population.

The Kate B. Reynolds Charitable Trust recognized these issues and asked The North Carolina Institute of Medicine (NC IOM) to convene the Task Force on Primary Care and Specialty Supply to analyze current and projected trends in practitioner supply and to examine whether the existing production of physicians, PAs, NPs, and CNMs would address the state's growing health care needs. In addition to providing the impetus for the task force, the Kate B. Reynolds Charitable Trust graciously funded the work and offered its years of experience increasing practitioner supply in underserved areas of the state to guide and inform the task force. The task force was a collaborative effort with the North Carolina Area Health Education Centers Program (AHEC), the Southeast Regional Workforce Center, and the North Carolina Health Professions Data System in the Cecil G. Sheps Center for Health Services Research at the University of North Carolina at Chapel Hill (UNC-CH). The task force met for more than a year, and its work culminated in a one-day summit to obtain feedback from a larger group of practitioners, leaders of academic health centers and health professional schools, and community leaders. This issue brief summarizes the findings of the task force along with its priority recommendations. The paper is organized into 4 sections: overview of future supply, areas of the state experiencing persistent shortages, trends in practitioner supply by practitioner specialty (including primary care), and underrepresentation of minorities in health professions.

Overall Supply

For most of the last 20 years, North Carolina experienced a steady increase in the ratio of practitioners-to-population because the number of licensed practitioners grew faster than the population. However, the rate of growth has slowed over the last 5 years. The physician-to-population ratio increased by approximately 2.1% annually between 1985 and 2000 but has slowed to a 0.9% growth rate since 2000.

The physician workforce is aging. A sizable portion of physicians are likely to retire in the next 25 years, and older physicians who do not retire tend to work fewer hours in direct patient care. A significant proportion of nurse practitioners and, to a lesser extent, physician assistants also will reach retirement age within the next 25 years. Absent significant increases in production, in-migration, or retention of practitioners in North Carolina, the supply of practitioners is unlikely to keep up with growing demand. Assuming current growth trends, the number of primary care and specialty practitioners is expected to grow between 23% and 39% between 2005 and 2030 while the population is expected to grow 42% during this same time period. The aging of the population and increased number of people with chronic illnesses will lead to the growing demand for health services beyond that due to population growth.

It is impossible to fully predict the demand for and supply of practitioner services 25 years into the future. There are a number of different factors that must be considered in projecting practitioner supply and increased demand for health services. Some of these factors include the anticipated growth in supply of new physicians, PAs, NPs, and CNMs; anticipated exodus of practitioners from the profession (due to death, retirement, moving out of state, or other factors); growth in the overall state population; aging of the population (which affects demand for services); and overall prevalence of chronic illness. The combined effect of 3 of the primary drivers of demand—growth of the overall population, aging of the population, and increased prevalence of chronic illnesses—is expected to increase demand for services in North Carolina (measured in annual visits) considerably. The first two factors alone will lead to a 52% increase in annual visits between 2005 and 2030. The increasing prevalence of chronic disease may add an additional increase of 5%.

The NC IOM Task Force on Primary Care and Specialty Supply developed different workforce projections based on different assumptions, including a "best case" and "worst case" scenario. (See Table 1.) The "best case" scenarios are based on

Table 1.
Projected Change in Practitioner-to-Population Ratios, North Carolina, 2020 and 2030

	Projected Change in Practitioner-to-Population Ratios		Projected Change in Practitioner-to-Adjusted Population Ratios	
	2020	2030	2020	2030
Physicians only	-8%	-21%	-12%	-26%
All practitioners				
Best case	4%	-2%	-1%	-8%
Worst case	-4%	-13%	-8%	-19%

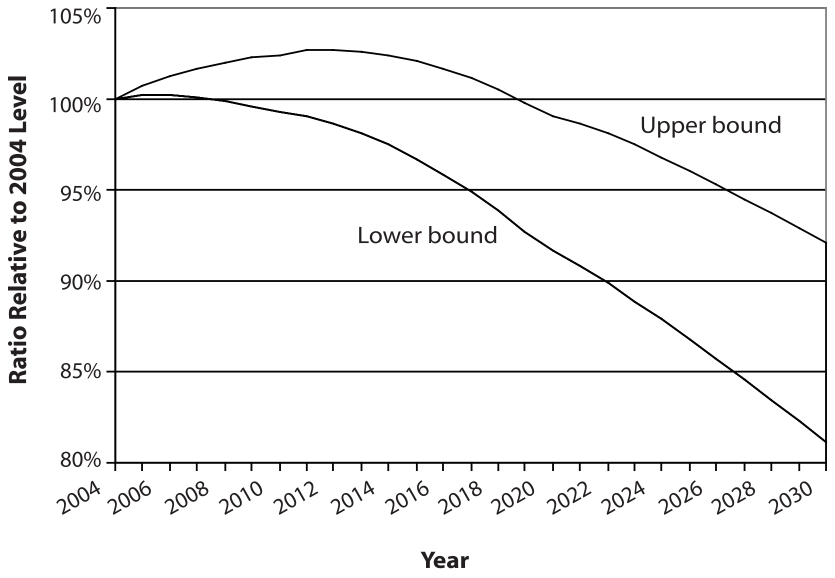
Source: NC Institute of Medicine and the North Carolina Health Professions Data System.

current growth of physicians and the higher than average rate of growth of PAs, NPs, and CNMs experienced in the last 5 years. These projections weigh PAs, NPs, and CNMs at 0.75 full-time equivalent (FTE) of a physician.[6] The "worst case" scenarios are based on current growth of physicians and average rate of growth of PAs, NPs, and CNMs averaged over the last 25 years. These projections weigh PAs, NPs, and CNMs at 0.50 FTE of a physician (as used by federal workforce projections). In addition, there are separate estimates for practitioner-to-population only and practitioner-to-adjusted population (based on increased demand due to aging of the population). These projections do not factor in growth in the number of people with chronic illnesses because current projections for disease prevalence and its effect on ambulatory services are too tenuous. By 2030, under almost any realistic scenario, North Carolina is likely to experience significant practitioner shortages absent any changes in supply or productivity.

Chart 1 presents the best and worst case projections for the age-adjusted populations between 2005 and 2030. The supply of practitioners-to-population is expected to increase until 2015, at which time North Carolina will see a precipitous drop in the overall supply of practitioners.

There are two fundamentally different approaches the state can take to address future practitioner shortages: (1) restructure the health care delivery and finance system to create new and more efficient systems of care (particularly for people with chronic illnesses) or (2) increase practitioner supply.

Chart 1.
Range of Projected Practitioner-to-Population Ratios, North Carolina, 2005-2030



Note: Lines represent upper and lower bounds of reasonable estimates of practitioner supply per North Carolinian, relative to 2004 levels.

Source: NC Institute of Medicine and the North Carolina Health Professions Data System.

The state should explore ways to restructure the health care delivery and financing systems to increase quality and efficiency so that practitioners, practices, and health care systems can appropriately manage a higher caseload. Theoretically, this goal could be accomplished through expanded use of PAs, NPs, and CNMs or interdisciplinary teams of practitioners. Lloyd Michener discusses these new models of care in his commentary of this journal issue. Another trend which may increase the number of patients that practitioners can see in an ambulatory setting is use of hospitalists. Hospitalists free up community practitioners' time by assuming care of patients once they are admitted to hospitals. While these options are conceptually attractive, few large-scale system redesigns have led to major increases in productivity. Yet these models are worth further study. **Thus, one of the task force's priority recommendations was that North Carolina foundations fund and evaluate new models of care to improve quality and efficiency of existing practices. If effective, insurers and other payors should reimburse practitioners to support these models.**

Absent new models of care or improvements in the underlying health status of the state's population, North Carolina is likely to need a significant increase in the number of practitioners practicing in the state. The state must either increase the number of practitioners entering practice, decrease attrition, or both. (See Figure 1.) There are short-term and long-term strategies to address the practitioner shortage. Over the short term, the state can try to recruit more practitioners from other states to practice in North Carolina. However, as Tom Ricketts describes in his commentary, most other states also will be experiencing a physician shortage.[b,7] As a result, there will be increased competition in recruiting the limited number of physicians.

Over the long term, there is a need to educate and train more physicians by increasing undergraduate medical education and residency positions.[c,8] **The task force recommended that North Carolina increase the number of physicians trained in North**

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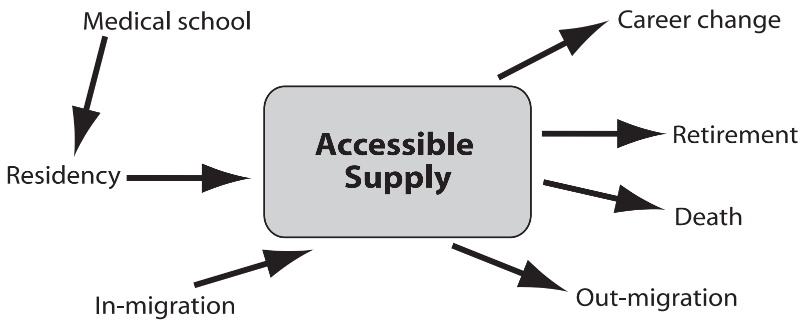
[b] The following states have issued reports highlighting physician workforce shortages: Texas (2002), California (2004), Mississippi (2004), Wisconsin (2004), Arizona (2005), Georgia (2005), Kentucky (2005), Massachusetts (2005), Michigan (2005), and Oregon (2005).

[c] The Association of American Medical Colleges recently recommended US medical schools increase the number of undergraduate medical students they enroll by 30% in order to meet the need for physicians in the future.

Figure 1.
Factors in Physician Supply



Carolina medical schools either by increasing enrollment on existing campuses, by creating a satellite campus, or by creating a new medical school. James McDeavitt and Kara King discuss the potential to expand the medical school class of UNC-CH through a satellite campus at Carolinas Health Care System in Charlotte, while Gary Bowers, Teck Penland, and Joseph Damore discuss the potential for creating a medical school expansion in Western North Carolina. Nevertheless, it is not sufficient to train new physicians if these physicians ultimately choose to practice in another state. Over the last 40 years, only 40% of students trained in North Carolina medical schools ended up practicing in-state.[9] Those who complete their training in a publicly-funded medical school with a mission to serve the state are more likely to practice in-state. (See Table 2.)

The task force also recommended that North Carolina medical schools expand enrollment and the priority recommendation suggested that state funding be targeted to medical schools that produce North Carolina physicians that fill the unmet health needs of the state's population. The task force also recommended the state expand the number of residency positions. Almost half (49%) of physicians who completed their residency in North Carolina over the last 40 years set up practice in-state. This percentage is even higher among residents who completed their residency at AHEC family practice programs: more than two thirds (67%) of these physicians remained in-state. Unfortunately, the federal government has frozen funding for new residency positions so any expansion would need to be supported with state funds. **The task force recommended that the General Assembly appropriate money to support 100 new residency positions across the state targeted toward the high priority specialty areas of primary care, general surgery, psychiatry, and other types of specialties experiencing shortages as well as to support programs designed to graduate physicians likely to settle in rural or other underserved areas of the state.**

North Carolina also needs to train more PAs, NPs, and CNMs to meet the state's health care needs. Justine Strand, Nancy Short, and Elizabeth Korb discuss the important role of PAs, NPs, and CNMs in meeting the health care needs of the state's population. Expanding the number of PAs, NPs, and CNMs is a less expensive option and yields more immediate results than increasing the number of physicians. Unlike medical schools, which typically require 4 years of training and 3-year, postgraduate residency programs, NPs, PAs, and CNMs can complete their education and training within 2 to 3 years after completing their undergraduate degrees. In North Carolina, the PA, NP, and CNM schools collectively graduate approximately the same number of practitioners as do the medical schools. **Along with increasing medical school enrollment, the task force recommended that North Carolina health professional schools increase enrollment of PAs, NPs, and CNMs, but that state funding be tied to those schools that produce practitioners who meet the health care needs of the state.**

Table 2
North Carolina Medical School Enrollment and Graduates Practicing in the State

	2004-2005 Academic Year			
School	Total Enrollment	New Entering Students	% New Students In-State	% Graduates Practicing in NC*
Brody School of Medicine, East Carolina University	290	72	100%	59%
Duke University School of Medicine	467	101	20%	24%
University of North Carolina School of Medicine	649	160	85%	49%
Wake Forest University School of Medicine	427	108	40%	39%

Source: American Medical Association. Medical schools in the United States. *JAMA*. Medical Education Issue. September 7, 2005;294(9):1119-1127; NC Health Professions Data System. September 2006.

There are many challenges to creating new schools or expanding existing schools including the costs of expansion, limited classroom space or lab space in existing schools, and limited faculty (depending on the type of program). Lack of clinical training sites is a challenge for existing programs and would be exacerbated if new programs were created or existing programs expanded. As Tom Bacon discusses in his commentary, there are challenges to creating new clinical training sites.

Further, clinical training sites often impact where health professional students choose to practice. Thus, there have been attempts to move clinical rotations out of academic health centers and hospitals and into communities, particularly underserved communities, in an effort to enhance clinical training and to encourage practitioners to set up practice in those locations. **The task force recommended that the General Assembly provide additional funding to the North Carolina Area Health Education Centers Program to support the development of additional clinical training sites necessary for the training of additional health professional students.**

The task force also recommended other options to increase overall practitioner supply including expanded marketing efforts to recruit out-of-state practitioners to North Carolina, maintaining and/or improving the practice environment for health care practitioners, and expanding the supply of trained practice managers to help physicians and other health professionals maintain financially viable practices. To continue examinations of impending practitioner shortages and develop workable strategies to expand the health professional workforce, **the task force recommended that the General Assembly appropriate funding to support and expand the current Health Professions Data System, housed within the Cecil G. Sheps Center for Health Services Research at the University of North Carolina at Chapel Hill, and create an ongoing Health Workforce Policy Board.**

Maldistribution

North Carolina's practitioner-to-population ratio is similar to the rest of the country; the ratio of physicians per 10 000 population in North Carolina reached 20.7 in 2005. This ratio is lower than the US average of 22.77 per 10 000 but is consistent with ratios for states that border North Carolina.[10] However, this statewide average masks some stark differences in practitioner supply. Some areas of North Carolina have an abundance of health professionals while others lack sufficient practitioners, forcing individuals to travel long distances for health care. Shortages typically exist in rural areas, but there also are pockets of low practitioner supply in low-income areas of larger cities.

The Bureau of Health Professions in the US Department of Health and Human Services has designated certain communities, population groups, or medical facilities as health professional shortage areas (HPSAs).[11] Certain counties, or parts thereof, are considered primary care HPSAs if they have more than 3500 people per primary care practitioner.[d] In 2005, 11 whole counties and parts of 40 additional counties in North Carolina were designated as HPSAs.

Some counties change their HPSA designation from one year to the next depending on growth in the population and whether the county gained or lost a physician. However, other counties are persistently considered HPSAs. The task force focused on areas of the state designated as HPSAs in 6 of the last 7 years or as "persistent health professional shortage areas" (PHPSAs). Eleven counties in North Carolina are considered whole-county PHPSAs and 27 counties are part-county or special population PHPSAs. (See Map 1.) In the last 5 years, more than half (55%) of the 38 PHPSAs experienced a decline in their primary care practitioner-to-population ratios. Whole-county PHPSAs are more likely to be rural and to be located in eastern North Carolina than non-PHPSAs and have a higher percent of the population living below the poverty line (15.2% for whole, 10.4% for non-PHPSAs).[12]

Populations with lower physician supply may be less able to address their health care needs in a timely manner. Not only does lack of practitioners have an impact on access to health services, it also can have an adverse impact on the economic health of a community. In his commentary, Aaron McKethan discusses the importance of having a stable health professional workforce when recruiting industries into rural areas. The current and future health professional shortage has implications that go beyond the specific health care needs of individuals.

Historically, North Carolina's Office of Rural Health was considered a national leader in recruiting physicians and other practitioners into rural areas.[13] Torlen Wade, director of the North Carolina Office of Rural Health and Community Care (ORHCC), Maggie Sauer, director of the North Carolina Community Practitioner Program, and Christine Kushner discuss the state's past experience recruiting practitioners into rural and medically underserved areas of the state. North Carolina made significant headway in addressing practitioner maldistribution problems in the 1980s and 1990s; however, improvements have stagnated, and now maldistribution problems appear to be getting worse.

Practitioners choose their location of practice based on a number of factors including economic potential, lifestyle, family preference, and training location. Provider practices must be financially sustainable, which is a challenge in rural areas that lack population density and in low-income communities where a higher proportion of people lack health insurance. Financial incentives and practice support (eg, information technologies) will increase the financial viability of practices treating historically underserved areas and populations. **To address these maldistribution problems, the task force recommended that the General Assembly appropriate additional funding to ORHCC to recruit practitioners and provide them with loan repayment or other financial**

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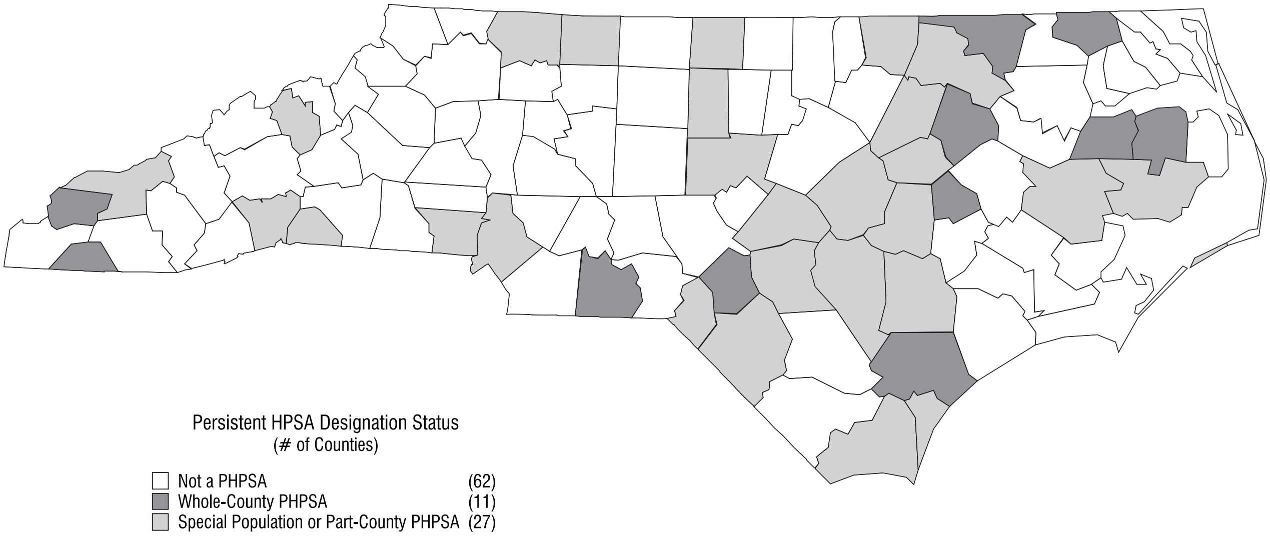
[d] Areas that are designated as HPSAs must define and justify a rational service area for the delivery of health services (often a county), have a sufficiently low practitioner-to-population ratio, and show evidence that nearby resources are overutilized, too distant, or otherwise inaccessible. For primary care professionals, areas with more than 3500 people per primary care provider can qualify as HPSAs, although the standard is lower for certain "high need" areas. An area is designated as "high need" if the area has more than 100 births per year per 1000 women aged 15-44, has more than 20 infant deaths per 1000 live births, or has more than 20% of the population (or of all households) with incomes below the poverty level.

Map 1
Persistent Health Professional Shortage Areas* (PHPSAs) in North Carolina, 2005



Source: Area Resource File, HRSA, DHHS, 2005; Bureau of Health Professions, Shortage Designation Branch, 2005.

Persistent HPSAs are those designated as HPSA by the Health Resources and Services Administration (HRSA) from 1999 to 2005 or in 6 of the last 7 releases of HPSA definition.

incentives to encourage them to establish practice in underserved areas of the state. In addition, the task force recommended that North Carolina foundations fund regional, multi-county demonstrations to test new models of care to serve patients in rural and urban underserved areas.

Primary Care and Specialty Shortages

Examining overall supply of physicians, PAs, NPs, and CNMs can mask shortages in particular specialty areas and overlook the importance of having an appropriate mix of practitioners. The task force was unable to examine every medical specialty. Instead, the task force focused on the supply of primary care practitioners, practitioners who deliver babies, general surgeons, and psychiatrists. As Erin Fraher, director of the North Carolina Health Professions Data System, discusses in her commentary, North Carolina currently has an adequate supply of most practitioner types when compared to national or regional averages. However, practitioner types are not well distributed throughout the state, and North Carolina is likely to experience severe shortages among many of these practitioner types in the future.

Primary care: Primary care practitioners (PCPs) serve as the entry point into the health care system for most patients.[e] They provide preventive, primary, and acute medical services that can address most of a person's health care needs.[14] Recent evidence suggests fewer practitioners, including allopathic trained physicians, PAs, and NPs, are going into primary care than in the past. For example, between 1997 and 2005, the number of medical student graduates choosing primary care residencies dropped 50%.[15] Instead, students are moving into specialty areas. PAs and NPs also are less likely to practice primary care today than 4 years ago.[16] As noted in the maldistribution section, primary care practitioners are not well distributed throughout the state.

One reason for declining interest in primary care is that primary care practitioners experience increased demands with lower overall reimbursement. The number of and need for recommended preventive and chronic care treatment services has increased to the point that it is impossible for physicians to provide all recommended care to their patient mix in a regular workday.[15] Although the scope of care has increased, primary care practitioner reimbursement has decreased in inflation-adjusted dollars. Between 1995 and 2003, inflation-adjusted salaries decreased 7.1% for all physicians but 10.2% for primary care physicians.[17] Primary care practitioners are paid less for their services than are specialists. Insurers generally pay more for procedures and less for cognitive and diagnostic skills, which make up a greater proportion of the clinical work of primary care practitioners. (See Chart 2.)

Primary care is very important for preventing disease, increasing quality of care, and reducing costs. Barbara Starfield and Leiyu Shi discuss the influence of primary care practitioner supply on community health. Evidence indicates that unnecessary hospitalization rates are higher in communities with limited

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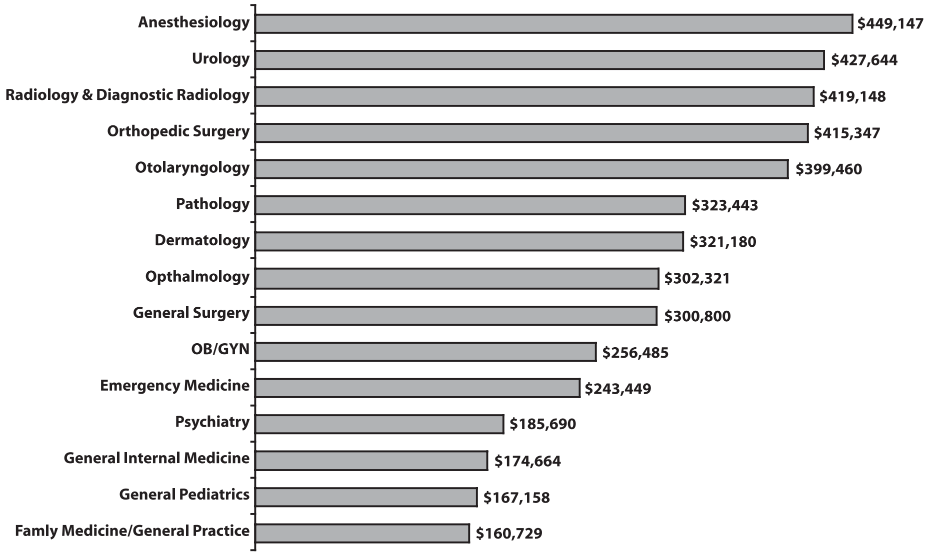
[e] PCPs include PAs, NPs, CNMs, and doctors both of allopathic medicine (MD) and osteopathic medicine (DOs) who are family practitioners, general practitioners, internists, pediatricians, or obstetrician/gynecologists.

Chart 2.
Median Physician Salary by Specialty, 2006



Source: Cohen J. Presented at: North Carolina Institute of Medicine Primary Care and Specialty Summit; December 21, 2006; Raleigh, NC. Citing MGMA Physician Compensation and Production Survey 2001-2006

access to primary care practitioners. Studies also show quality of care is higher and expenditures are lower in states with higher generalist-to-population ratios compared to those with higher specialist-to-population ratios.[15] **To encourage more practitioners to become primary care practitioners, the task force recommended that public and private insurers enhance payments to primary care practitioners to recognize the value of their diagnostic and cognitive skills. Specifically, primary care practitioners should be provided financial incentives to create a primary care home where patients can obtain preventive health services, chronic disease management, and case management.**

Practitioners who deliver babies: Ensuring women have continuous and early prenatal care is critical to the well-being of the infant and mother. Women need access to physicians and other clinicians who are trained to deliver babies and who can address any complications that might arise during delivery. North Carolina appears to have an adequate number of practitioners who offer prenatal care and delivery statewide, but the statewide average masks significant practitioner shortages in certain parts of the state. Currently 13 counties in the state have no physicians reporting a practice location that provides prenatal care services. Eight of these counties have no practitioners (physician, PA, NP, or CNM) who report providing prenatal care on their licensure files. Community members in these counties have access to some prenatal care through their local health departments, but delivery services are not available in these counties. Even in counties with prenatal practitioners, there is wide variation in the ratio of practitioners to women of childbearing age.

There is even more of a maldistribution problem of physicians who deliver babies. In 2004, there were 19 counties without physicians who reported delivering babies; 12 of these counties had not had a physician deliver a baby in the prior 5 years. More than one half of all North Carolina counties had either a decline in the ratio of physicians delivering babies to women of childbearing years between 2000 and 2004 (40 counties) or no physicians providing deliveries in either 2000 and 2004 (12 counties). **To address the shortage of practitioners delivering babies in underserved areas, the task force recommended that the General Assembly appropriate funding to help subsidize the malpractice premiums for physicians and CNMs who provide delivery services in medically underserved areas of the state.**

General surgeons: North Carolina currently has more general surgeons per 10 000 population (0.75) than the nation as a whole (0.60) or the south (0.64). However, trends indicate fewer medical graduates are choosing to practice in general surgery. For most entering surgeons, progressive specialization is narrowing their scope of practice. In addition, supply of general surgeons varies drastically across the state. In 2005, North Carolina had 22 counties with no surgeons while another 35 counties had below the state average of 0.62 general surgeons to 10 000 population. The majority of the counties with no surgeons or fewer than 0.62 surgeons per 10 000 population are found in the eastern and western parts of the state. As Larry Chewning and Jeff Spade discuss in their commentary, general surgeons are critical to the viability of small rural hospitals. **The task force recommended that medical schools be incentivized to produce the type of physicians (eg, physicians who deliver babies, general surgeons) needed to meet the state's health care needs. In addition, special consideration should be given to funding a track in an existing residency program that focuses on training general surgeons for rural practice. The task force also recommended that some of the funding to the ORHCC be used to provide incentives to general surgeons who practice in underserved areas.**

Psychiatrists: Nationally, almost one third of nonelderly adults and a sizeable number of children experience a mental disorder in any given year.[18] Many types of health professionals treat mental health disorders including, but not limited to, psychiatrists, psychologists, primary care practitioners, social workers, and clinical nurse specialists. While these practitioners are all trained to provide psychotherapy, some people need further consultations and treatment by psychiatrists or other physicians who can prescribe medication therapy. Aside from primary care practitioners, psychiatrists are among the lowest paid of physician specialties (Chart 2) which may discourage some physicians from choosing to specialize in this field.

As with other types of health care professionals, the statewide ratio of psychiatrists-to-population masks severe maldistribution problems. In 2004, there were 17 counties with no psychiatrists and another 27 counties with ratios low enough (0.33 or below) to be designated as mental health HPSAs.[19] Psychiatrists are most densely located close to the state's 4 mental health hospitals, in counties with major medical centers, and in large metropolitan areas. In general, psychiatrists are less likely than all other physicians to locate in rural areas or in HPSAs.

North Carolina's mental health reform has also impacted the provision of care to mental health patients in the public sector. Mental health services in North Carolina are coordinated by local management entities (LMEs). Between 2003 and 2005, the number of LME psychiatrists per capita fell 16%. Per capita losses were higher in rural areas (20%) compared to urban areas (14%). Small-population LMEs experienced an even larger decrease (44%) in the number of psychiatrists per capita.[20] In the absence of psychiatrists, primary care practitioners often are faced with the responsibility of diagnosing and managing the care of people with mental illness. However, 7 of the 17 counties with no psychiatrists are also whole-county primary care HPSAs.

To address the shortage of psychiatrists, the task force recommended that the General Assembly and North Carolina Division of Mental Health, Developmental Disabilities and Substance Abuse Services provide funding to establish new models of care to serve public patients in rural and underserved areas. In addition, public and private insurers should reimburse psychiatrists to consult with primary care practitioners and other clinicians through face-to-face consultations or telemedicine. John Frank, Director of the Kate B. Reynolds Charitable Trust, discusses one such model, ICare, in the Philanthropy Profile of this journal issue.

Underrepresentation of Minorities in Health Professions

Minority populations comprise 30% of North Carolina's population, but they account for only 15% of physicians, 12% of PAs, and 10% of NPs in the state.[21] African Americans, American Indians, and Hispanics are particularly underrepresented in health professions. (See Chart 3.)

When given the option, people are more likely to choose a practitioner that has a similar racial and ethnic background.[22] Concordance of practitioner and patient race or ethnicity might be particularly important for members of minority populations who, because of real and perceived past discriminatory treatment, have lower levels of trust in practitioners of other racial groups.[23]

Underrepresented minority practitioners also are more likely to practice in underserved areas than are white practitioners.[f] Similarly, health care practitioners from underrepresented minority ethnic and racial groups are more likely to serve patients of their own ethnicity or race and patients with poor health.[24,25,26] This practice is very important because African Americans, American Indians, and Hispanics are more likely to lack health insurance, suffer from certain chronic health conditions, and report access barriers to health care.[27]

In order to increase the supply of underrepresented minorities in the professions, the task force recommended that North Carolina medical and health professional schools develop new strategies to increase the number of racial and ethnic minorities admitted and trained in North Carolina. For example, the state could expand minority scholarship programs or develop new or satellite health professional schools in historically minority public or private colleges or universities. Schools could modify their admission policies to facilitate the enrollment of minority applicants or hire faculty and chairs who are members of underrepresented minorities in order to reduce the professional isolation of minority health professional students. **The task force also recommended that the state evaluate existing minority health professional pipeline programs and tie future state funding to the programs that are most effective in increasing underrepresented minorities in the health professions.**

More bilingual and bicultural practitioners are needed to reduce language and cultural barriers to health care services. In North Carolina, there are approximately 150 000 Spanish-speaking residents who do not speak English well or do not speak English at all.[28] Studies show people with limited English proficiency are more likely to report being in fair or poor health and are more likely to defer needed medical care, miss follow-up appointments, and experience drug complications.[29,30] Bilingual and bicultural practitioners can help address language and cultural barriers for the growing Latino and immigrant populations. **The task force recommended that medical and health professional schools recruit and admit more bilingual and bicultural students into their programs and encourage others to take Spanish medical language courses as part of their training.**

Conclusion

Access to health care practitioners including physicians, PAs, NPs, and CNMs is very important to the health of individuals and populations. However, North Carolina is likely to face challenges meeting the population's demands for care over the next 25 years. Although the potential shortfall is considerable, the state has a number of policies that could be used to reduce

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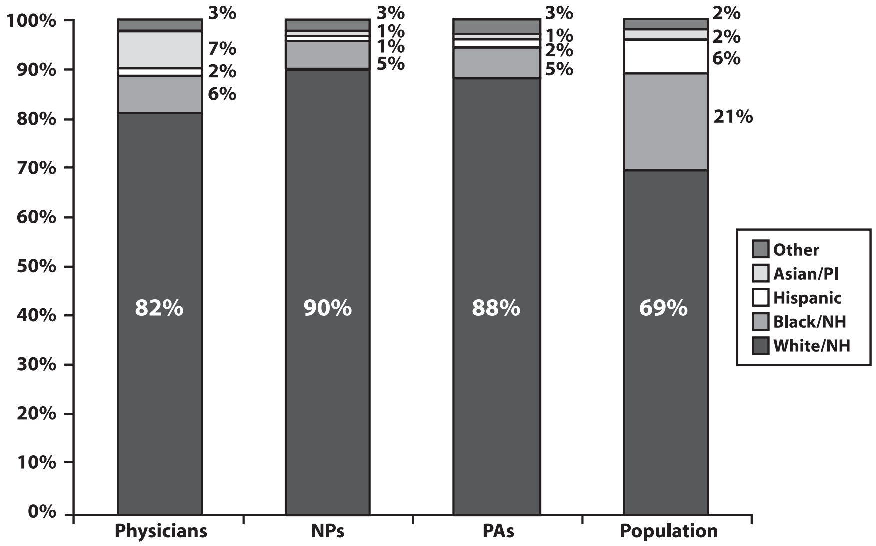
[f] Underrepresented minority practitioners are 3 times more likely than white practitioners to serve in whole-county PHPSAs (12% for minority practitioners compared to 4% for white practitioners) and are more likely to serve in part-county PHSPAs (42% for minorities and 34% for whites).

Chart 3.
Race of Population and Practitioners, North Carolina, 2004



Source: NC Health Professions Data System and US Census.

this deficit. The state should identify options to improve the quality and productivity of existing practices so that health professionals can provide high-quality health services to more North Carolinians. The state should concurrently examine options to develop new models of care that would reduce the need for health care practitioners and/or expand the supply of physicians, PAs, NPs, and CNMs. North Carolina needs to engage in multiple strategies, simultaneously, to increase the balance of supply with needs. If new medical school slots are created without new residency slots, then in-state retention of the expanded number of medical school graduates will not be realized because many will need to leave the state for residency and are not likely to return. Similarly, initiatives to increase awareness of health careers among rural and minority middle and high school students will have little impact without also expanding available enrichment programs to help students overcome the hurdles to being accepted into medical school. North Carolina also should explore ways to recruit physicians and other practitioners into North Carolina and to encourage existing practitioners to remain in practice in North Carolina. In short, many of the policy options are interdependent. Success requires adoption of many complementary strategies.

North Carolina need not implement all the practitioner supply strategies in order to maintain the current practitioner-to-population ratio. For example, the state does not need to increase the number of physicians, PAs, NPs, and CNMs each by 30% in order to maintain current ratios. To some extent, these recommendations are alternate strategies that depend, in part, on when the strategies are implemented. If implemented *today*, the state could maintain its current ratio over the next 25 years by:

1. Increasing yearly educational production of physicians by 20%, *or*
2. Increasing production of PAs, NPs, and CNMs by over 30%, *or*
3. Increasing in-migration to produce a net increase of physicians by 15%, *or*
4. Increasing capacity of the health system to manage effectively the health of more North Carolinians or improve the health of North Carolinians to reduce the need for health services by 15%.

The time to act is now. The longer the state waits to implement the recommended strategies, the greater the number of practitioners it will need to produce on a yearly basis to address anticipated practitioner shortages. The state must take the necessary steps to ensure we have the right mix of practitioners in the right locations to meet current as well as future health care needs. **NCMJ**

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COMMENTARY

Reinventing the Wheel, Yet Again!

E. Harvey Estes Jr., MD

In 1966, I became the chair of a new department at Duke University created to address the growing shortage of primary care physicians in North Carolina and the nation. Computers, physician assistants, and new models of care were among the "solutions" that emerged from this effort. In 1978, I chaired a major task force of the Institute of Medicine of the National Academies to "formulate a cohesive health manpower policy for assuring the accessibility and appropriateness of primary health delivery." Reduction in payment disparities between primary care physicians and other physicians and payment to physicians for health education and preventive services were among the recommendations. Preferential selection of medical students likely to go into primary care, clinical experience in primary care settings, and training of all medical students in a team approach were some of the other recommendations.

Forty years later, we are facing the same problems of insufficient numbers of primary care physicians and maldistribution of practitioners, plus an added shortage of other essential medical specialists and a projected shortage of all medical practitioners. As can be seen in the North Carolina Institute of Medicine Primary Care and Specialty Supply Task Force report, we are proposing many of the same solutions. Why have we not solved these problems? Why were many of these recommendations not implemented?

The health care system is a ponderous, complex, and expensive system with many parts and no single controlling authority. Each of the component parts has decades of experience and investment in the *status quo* and resists change. The system clearly responds to new infusions of money, but there has been little investment in ordinary medical care and the infrastructure for its delivery. At the same time, there has been a huge investment in science and technology. Each advance brings forth a call for even more investment and the promise of even more spectacular new advances, but at an ever increasing cost. New specialized treatment centers and new "dreaded disease" research centers have more appeal to citizens at large and to legislatures than new investments in primary care or other shortage specialties.

> *"New specialized treatment centers and new "dreaded disease" research centers have more appeal to citizens at large and to legislatures than new investments in primary care or other shortage specialties."*

The disparity in available health care between larger cities and small communities and rural areas seems greater now than 40 years ago, in spite of a modest increase in per capita supply of physicians. At that time, generalist physicians and doctors delivering babies were available in most small communities, and small hospitals were still viable. In the interval, general internists and pediatricians have joined general practitioners and family doctors on the endangered list, and small hospitals are disappearing at an increasing rate. Large hospitals and technical specialties appear to thrive, but the expense of possessing and maintaining the latest technology and keeping up with similar enterprises is taxing their financial capacity.

No logical person would argue that every North Carolina town should have the same medical facilities and personnel as the major medical centers. But the fact is that even in our most privileged communities, well-insured citizens now have difficulty obtaining the personal medical advice and care that was generally available 40 years ago. This disparity is compounded when the community is hours away from a medical center, is economically

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distressed as a result of recent plant closings, and has no major shopping centers or desirable social amenities.

The recommendations in the NC IOM report are aimed at increasing the overall number of medical practitioners, but they are principally directed at those areas and communities that are at the bottom of the pile in practitioner supply. They call for both increased production and measures to move practitioners into shortage areas and to increase the number of minority practitioners. Many of the recommendations are remarkably similar to those made decades ago. Why should we think that these recommendations will work now, when they have not solved the problem in the past?

Perhaps the fact that the problems are worse will convince decision makers in the health care system to work harder at solutions and to make the needed changes. More and more ordinary citizens and recipients of health care are unhappy with our system. Business and industry leaders are increasingly alarmed with the cost of health care and the fact that we are not achieving the level of benefit seen in other countries with less expensive systems. The lack of care available in some areas of our state, combined with the financial distress of poor counties that must pay their share of Medicaid costs, leads to calls for adjustments in the distribution of state tax dollars.

The unpleasant predictions of this new task force may not seem very alarming to most people or to most health professionals. A shortage of medical practitioners in 2030 may seem to be a distant and even unlikely possibility, in spite of the sound analyses upon which this prediction is based. To some, asking the legislature, philanthropic organizations, and the public to support this set of recommendations will seem foolish, especially to those who fear bigger government roles, higher taxes, and intrusions into personal and professional lives. Why should legislators risk their political future by directing new money to increase the supply of medical practitioners several decades in the future? Why should leaders of academic medical centers retool to recruit a new type of student, change curricula, increase enrollment, and take other measures when this course can be predicted to divert resources and attention from the current highly rewarding path of research and the development of technical superiority in highly specific diagnostic and treatment methods?

The first task is to convince citizens of the state that the predictions contained in the report are valid and that change is needed. Most will turn to physicians, other health care leaders, and government experts for confirmation. This report is the first step in this process. It must receive wide attention, and the serious consequences of inaction must be recognized. Community leaders must have access to the details and understand that our state must compete with our neighbor states and other parts of the country, which face the same problems and have not previously worked as hard as North Carolina to recruit new practitioners. We must accept that change is necessary and be willing to work unselfishly to achieve it.

Even with widespread acceptance of the impending shortage of practitioners, can we be assured that the needed changes will occur? The leaders of our current academic health centers must play a huge role in achieving the objectives outlined in the report. They face a daunting task. How can they recruit more students from minorities and from small North Carolina communities (those most likely to settle in small towns) without curtailing those activities in their current mix that produce a large part of the financial rewards supporting their work? How can they convince their current faculty, largely engaged in research and cutting edge practice, that these new students have equally important life goals which must be nurtured and respected? How can they be convinced that training family doctors for rural towns is equal in importance to training potential Nobel prize winners and achieving a higher score in the *US News and World Report* annual ranking? Financial incentives and added attention to their role in achieving these new goals must be among their rewards.

One of the most important ways to improve the supply of needed specialists is to reduce the current payment disparities between specialties. It is no coincidence that the specialty groups in short supply are those in the bottom tier of professional incomes. An anesthesiologist earns 2 or 3 times as much as a family physician, yet has a more predictable schedule and personal life. It is not hard to see why career choices are made as they are today. This could be corrected by increasing reimbursement for low paying specialties, by reducing the pay of higher paying specialties, or by a mixture of both. Payment of physician services is largely determined at a federal level through the Medicare payment scale but North Carolina legislators and administrators have an important role through their influence in the NC Medicaid Program and the State Employees Health Plan.

These and other key objectives can only be achieved with the approval and support of the North Carolina General Assembly. It has an absolutely critical role in assuring that we have the practitioners we need in 2020 and 2030. This group must work in a bipartisan fashion and show great political courage because adopting these recommendations will face opposition from powerful groups including some that will receive less as a result of reallocations of funds. The NC General Assembly must recognize that good medical care is a necessary component in the restoration of prosperity in areas of the state that have been hardest hit by the decline of tobacco as a crop and the relocation of manufacturing to other countries. Legislators must see that the greatest potential for economic recovery lies in achieving productive employment for the young people in these communities. They must see that there is no better solution to this problem than the creation of higher level health careers and investing these careers in health care in their own home towns.

Other groups critical to implementing the recommendations of the current report are the professional groups representing health care providers such as physicians, nurses, and hospitals. They too must recognize that investments to enhance the prosperity of low-wealth counties eventually enhance the prosperity of the state as a whole. Some who have prospered from previous investments may see this as a setback for their own prosperity, but, in the longer time frame, these groups will also benefit from the more equitable distribution of both health and prosperity in the entire state.

It is also important to recognize that the recommendations in the NC IOM report involve more than the health care sector. Our educators and educational institutions are heavily involved. Identification of young people who have the intellectual and personal skills to become caregivers, guiding them into careers without limitations as to level, and equipping them to assume professional roles in needed areas of our state, is a major objective of this report. This investment has profound implications for our state which state leaders must recognize and support.

It is my sincere hope that the North Carolina Institute of Medicine Primary Care and Specialty Supply Task Force report will produce a more profound and long-lasting effect than those activities cited at the beginning of this article. I see it as blazing a trail for a more prosperous and optimistic North Carolina, with more equitable opportunities for young people, with more equitable health care, and an even better state in which to live. I also hope that those who must clear the trail and make it a well established roadway to progress will share this vision. **NCMJ**

New Models of Care:

Building Medical Homes in Empowered Communities

J. Lloyd Michener, MD

Quality health care has long been viewed as a relationship between a competent and compassionate physician and a patient who seeks advice and guidance.[1] Unfortunately, for a growing number of North Carolinians such relationships are increasingly hard to find, and the health outcomes, even in the best of circumstances, are often less than ideal.[2]

There is no question that having an adequate number of physicians is essential to ensuring health, but it is also increasingly clear that doctors alone are not sufficient. This is not because individual physicians have become less important, but rather because there is not enough time for individual physicians to provide everything a patient needs; the challenges our patients face today require new models of care that build on the work of physicians and extend out to involve entire communities.

The growing rates of chronic disease, rising numbers of uninsured, unrelenting racial disparities, and soaring obesity rates are problems for which physicians have essential roles but which require multidisciplinary teams across multiple locations to provide the continuum of needed services. From the public health department dietitian or agricultural extension agent encouraging healthy eating and exercise habits to the church members who are providing health ministries about chronic illness, every part of the community has a role to play.

> *"...the challenges our patients face today require new models of care that build on the work of physicians and extend out to involve entire communities."*

The traditional focus on individual patients in the office and hospital, which is necessary to deal with acute care needs, has often obscured the need for physicians to collaborate and partner with community groups who can help institute the larger changes needed to confront the growth of chronic disease. This new model seeks such collaboration and resolves the growing time demands on practicing physicians by sharing tasks—in particular, those dealing with prevention and education—with members of the office team and other groups within the local community. In doing so, this model extends the efforts of each physician.

The Time Trap

Primary care physicians today face a scarcity of time due to our exceptional fortune in finding effective therapies to prevent or treat illness in primary care settings. As the number of prevention and treatment guidelines has increased, so has the burden of following those guidelines. In our own research at Duke University, we found that it takes an average of 7.4 hours a day for a physician to deliver recommended prevention messages and services to an average panel of patients. To deliver all recommended care for patients with chronic conditions takes an additional 10.6 hours a day.[3]

A vicious cycle ensues. There is not enough time for individual doctors to properly encourage prevention and, too often, this lack of prevention leads to the onset of chronic conditions. A lack of good chronic disease management leads to increased acute care visits that are more painful for the patient, difficult for the physician, and costly to the system. The increased level of acute care cases (and the higher reimbursement rates for

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procedures associated with them) encourages physicians to choose specialties other than primary care.

The number of medical students attracted to primary care has been steadily declining in recent years in part because of the inflexible demands on their time. Students, as well as currently practicing doctors, care about having time for their personal lives. Among physicians under the age of 50, time for family is cited as very important by 69%—more than any other factor. Of physicians under 50, 80% would reduce their hours if they could.[4]

This cycle seemingly indicates that primary care is a Sisyphean effort—only doomed to failure. The time needed is impossible for one physician who holds her or himself accountable for delivering all needed care. However, it is quite possible for an interdisciplinary team of physicians, nurse practitioners, physician assistants, nurses, health educators, social workers, and other professionals assisted by technology who work with each other and in tandem with their community.

Interdisciplinary Teamwork

Primary care has been traditionally centered on the role of the physician with subordinate roles for all other members of the health care team—including the patient. But as the demands and expectations on practices grow, the role of the physician needs to shift. With medical practice increasingly faced with the challenges of managing chronic disease, the role of the nurse practitioner, physician assistant, nurse, health educator, social worker, psychologist, and dietitian become more important. And with so many of the underlying cases of chronic disease rooted in personal behaviors, the role of community health and nonhealth agencies in supporting long-term behavior change becomes as important as the work done in the office.

The idea of interdisciplinary teams is not new. Literature abounds with examples of successful interdisciplinary teamwork in all fields of medicine. In primary care practices across the nation, private and group practice physicians have invested in training their office staff, physician assistants, nurse practitioners, and nurses in office systems that rely on technology to seamlessly capture patient information, ease scheduling and billing, consistently provide patient education, and ensure follow-up.[5,6,7,8] Physicians based solely in the hospital managing inpatient care are also helping to streamline care and free up doctors in outpatient settings. What is different in all of these new models is the shift from the physician being the center of the team, coordinating all of the care, to the patient being at the center of the team with the physician playing a key leadership role.

Here at Duke, we are working to change our primary care offices systemwide. By shifting staffing, we are able to better support our many patients with chronic illness. We are adding dietitians, social workers, physician assistants, and nurse practitioners to enhance the services of our clinics and make appointments and care more available. Developing new electronic medical records helps our clinics coordinate information across offices and hospitals.

The transition from physicians operating as independent practitioners to their participation in and sharing of tasks and responsibilities within interdisciplinary teams is a significant challenge by itself. But teamwork alone is not the answer to improving primary care if it means that care begins only after patients choose to come to us for help. Teamwork must be accompanied by delivery systems that are accessible to those we seek to serve. Although the science of prevention and chronic disease management has grown stronger, racial and ethnic minorities and the poor have not benefited from these advancements as much as other groups. For example, minorities and those with lower incomes are more likely to be at risk for cancers and chronic diseases and less likely to be screened or treated effectively. Waiting for people to be seen in the medical office is not sufficient. For too many, the office is too far, too threatening, or too expensive.

Empowered Communities

We also need to be effective not only in forming teams downstream with specialists, hospitalists, and others involved in the care of our patients but also upstream with organizations and leaders in our communities that have the capabilities to support the difficult lifestyle changes that our patients increasingly need.

Careful coordination of resources at all levels on the continuum —upstream and downstream—is the keystone to the overall health of a community. Data from the United Health Foundation, which ranks health status in each state, find that offering and rendering more services does not always equate to better overall health care and, in fact, in some states greater use of services goes hand-in-hand with poorer quality and lower satisfaction.[8]

Instead, we need to think creatively about how and where to deliver health care services and information in a way that centers on the patient. For example, care does not always need to be provided in the doctor's office. Community-based teams of health educators and social workers can ably assist patients in caring for their illnesses, as has been demonstrated in communities across the state by Community Care of North Carolina.[9,10] Senior center-based physician assistants using laptops with electronic medical records and backed up by physicians, can dramatically improve outcomes for senior citizens—and decrease inpatient admissions as well—even when these patients already have primary care physicians.[11]

The effectiveness of the office encounter is greatly enhanced when it works in tandem with communities. At Duke, we are working with neighborhoods across the state to find ways to reduce the risk of chronic disease from obesity and inactivity, building on the strengths and resources of not only doctors but also schools, health departments, and community agencies. Through the Just for Us program, in-home chronic disease management visits are provided to over 350 Durham seniors living in 10 low-income apartment complexes.[12] The LATCH program connects thousands of Latino immigrants in Durham to health care services and culturally and linguistically appropriate health education classes. We operate 4 school-based clinics and 2 neighborhood clinics offering easier access to services for hard-to-reach populations. Community health isn't just a concept. It's a reality that improves the health of thousands of North Carolina residents every day.

These innovations are not ideas that can be instantaneously dropped into place. A rural county with rampant poverty and a dearth of providers or a wealthier suburban area with higher rates of insurance but care that isn't integrated will require different solutions.[13] Diverse communities require diverse solutions, but the common thread to each is teamwork and new roles for all the members of the primary care team including the physician.

Preparing physicians for both teamwork and a focus on community-centered care requires new approaches at every level of education. In undergraduate and graduate medical education, students must be afforded opportunities to practice teamwork so they can appreciate the overlapping and complementary skills of different disciplines. And those who teach them must model that teamwork and interdisciplinary collaboration.

Communicating across disciplines is also a challenge and educators in programs for nurses, physicians, social workers, dietitians, physical therapists, nurse practitioners and physician assistants need to standardize how teamwork is conceptualized and taught. In real-world situations, this highly coordinated communication and collaboration among teams is facilitated by technology. Educational programs need to address teamwork and define explicit goals, methods, and outcomes so that graduates are competent to practice in this new environment.

As has been widely reported, Duke is restructuring our Family Medicine Residency program to better prepare family physicians for teamwork both upstream with the community, downstream with hospitalists and specialists, and horizontally within the office. Part of our effort to restructure the program is a shift in emphasis from the inpatient setting to the community. Hospitalization rates for primary care have dropped by almost 72% over the past decades[14] so it no longer makes sense to focus family medicine residencies in hospital settings. Instead, we should be training residents in the settings where needs are greatest and there is more opportunity to practice prevention and early intervention. In addition to moving where we train residents, we are changing how we train residents. We want to find ways to better instill teamwork with physician assistants, nurse practitioners, physical therapists, and other health professionals.

Put all of these pieces together and the result is a very different form of medical practice. It begins by asking the community what services it needs, provides an analysis of the areas for potential improvement in health status (and in North Carolina there are plenty of opportunities) and then seeks to provide those services in ways acceptable to those being served. The practice does not wait for a patient to come to the office with a problem; the practice is engaged with community groups, employers, schools, and health departments to identify ways in which it can help support needed services without duplicating them. It uses health educators to supplement the individual instruction in the office and to empower and educate patients to take control of their health and take on primary leadership roles in their care. It uses physician assistants and nurse practitioners in the community and in the office to provide care in settings and frequencies beyond what the most dedicated physician can provide.

To many old timers and small town physicians, this may not seem radical or even new. Those who trained in community-oriented primary care, and/or public health, or who have already evolved this community-integrated form of practice, are familiar with these concepts. But to mitigate, and eventually reverse, the decline of primary care, what once was an interest of a few now needs to become a core skill of all.

An obvious critique of all these ideas is, "How do you pay for it?" The financial challenges to primary care are well documented.[15,16] The reimbursement system is currently not equipped to encourage or sustain these types of innovations and to build the case for change requires evidence of success. So should we wait or should we try? Funding for innovation is difficult but not impossible. At Duke, we have used a mixture of grants, contracts, public and private insurance funding, and our own funds to create sustainable, community-oriented programs.[17] It has not been easy, but it is possible. It is the obligation of physicians, and especially academic physicians, to help find ways to improve the health of our citizens.

What if we succeed in redesigning care? Imagine that interest in primary care is rekindled by medical students who know they do not have to do it all, who are equipped with the knowledge, skills, and attitudes to not only be excellent clinicians but also excellent leaders, and who can effectively harness the power and spirit of teamwork to improve the health of their communities. Imagine empowered, informed populations that become leaders in managing their own health, instigating a culture of accountability, and improving access to and quality of care in their communities. Imagine that the racial and economic gaps in health care delivery narrow and evaporate, that the incidence of chronic disease is lowered, and that those who do live with chronic disease find their challenges eased. If we succeed in this effort to build and test new models that allow adequate time for prevention and disease management, we just might find a North Carolina with healthier people and happier and more productive doctors. **NCMJ**

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COMMENTARY

Medical Practitioner Supply from a National Perspective

Thomas C. Ricketts III, PhD, MPH

Medical practitioners are the central asset of our health care system. As a society we have committed substantial resources to preparing skilled and effective professionals. We use public tax revenues and funds collected under the Medicare program to support their training. Our state and federal laws give them special privileges and freedoms to treat injuries and cure disease. For these reasons, the question of whether there are enough practitioners to meet the health care needs of our population is a public issue.

Medical care in the United States through much of the twentieth century had been the exclusive preserve of physicians. In 1950, the professional medical care supply for the nation could be described almost exclusively by the total number of allopathic physicians in active practice. There were alternative groups of practitioners but their numbers were small and they were not fully recognized as "doctors" in many states. At that time, most physicians were generalists practicing in small communities and larger cities and many rural parts of the country had no doctor. By 1960, the nation began to recognize there was a doctor shortage and that it was primarily affecting the generalists. By the late 1960s and into the 1970s, Congress took note and began to support the medical education of primary care practitioners and to encourage them to practice in less well served communities. Some of the programs developed included the National Health Service Corps (NHSC), which placed doctors in health professional shortage areas; Area Health Education Centers (AHEC), which trained doctors in rural settings; and a series of programs that came to be known under the generic term Title VII, which encouraged minorities to consider medical careers and promoted the development of family medicine and primary care training programs. In the 1980s, federal programs were introduced to support rural practice and training.

> *"...we are faced with the question of whether we have the right number and the right kinds of health care practitioners in the right places to meet our current health care requirements."*

Over the same time, states also recognized their role in expanding the supply of physicians and began the process of expanding the medical franchise to other professions. In the 1960s and 1970s, new medical schools were opened to train predominantly primary care physicians with an emphasis on rural practice. East Carolina University, East Tennessee State University, The University of South Carolina, and Eastern Virginia Medical School were all of this generation of new, primary care-oriented medical schools. The profession of physician assistants (PAs) was developed at Duke University and the University of Washington, and programs to train nurse practitioners (NPs) were opened. North Carolina graduated the first NPs who were soon working in the state's new rural health clinics (RHC), which were developed by the nation's first Office of Rural Health.[a]

These national and state efforts should have alleviated the problems of physician supply and distribution, but they have not. In 2007, we are still talking about an impending shortage of doctors, as well as nurses, and a need to reorganize the structure and financing of medical care to achieve an effective health care delivery system focused on the patient with primary care, or as

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[a] See the January/February 2006 issue of the *North Carolina Medical Journal* for detailed descriptions of the rural programs.

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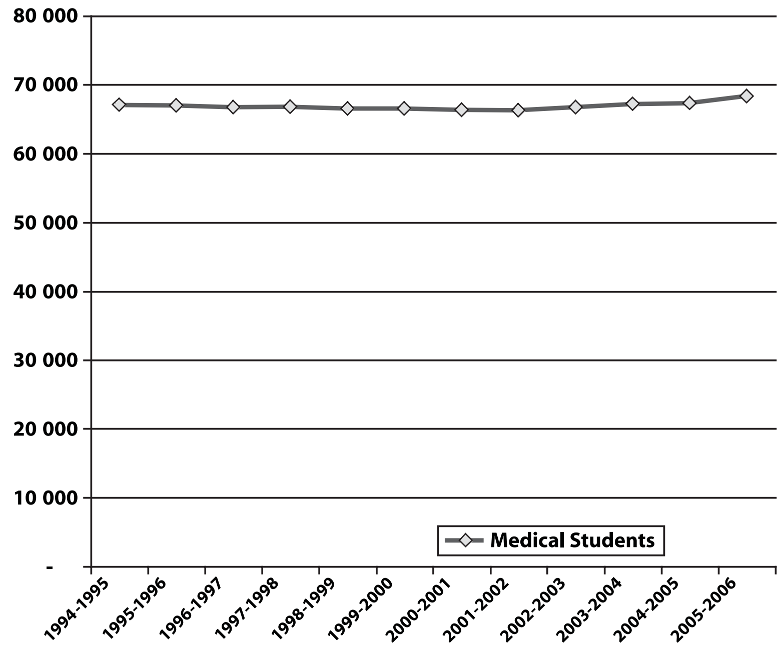
Figure 1.
Total Enrollment in US Medical Schools, 1994-2006



Source: Barzansky B, Etzel SI. Medical schools in the United States, 2005-2006. *JAMA*. 2006;206(9):1147-1152.

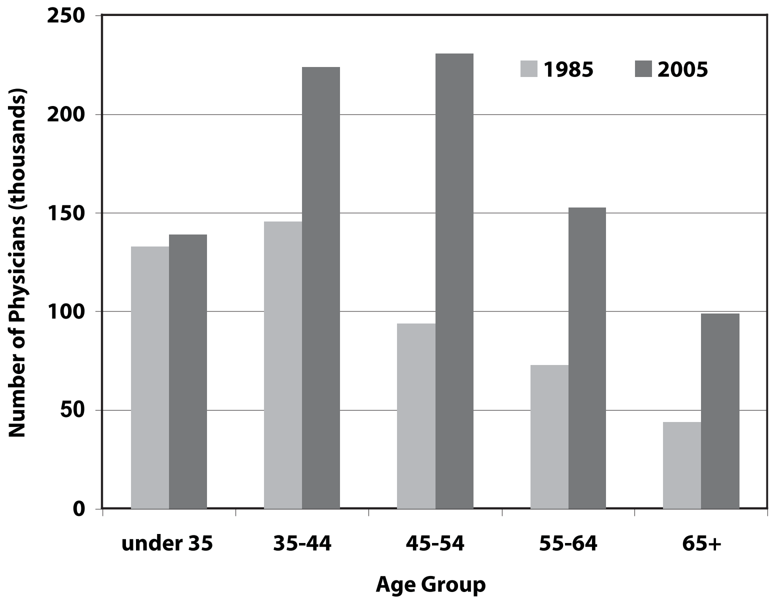
we now term it, the medical home, at the center of the system. One primary reason for this situation is the countervailing influence of the largest input into physician training—graduate medical education payments. Graduate medical education payments go to teaching hospitals through the Medicare and, to a lesser extent, Medicaid programs. They are combined with the physician component of the reimbursement structure of Medicare itself and tend to favor specialty medicine practiced in large cities.

The past 30 years have seen a diffusion of authority and privilege to other practitioners. Thus, we need to look beyond physicians to understand how many and what kinds of human resources are available to meet our health care demands and needs. Nurse practitioners, physician assistants, and certified nurse midwives have become important contributors to the equation that balances supply of practitioners to needs and demands for health care.

In this first decade of the 21st century, we are faced with the question of whether we have the right number and the right kinds of health care practitioners in the right places to meet our current health care requirements. This is due to a growing recognition that we have not invested in expanding the ways and means to prepare physicians in the United States while the population has grown and become proportionately older. We have expanded the number of new primary care clinicians we train—nurse practitioner and physician assistant programs have increased rapidly in recent years. For example, in 1990 there were 1000 students enrolled in PA programs; by 2005 that number grew to 4460. There were an estimated 140 000 nurse practitioners at work in the US in 2005, up from 104 000 in 2000. Despite that growth, these new clinicians will not allow us to meet growing requirements brought on by population growth, especially among older people, and to utilize the opportunities to cure and prevent disease fostered by technology changes.

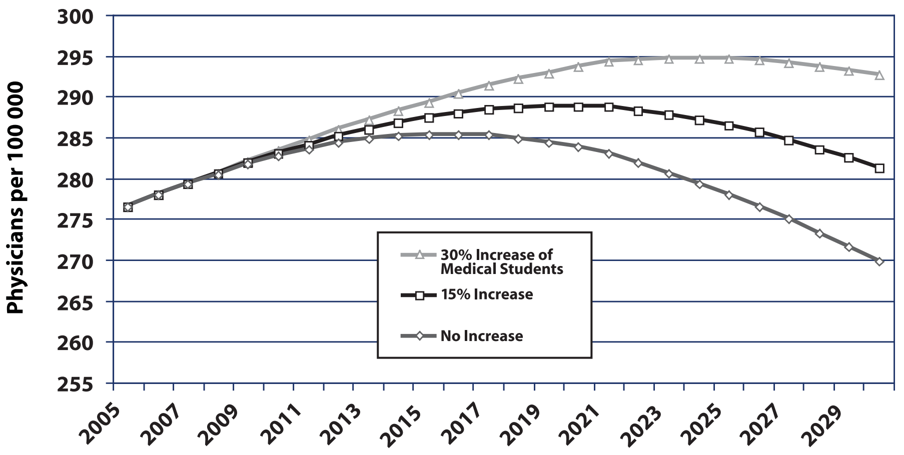
A tightening in physician supply appeared during the period around 2000. Studies of consumer and practitioner behavior found patients waiting longer for appointments and physicians reporting inadequate time with their patients.[1] One promising development in the supply situation during this period was that physicians did work more often with nurse practitioners and physician assistants. In 1980, the ratio of first year medical students per 100 000 people in the US began a steady decline from 7.3 that year to 5.6 in 2005.[2] This trend in medical education reflects the

Figure 2.
Age Structure of US Physician Supply



Source: Association of American Medical Colleges. Center for Workforce Studies. Help wanted: More U.S. doctors. Washington, DC: AAMC; 2006. http://www.aamc.org/workforce/helpwanted.pdf. Accessed April 23, 2007.

Figure 3.
Anticipated Trends in US Physician Supply



Source: AAMC Center for Workforce studies. Unpublished data, 2005.

policy decisions of earlier decades based upon incorrect predictions of a persisting physician surplus by 2000 and beyond.

In response to those predictions, there were practically no new allopathic medical schools established in the US between 1980 and 2000, and total medical school enrollment stayed steady at around 68 000 students. In 1985 there were 126 allopathic medical schools graduating 16 117 students. In 2006 there were 17 370 entering first year medical students in 125 allopathic medical schools, a very meager growth rate of 7% given the US population grew 25% in the same period. In 1985 there were 1560 osteopathic medical students graduating from 15 schools. In 2005 there were 2740 from 20 schools. The growth in the number of osteopathic medical schools has been rapid and will continue; six new schools opened since 2000 and 6 more are set to open. In comparison, there are only 2 new allopathic schools, both in Florida, that are on schedule to accept students. Osteopathic medical doctors are licensed equivalently in all of the states with osteopaths practicing more often in primary care and rural areas than allopathic physicians.

This slowdown in production has been filled in the recent past by international medical graduates (IMGs) coming into the US for their post graduate training or as immigrants. Slightly more than a quarter (25.3%) of all US physicians are IMGs. Half of these are US citizens or permanent residents.[3] Similarly, a quarter of all physicians in post-graduate training (residencies) are IMGs. Again, 45.6% of these are US citizens or permanent residents.[4] This trend may not persist because many other nations have also turned to our traditional sources of IMGs to bolster their medical practitioner supply. Furthermore, there are efforts to stem the importation of physicians into the developed countries to stop what has been termed "brain drain," which is seen as thwarting health status improvement in the developing world.[5]

The term "shortage" has evoked a good deal of controversy because many see the human resource problem of our health system as being a problem more of organization and financing than of numbers. However, there is more predictability in the demography of the workforce than there is in the policies that structure those professionals. The demographic trends point clearly toward a period of stress between what we expect from medical practitioners in terms of numbers and access to care and what can be delivered. **NCMJ**

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COMMENTARY

Carolinas Medical Center Academic Infrastructure:
Implications for Physician Workforce Expansion

James T. McDeavitt, MD; Kara C. King, PhD

The city of Charlotte is known for being the second largest banking center in the country after New York. Its growth rate in recent years—in terms of new businesses, jobs, and population—has been nothing short of explosive. While such distinctions are positive, Charlotte has one other distinction that renders the city something of an anomaly in the world of medical education: it is one of the largest cities in the United States without a medical school.

> *"...Charlotte has one other distinction that renders the city something of an anomaly in the world of medical education: it is one of the largest cities in the United States without a medical school."*

However, this may change. Late in 2006, leaders of the University of North Carolina School of Medicine (UNC-SOM) approached Carolinas HealthCare System (CHS) with a proposal to develop a second UNC medical school campus in Charlotte. The plan as initially proposed by UNC would expand the existing class size by 50 students, from 160 to 210. The students would complete their first two years of training in Chapel Hill. To accommodate the expanded class during the last two years of training, a new campus would be developed in Charlotte in association with the Carolinas Medical Center (CMC).

One major advantage of the UNC proposal is that it builds on the existing academic infrastructure at CMC. Carolinas Medical Center, the 861-bed flagship facility of CHS, has a long history of involvement with education and research and serves as one of 5 state designated academic medical center teaching hospitals. The academic nature of the other 4 hospitals is probably more apparent because all are affiliated with highly visible universities (Duke University, Wake Forest University, The University of North Carolina at Chapel Hill, and East Carolina University). Nonetheless, CMC hosts residency and fellowship programs that serve over 200 medical school graduates at a given time. These students come from 32 states and represent 84 different US medical schools. In fact, CMC has hosted approximately 1000 medical students from UNC-SOM in the past 4 year years alone as part of the school's normal clinical rotations. As a result, the addition of a more formal program, should it occur, would be a fairly logical extension of current capabilities.

There is growing consensus that North Carolina, and the nation, face a significant physician shortage. The Association of American Medical Colleges, for example, recently called for a 30% increase in the number of trainees being produced by American medical schools over the next decade.[1] The North Carolina Institute of Medicine recommends similar sharp increases in training of physicians and other health care practitioners.[2] To better understand the benefits of a proposed collaboration between UNC-SOM and CHS, it is helpful to know something about the origins of CHS and its long history of involvement in both medical education and research.

Carolinas Medical Center traces its history, which is extensively documented,[3] to the years following the Civil War. In 1876, Charlotte Home and Hospital of St. Peter's Episcopal Church was established as the state's first civilian general hospital. The hospital grew and relocated several times during the next 50

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years, and the name eventually changed to St. Peter's Hospital.

By the 1930s, local physicians were pioneering a movement to construct a new public hospital that would be spacious enough to eventually accommodate more than 800 patients. Their goals at the time were to practice medicine to the best of their abilities, serve the community, including the indigent population, and reflect the superior training of Charlotte's physicians through high-quality care. Other key objectives were to take advantage of that same physician training to educate and train medical residents and encourage research.[3] After start-up proposals were thoroughly investigated and justified, a decision was made to construct a new facility known as Charlotte Memorial Hospital. Charlotte Memorial, which formally opened in 1940, was constructed utilizing land donated by St. Peter's Hospital.

The hospital grew steadily over the years and in 1990 was renamed Carolinas Medical Center to more accurately reflect the growth and regional presence of the institution. Today, CMC is the highest-volume provider of tertiary/quaternary medical services in the state. During this same period CMC's parent corporation, Carolinas HealthCare System, was beginning a period of steady regional expansion that involved acquiring, leasing, or managing hospitals and physician practices primarily in North Carolina but extending into South Carolina as well. Today CHS is the third largest public health care system in the United States behind only the University of California system and the nationwide system of Veterans Affairs hospitals.

Carolinas HealthCare System owns, leases, or manages 19 hospitals and has two more under development. Including 11 nursing homes, the system has nearly 4500 licensed beds. CHS has more than 150 delivery sites in all, including 75 Carolinas Physician Network medical practices, and employs approximately 29 000 part- and full-time employees. Carolinas Medical Center's commitment to graduate medical education took root at the time of its founding, in 1940 with the establishment of a variety of graduate training programs. Residency programs grew steadily during the 1960s, prompting CMC to begin recruiting full-time teaching faculty to supplement the strong support already being provided by private practitioners.

Physician residency programs are currently offered in 10 fields including emergency medicine, pediatric emergency medicine, family medicine, rural family medicine, internal medicine, obstetrics and gynecology, orthopedic surgery, pediatrics, physical medicine and rehabilitation, and general surgery. Fellowships are offered in medical toxicology, sports medicine, orthopedic trauma, vascular surgery, and thoracic surgery. In addition, CMC is actively considering the addition of fellowships in gastroenterology and pulmonary/critical care medicine. All programs are fully accredited by the Accreditation Council for Graduate Medical Education (ACGME) and are competitive in attracting the best qualified of the nation's medical students. After completion of residency, approximately 80% of CMC-trained physicians enter practice directly while 20% pursue fellowship training. Current plans for CHS to merge with NorthEast Medical Center in Cabarrus County will also complement the overall educational portfolio. When the merger is complete, it will result in the addition of an innovative family medicine training experience that incorporates a strong rural focus as a part of CHS's expanding commitment to general and graduate medial education.

Currently, CMC's residency program includes 212 physicians. Additionally, there are 193 faculty members (up from three dozen less than 25 years ago) teaching in the following primary care and subspecialty departments: pediatrics, family medicine, internal medicine, obstetrics and gynecology, emergency medicine, general surgery, physical medicine and rehabilitation, orthopedics, oral medicine, vascular surgery, thoracic surgery, and neurology. All faculty physicians at CMC are expected to make contributions in the 3 areas of clinical care, education, and research.

Carolinas Medical Center has also served as a primary regional training site for medical students since the inception of UNC-SOM. Initially, UNC students received clinical experience in internal medicine at CMC. That program was soon expanded to include obstetrics and gynecology and pediatrics. The list of established clinical rotations has since expanded to include general surgery, family medicine, emergency medicine, physical medicine and rehabilitation, orthopedics, plastic surgery, and psychiatry. Although most of the student rotations at CMC are filled by UNC students, clinical rotations are also offered to medical students nationally. During the 2004-2005 academic year, approximately 444 undergraduate student months were provided through CHS facilities and physicians.

Supplementing its role in physician education, CHS also trains allied health professionals. The Carolinas College of Health Sciences (CCHS), located on CMC's main campus in Charlotte, educates nursing students and other personnel. The school was initially established as the Charlotte Memorial Hospital Authority School of Nursing in the late 1980s after a comprehensive feasibility study supported the need for more nurses, both locally and statewide. The school's name was changed to CCHS in 1996 when programs expanded to include disciplines other than nursing. Carolinas College of Health Sciences is fully accredited by the Commission on Colleges of the Southern Association of Colleges and Schools and currently has an enrollment of 450 students. Academic programs and courses are offered for prenursing; nursing; emergency medical sciences; radiologic, surgical, and medical technology; general education (ie, liberal arts); and nurse aide training.

Carolinas Medical Center also has a long history of involvement in continuing education. In 1972, CMC was invited by UNC-SOM to become one of 9 Area Health Education Centers (AHECs) in North Carolina. Area Health Education Centers act as regional extensions of universities and teaching hospitals, providing educational programs to physicians, health care professionals, and other students. The Charlotte AHEC serves an 8-county area. The AHEC programs reached approximately 27 000 care practitioners during the 2005-2006 academic year alone.

Charlotte AHEC also offers a variety of ancillary programs. For example, training opportunities in diversity management, foreign languages, and cultural immersion are offered to improve services to underserved populations. The AHEC digital library has facilitated the delivery of certain courses, educational materials, and literature online. This level of accessibility has vastly expanded the opportunities available for community-wide involvement. Finally, CHS and Charlotte AHEC have developed a program called Health Career Education—Reaching Out to Excellent Students (HEROES). This program is designed to educate precollege students, especially underrepresented minorities and disadvantaged populations, about health careers.

Carolinas HealthCare System has also invested heavily in medical research. The James G. Cannon Research Center, which opened in 1991, attracts clinical and basic science researchers to CMC. Cannon currently houses active laboratory research programs in general surgery, urology, emergency medicine, orthopedic biology/engineering, obstetrics-gynecology, internal medicine, and pediatrics. Additionally, it houses the McColl-Lockwood Laboratory for Muscular Dystrophy Research and the Heineman Medical Research Laboratories for cardiovascular disease research. More research laboratories are located in the Blumenthal Cancer Center.

Carolinas Medical Center-based investigators have contributed to expanded knowledge and successful outcomes in medicine. For example, recent work helped to develop a new technique to transplant insulin-producing cells into Type I (insulin-dependent) diabetics.[4-6] The first pancreatic islet transplantation in North or South Carolina was performed in Charlotte, and follow-up studies showed the recipient to be free from exogenous insulin injections 2 years postsurgery. The patient requires minimal immunosuppression.

Additionally, novel use of antisense oligonucleotide mediated therapy was used to improve Duchenne muscular dystrophy in an animal model.[7] Yet another CMC laboratory has identified an array of genes implicated in the progression of ovarian cancer.[8] These genetic markers may potentially serve as the basis for novel treatment strategies and/or the development of more sensitive and earlier screening tests. NIH funding has been utilized at CMC to support the development of a Carboximeter.™[9] The purpose of the device is to detect pulmonary emboli quickly and easily by means of a bedside test. Another NIH-funded study is focused on identifying oral cavity pathogens that may correlate strongly with ventilator associated pneumonia.

The R. Stuart Dickson Institute for Health Studies is a program of applied research and public health studies that is geared toward facilitating improvements in the quality of care and the effectiveness of clinical practice. Dickson staff members include epidemiologists, biostatisticians, health services researchers, database analysts, and database developers.

As this article goes to press, the feasibility of starting a Charlotte Campus of UNC-SOM is still being analyzed. If the initiative does come to fruition, however, the new campus will not need to be built from scratch. The proposed expansion will capitalize upon a long established and mature relationship between UNC-SOM and CMC. A large part of the infrastructure necessary to support expanded medical educational opportunities is already in place. Additionally, a tradition of high educational standards, in conjunction with top-quality patient care and cutting-edge research, is well established. Therefore, the main questions under review tend to revolve around funding, logistics, timing, and capacity.

The medical school expansion concept proposed by UNC-SOM builds upon existing strengths of two organizations with a long-standing commitment to educating tomorrow's physicians. Assurance of an adequate supply of accessible physicians is an issue of seminal importance to the public today and for years to come. The UNC proposal represents a means of increasing the state's production of physicians in a rapid and cost effective manner. **NCMJ**

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The Potential for Medical School Expansion:
A Western North Carolina Perspective

Gary Bowers; Teck Penland, PhD; Joseph F. Damore

The North Carolina Institute of Medicine (NC IOM) 2007 Primary Care and Specialty Supply Task Force report indicates that the overall supply of practitioners in North Carolina may currently be adequate, but escalating trends in the environment threaten a substantial future shortage. The overall population growth, combined with the aging of native residents and the influx of retirees from other states, presents a serious threat to quality health services in Western North Carolina (WNC), which is experiencing both of these phenomena at an accelerated rate.

The region's population is projected to increase by 21% over the next 18 years.[1] Of the 15 counties in North Carolina with the highest percent of older adults, 10 are in WNC, and, based on 2000 data, the population aged 65 years and older in WNC is proportionately greater than for North Carolina and the US (17.8%, 12.0%, and 12.4%, respectively).[2] Already, the ratio of physicians to population in WNC is substantially below the statewide average (14.8% and 20.7%, respectively),[3] and as the population ages, they require more health care services.[4,5]

The State Needs to Consider New Options and Alternatives for Training Medical Students

The NC IOM task force has recommended that North Carolina medical schools expand their enrollment by 30% in order to meet the future shortages. An increase of this magnitude would push existing schools well beyond their facility and faculty capacity, leading to potential quality concerns. A more reasonable approach would be to consider off-campus teaching sites in WNC hospitals and private practices for up to a total of 100 third-year and fourth-year students. With additional resources, these sites could utilize existing faculty from community hospitals, including the 750-bed Mission Hospitals regional referral center, and Mountain Area Health Education Center (MAHEC) residency programs. These types of rotations would be new to the region but have proven successful in other states such as Michigan, Indiana,

> *"The region is relatively compact but offers a wide range of characteristics including metropolitan areas and relatively isolated rural communities, a growing elderly population, a strong tradition of collaboration, a sophisticated and high quality medical community, and recognized successful residency programs."*

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and South Carolina. It is believed that this method would be a more economically feasible approach to increasing practitioner supply because existing community hospitals and MAHEC resources could reduce program costs to the state.

Why Utilize Western North Carolina for Training Medical Students?

Western North Carolina possesses assets that make the region ideal for training medical students. The region is relatively compact but offers a wide range of characteristics including metropolitan areas and relatively isolated rural communities, a growing elderly population, a strong tradition of collaboration, a sophisticated and high quality medical community, and recognized successful residency programs. The region can stand apart in offering programs for training practitioners for a variety of settings and environments.

Much of the region is nestled in areas somewhat isolated by the topography of the southern Appalachian mountains. The area is composed of many close-knit communities and residents depend on their local hospital and health care providers for their primary care needs. This setting exposes medical students to genuine rural practice with reasonable access to a large major tertiary care hospital. As more students are exposed to this environment and become integrated into the community, more may decide to practice in the rural settings,[6] which often have the greatest demand for physicians.

The quality of health care in WNC has received national recognition. Mission Hospitals has been ranked as a "Top 50" and "Top 100" hospital in several clinical areas such as cardiology, cardiovascular surgery, and orthopedic surgery. Several other WNC hospitals have been recognized nationally for their quality health care services. In addition, the utilization and cost data in WNC is also perceived as low cost, as demonstrated by the Dartmouth Atlas database. The region has every major specialty covered and provides all 3 levels of care.

The region also has a very successful history of collaboration among health care providers. The 16 WNC hospitals, MAHEC, and 14 public health departments work together closely through the WNC Health Network with the goal of improving access, enhancing quality, and reducing the costs of health care throughout the region. The hospitals formed one of the first initiatives in the country, the WNC Data Link project, to access and exchange electronic patient data across the region to facilitate care and treatment of patients. Western North Carolina community colleges and universities have a cohesive bond with the hospitals and MAHEC to project future demand for health care services and provide adequate training for professionals offering these services.

The region also has experience developing and maintaining very successful residency programs. Led by MAHEC, Mission Hospitals, and Margaret R. Pardee Memorial Hospital, with the cooperation and support of other regional hospitals, these programs have proven successful in attracting and maintaining health care practitioners in WNC. The residency programs boast a retention rate of 56% since their first graduating classes in 1978.[7]

Similar to other areas of the state, WNC has experienced a steep decline in the number of furniture, textile, and other manufacturing jobs over the past decade. The hospitals have partnered with AdvantageWest, the regional economic development team, to enhance and promote the region's strong health care services in order to attract more business and industry. A medical student training program could boost those efforts and help the economic development of the region.

Through the resources and attributes noted above, Western North Carolina can provide a high quality educational experience for third-year and fourth-year medical students. We are prepared to explore the feasibility of this program to ensure an adequate supply of physicians for our future. **NCMJ**

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COMMENTARY

The Roles and Supply of Nurse-Midwives, Nurse Practitioners, and Physician Assistants in North Carolina

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Certified nurse-midwives (CNMs), nurse practitioners (NPs), and physician assistants (PAs) play a significant role in health care delivery in North Carolina. Within their scopes of practice, these health care professionals provide quality care with high levels of patient satisfaction.[1] Studies in many settings and specialties demonstrate the quality of care provided,[2-7] cost-effectiveness,[8-12] and patient satisfaction.[13-19] The PA and NP professions have been in existence for just over 40 years and CNMs for 50; but the impact of these clinicians on access to quality care is significant. Over half of the 464 primary care practitioners gained in rural North Carolina from 1998 to 2003 were NPs or PAs, and they comprise 35% of all primary care practitioners in whole county persistent health professional shortage areas.[20] In 2002, it was estimated there was one PA and NP practicing for every 10 practicing physicians.[21] As policy makers and health care leaders consider strategies to confront the impending physician shortage, it is appropriate that the positive impact of CNMs, NPs, and PAs be considered.

Certified Nurse-Midwives

There are 202 CNMs approved to practice in North Carolina. The first nurse-midwives were approved to practice in the state in 1976, and they practiced in major cities throughout the state where more physicians were early adopters of the CNM concept. Their utilization was limited until 1989 when North Carolina's rank of 49th in the nation in infant mortality prompted the Division of Maternal Child Health to conduct a feasibility study for creating a nurse-midwifery education program and the Office of Rural Health to increase its efforts to place CNMs in underserved areas. The CNM degree program was established at East Carolina University and admitted its first class in 1992.

"North Carolina is the birthplace of the PA profession, with the first PA education program established at Duke University in 1965."

Nurse-midwives are trained as women's health care practitioners specializing in care of women throughout their lives. Nurse-midwives regard the North Carolina practice environment as tenuous—North Carolina is one of only 6 states with supervisory language in statutes regulating nurse-midwives.[22] This legislative barrier prohibits CNMs from hospital admitting privileges. This results in an inability to statistically quantify their contributions to health care in the state because patients must be admitted under the supervising physician's name. The supervisory requirements force many nurse-midwives to work in labor and delivery units as nurses, which limits their impact on women's health. Many more CNMs could be trained and utilized in rural and underserved areas if the regulatory environment were improved.[23,24]

Nurse Practitioners

In North Carolina, 8 universities graduate about 190 master degree prepared nurse practitioners annually. In 2005 there

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were 2440 nurse practitioners approved to practice in North Carolina. The last decade has seen substantial growth in the numbers of NPs with North Carolina growing faster than the national average. The potential to expand existing NP programs in North Carolina is limited by access to clinical sites and preceptors. Another challenge is the worsening nurse faculty shortage. The major factors driving the faculty shortage are insufficient funds to hire new faculty, inability to recruit qualified faculty, lack of qualified applicants, noncompetitive salaries, and high faculty workload.[25] Recommendations to relieve the faculty shortage include developing and implementing nontraditional methods of instruction to educate future instructors, increasing public and private funding to expand nursing education programs and improve the profession's image, creating a work environment conducive to recruiting and retaining nurse faculty, increasing formal partnerships between schools of nursing and clinical facilities, and engaging retired nursing faculty in support of current faculty.

Physician Assistants

There were 2674 physician assistants in practice in North Carolina in 2005.[26] North Carolina is the birthplace of the PA profession with the first PA education program established at Duke University in 1965. For many years there were two PA programs in the state, at Wake Forest University and Duke, graduating fewer than 80 PAs a year. East Carolina University and Methodist College established PA programs in the mid 1990s, and the annual output of PAs in the state is now greater than 150. The number of PAs in the state has increased 140% since 1990. The practice environment for PAs in North Carolina has been rated the best in the nation, and this serves as a powerful incentive to in-migration.[27] Physician assistants are all trained as generalists, and thus they can provide primary care or be deployed in a variety of surgical and medical specialties. The Bureau of Labor Statistics ranks PA the 4th fastest growing occupation from 2004 to 2010,[28] and the applicant pool to PA programs nationally remains robust. Barriers to expansion of PA programs, nationally and in North Carolina, include adequate financial aid, expanded clinical rotation sites, and local constraints on facilities and resources within institutions.

Recommendations

The North Carolina Institute of Medicine Primary Care and Specialty Supply Task Force recommendations recognize the contributions of nurse-midwives, nurse practitioners, and physician assistants to access to high quality health care for North Carolinians. One option identified to address the practitioner shortage is to increase the production of CNMs, NPs, and PAs by 30%. Although the challenges to such an expansion vary by discipline, there are some overarching themes: the need for adequate faculty and educational resources (including clinical rotation sites and financial aid for students) and the impact of the practice environment on retention of clinicians trained in the state.

A shortage of nursing faculty is an ongoing concern because many educators are approaching retirement. Strategies for increasing the number of faculty in nursing programs include improved salaries, faculty development opportunities, and improved work environment. While the number of physician assistant faculty is currently adequate, expansion of PA programs would likely engender similar difficulties.

Adequate funding for education programs is critical, as is access to clinical training sites. Clinical rotation availability is often cited as a reason not to expand medical school class sizes, and the situation is no different for CNM, NP, and PA educational expansion. In North Carolina, adequate funding of the Area Health Education Centers (AHECs) to expand the stipend for primary care preceptors will be a key factor in assuring adequate clinical training sites.

Underrepresented minorities and disadvantaged candidates for health professions programs face greater barriers to affording education, yet they are more likely to care for the medically underserved. Adequate financial aid packages, including scholarships and loan forgiveness programs, are central to enhanced diversity and deployment of clinicians to where they are needed most.

The foundation for recruitment of CNMs, NPs, and PAs from other states and retention of those educated here once they graduate is the regulatory environment. From the physician assistant perspective, North Carolina's environment is ideal, and it is ranked first in the nation for PA practice.[27] Nurse practitioners and nurse-midwives see the need for improvement in the practice environment to better align regulation with appropriate scope of practice and utilization.[24] For all three disciplines, legislated authority should coincide with clinical ability as precisely as possible. This requires an appropriate balance between assuring protection of the public and enhancing the ability of these clinicians to deliver care within their scopes of practice. **NCMJ**

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COMMENTARY

Recruitment and Retention of Physicians and Primary Care Practitioners for North Carolina:

A Partnership Approach

Torlen Wade; Margaret L. Sauer, MS, MHA; Christine Kushner

Population growth, the aging of the population, and an increase in chronic disease—all are expected to increase North Carolina's demand for physicians, physician assistants, nurse practitioners, and other practitioners. Overall in North Carolina, the ratio of all practitioners-to-population is expected to drop between 2% and 13% by 2030.[1]

This will continue to strain counties and communities that historically have had practitioner shortages. In 2005, all or parts of 38 counties in North Carolina remained persistently medically underserved.[2] Without targeted strategies to recruit medical practitioners, access to health care in underserved areas of North Carolina will likely be more difficult than ever. In an effort to defray the effects of these trends, the NC Office of Rural Health and Community Care (ORH, formerly the Office of Rural Health Services) and the NC Medical Society Foundation's Community Practitioner Program (CPP) work as allies to offer loan repayment, financial incentives, and expert technical assistance to support primary care medical practitioners serving medically underserved patients in rural communities. Together, and with other key partners in the state, these organizations have created additional medical access points in rural North Carolina and powerful tools to attract and retain primary medical care services in our state. These partnerships have created one of the strongest recruitment and retention systems in the nation. Yet, while North Carolina is still seen as a leader, many other states are catching up, providing community development, comprehensive and compatible matching in recruitment, and other longer-term support for rural and underserved practices. Now, more than ever, the partnership is critical to meeting the state's growing need for primary care practitioners.

> *"In order for North Carolina to maintain its competitive advantage, collaboration among all the stakeholders is critical and funding is essential to meet the present and future demands on our health care system."*

Recruiting Health Care Practitioners to North Carolina

In 1973, the NC ORH began its mission of establishing community-based primary care medical centers in rural and underserved parts of North Carolina. The staff soon found they needed the capacity to recruit physicians, physician assistants, nurse practitioners, and other practitioners to these sites, so in 1975 the ORH began its Medical Placement Services (MPS) program. In the mid-1990s, the NC General Assembly recognized the severe shortage of general dentists in many parts of North Carolina, and recruiting dentists and dental hygienists was added to the mission of the ORH Medical Placement Services.

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Accompanying the move toward recent mental health reform, in 2005 the legislature provided $1 million annually to ORH to expand the recruitment of psychiatrists to rural and underserved communities that had a shortage or absence of mental health professionals.

Since its inception, MPS has recruited more than 3000 primary care physicians, dentists, nurse practitioners, physician assistants, psychiatrists, and other practitioners to the state.[3] More than half of those placements have been at sites federally designated as health professional shortage areas (HPSAs). Over the course of its history, MPS has contracted with more than 300 communities across the state and at any given time has 350 to 450 different opportunities to offer, including private practice, health departments, federal community and migrant health centers, and state rural health centers.[3] Each year, the staff recruits approximately 140 practitioners to the state, almost all of them serving in medically needy communities, most of them rural towns and counties.

As incentives to placement, physicians, psychiatrists, and dentists locating in medically underserved communities are eligible for up to $70 000 in State Loan Repayment funds for a 4-year commitment. Physician assistants, nurse practitioners, and dental hygienists are eligible for up to $30 000 in State Loan Repayment for a 3-year commitment. MPS receives about $1.4 million each year for primary care and dental loan repayment incentives. One month into the state's fiscal year, most of the funds are obligated to practitioners waiting to receive the funds and relocate to North Carolina.[4] The MPS staff also coordinates applications for Federal Loan Repayment funds and offers state-sponsored High Needs Bonuses, providing greater flexibility in responding to each recruited practitioner's financial needs.

The ORH programs make a critical difference for both new and established practices across the state. Jo Hudson, an administrator with Benson Area Medical Center in Johnston County, said the health center has used ORH services for the past 28 years. "As a community-owned nonprofit rural health center, we often struggle to offer a salary and benefits package that can compete with those offered both in the private sector and in the federally-funded centers," she said. "The State Loan Repayment Program has made the difference for us."

Over the years, ORH staff members have developed strong and ongoing relationships with the state's primary care residency programs, the University of North Carolina at Chapel Hill School of Dentistry, and the 9 Area Health Education Center (AHEC) programs. ORH staff work to build an individualized and trusting relationship with each potential candidate, conducting in-depth interviews and creating an ongoing relationship to gather information on each candidate's professional qualifications, personal and professional goals, and specific individual needs. This one-on-one attention is continued throughout the recruitment process.

The success of the MPS staff hinges on its detailed knowledge of the communities it recruits for. ORH has helped establish numerous practices across the state, which enables staff to give prospective candidates unique details about each site. In addition, MPS staff regularly confers with ORH consultants, community representatives, business leaders, as well as hospital and other health care administrators to accurately assess local health personnel needs and develop effective recruitment strategies.

Adding Resources to Recruitment and Retention Efforts

In the late 1980s, state leaders recognized that the ORH alone was not able to fulfill all the state's recruitment needs. In particular, the state office had few options to help private practitioners who worked outside a community-based or publicly-financed medical system, yet many private physicians were struggling to enter or maintain a rural practice in high-needs communities—communities that needed primary care practitioners.

In 1989, the NC Medical Society Foundation (NCMSF), ORH, the NC AHEC Program, and the Kate B. Reynolds Charitable Trust conducted a needs assessment to determine new strategies, and a $4.5 million grant from Kate B. Reynolds Charitable Trust created the Community Practitioner Program. A program of the NCMSF, CPP was created to assist practitioners and sites not eligible for ORH incentives. The Community Practitioner Program uses its funds to provide loan repayment and financial incentives to physicians, physician assistants, and family nurse practitioners in return for 5 years of service in a targeted medically underserved community. The program typically pays up to half of a practitioner's educational loans and provides practice management assistance through its PractEssentials program to participants and their practice sites. Currently, 103 health care professionals participate in CPP in nearly half of North Carolina's 100 counties. Since its inception, 365 practitioners in 136 communities have been served by the program in 77 counties. About three-fourths of the participating practitioners remain in rural or economically distressed counties beyond their 5-year commitment, and 85% remain in North Carolina.

Beth Hodges, MD, said the chronic shortage of physicians was evident when she and her husband began their family practice in Asheboro with CPP help. "When we opened our practice, we acquired many patients who had not seen a doctor in more than 20 years," she said. "Now, 6 years later, hardly a day goes by that we do not receive thanks from someone for making such a difference in their mother's, father's, or grandparent's life."

From the initial grant provided by Kate B. Reynolds Charitable Trust, $10 million in program expenditures have been leveraged producing $226 million in health care to uninsured North Carolinians through CPP. In 2006, the Blue Cross and Blue Shield of North Carolina Foundation entered into a $10 million, 5-year partnership to sustain CPP; the grant requires a $5 million match from other sources. To date, some of the matching funds have been obtained from the NC Medical Society, Medical Mutual Insurance Co., the Physicians Foundation for Health Systems Excellence, individual physicians, and philanthropists. As a result, by 2010, CPP is projected to increase the number of practitioners assisted on an annual basis

Table 1.
North Carolina Loan Repayment Program Attributes

	NC Office of Rural Health-Medical Placement Services Program	NC Medical Society Foundation-Community Practitioner Program
Budget	$1.4 million primary care annually $1 million psychiatric care annually	$700 000 annually
Funding source	State of North Carolina	Grants from Kate B. Reynolds Charitable Trust, Blue Cross/Blue Shield of North Carolina Foundation, The Duke Endowment, Golden Leaf Foundation
Loan repayment limit	Maximum $70 000	At least half of medical school loan debt
Obligation	Up to 4 years	Up to 5 years
Eligibility	Must practice in community-based nonprofit in a health professional shortage area (HPSA)	Prioritize those practicing in HPSA designated regions, open to private practices treating patients and with a Medicaid, Medicare, and indigent care population constituting at least 30% of their practice
Provider eligibility	Primary care physicians, psychiatrists, dentists, dental hygienists, nurse practitioners, physician assistants, and nurse midwives	Primary care physicians, nurse practitioners, and physician assistants
Application process	Conducted through the Office of Rural Health staff	Application is completed for initial determination, followed by interview with the participant, practice manager, and supervising physician
Coordination of federal loan program resources	Yes	Applicant is ineligible if qualified for federal/state loan repayment programs
Practice management resources	Office of Rural Health and Community Care staff	PractEssentials through NC Medical Society Foundation
Flexible funding	Yes	Yes
Communities served	More than 400	More than 136
Counties served	100	77
Program participants 2006	198 (loan repayment and placements)	103 (loan repayment and placements)

from 103 to 160, increasing annual patient visits from 2 310 000 to 3 696 000.

Primary Care Recruitment: The Changing Landscape

The 1990s saw increased interest nationally in state-based recruitment programs. By 1996, there were 82 different programs in 41 states working to recruit health professionals to underserved communities.[5] Programs in other states include loan repayment, scholarship programs, financial incentives, and residency support. There continues to be greater national competition for practitioners interested in serving rural and remote communities.

With increased pressure on supply, in the 1990s greater emphasis was placed on retaining existing practitioners. Retention in rural North Carolina improved when the federal National Health Service Corps moved from obligating scholars to fixed years of service based on front-end medical school scholarships to loan repayment that recruited medical residents who had been through training and recognized a desire and willingness to practice in a rural or medically underserved area, according to Tom Tucker, a veteran recruiter with ORH. Practitioners who signed up as scholars to pay for medical school had low retention rates and usually left their NHSC site when their obligation was completed. Those recruited after residency through loan repayment have higher retention rates, he said.

In recent years, as the legislature expanded ORH's responsibilities to include recruiting psychiatrists, mental health professionals, and dentists, funding has not been commensurate with the increased demands to recruit practitioners. The 2007-2008 proposed budget allocates an additional $500 000 for loan repayment, funds that will increase the ORH's current resources of $1.2 million for primary care and $1 million for mental health. The proposed increase will help North Carolina stay competitive in the national recruitment process, but it does not return the ORH to the peak of $1.8 million it had in 2002 for primary care incentives. North Carolina remains unique with its extensive and varied resources for recruitment. Other states recognize the value of the programs piloted in North Carolina to meet critical access needs of their residents. In order for North Carolina to maintain its competitive advantage, collaboration among all the stakeholders is critical and funding is essential to meet the present and future demands on our health care system.

Working Together

Leaders from the Office of Rural Health and the Community Practitioner Program have coordinated efforts from the beginning. Staff members from ORH and CPP meet regularly to discuss candidates, look over opportunities, and discuss overall workforce needs and strategies. They also continue to meet regularly with key partners including the NC AHEC Program, the NC Hospital Association's Rural Health Center, the NC Division of Public Health, granting organizations, and other state agencies to analyze trends and strategies concerning health professional supply, workforce issues, and opportunities for collaboration.

"If it weren't for the close collaboration between the Office of Rural Health and the CPP, I would not have found Sampson County," said Art Apolinario, MD, who practices in Harrells and Newton Grove. "It just never really occurred to me that my perfect practice experience could come from one of the most rural counties in the state. Knowing they were behind me and my potential success in the communities of Newton Grove and Harrells made me that much more confident that a lifestyle and practice in Sampson County could work for me and my family. They worked hard to make sure I would match with these communities, and that has made the biggest difference in ensuring I would stay in the community."

North Carolina's ORH and CPP, together with their partners, give the state a national competitive advantage to recruit for medically underserved communities. By working together, they also maximize their resources and partner to recruit high-quality health professionals who will remain in North Carolina's rural and underserved communities. **NCMJ**

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COMMENTARY

Rural Hospitals and Rural Physicians:

Understanding the Physician Workforce Challenges that Affect Rural Communities and Providers

Larry H. Chewning, MHA, FACHE; Jeff Spade, CHE

Rural communities across North Carolina are constantly and increasingly facing significant challenges to their fragile health care systems. The health of rural North Carolina citizens depends on a delicate balance between health care providers; health system resources, facilities, and service development; community, public health, and social support structures; and the underlying health status of the community. Unfortunately, practitioner shortages have a significant potential to unbalance North Carolina's effective but fragile rural health care system.

Rural hospitals and their associated physicians and medical staff are particularly critical aspects of rural health care networks. As a consequence, rural hospitals and physicians are highly dependent upon each other to create services, resources, and access points that ultimately support community health improvements, prevention of disease, and treatment for chronic and acute illness and injury. In order to understand the community-wide impact of the availability of trained, reliable physician resources for rural North Carolina communities and hospitals, please consider the following North Carolina case studies.

> *"Physician recruitment and retention are among the most, if not, the most important issues faced by hospitals today. For rural hospitals, the success of the recruitment process is often termed as a "life and death" objective.*

Vulnerability to Specialty Practitioner Shortages

A 150-bed rural community hospital in eastern North Carolina has provided urology services for 80 000 citizens in the county and local communities for the past 40 years. Recently, one of the two urology physicians practicing in the community and providing care at the hospital decided to terminate his relationship with the practice and move out of state. The decision was based on family decisions as well as lifestyle issues. The physician was beleaguered by a call schedule that required 7 days on, then 7 days off, to provide coverage for the two physician practice.

The rural hospital and the urologist remaining in the practice developed a strategy to successfully restore full physician coverage to the urology practice, including amendments to the hospital medical staff bylaws to create a maximum call exposure of 10 days per month for any physician specialist. The rural hospital and the urologist then began an extensive recruitment process to replace the departing physician partner. Three months after the departure of the first urologist, the remaining urologist decided to depart the practice, leaving the rural hospital and the community as well. Thus, in just 6 months, a vibrant, thriving, and strong urology practice serving a significant rural community had completely collapsed. The consequences for patients in the rural community were devastating, requiring patients and families to seek care and physician relationships across county lines, further from home.

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For the rural community hospital, losing the urology practice led to an immediate loss of hospitalized patients, causing urology patients to bypass the rural hospital to receive basic outpatient services elsewhere and, ultimately, resulting in substantial decreases in surgical and diagnostic procedures and an estimated net revenue loss of $2 million annually.

Subsequently, the rural hospital worked diligently to negotiate a partnership with a multi-physician urology practice affiliated with a larger urban hospital more than 60 miles away for one day per week of urology coverage in the rural community. Eventually, a full-time urologist was recruited to join the group practice and encouraged to develop a satellite clinic. The rural hospital estimates that the 6-month disruption in urology services will require nearly 3 years of persistent effort to bring services and volume back to where it was prior to the departure of the physicians. Reflecting on the difficult and untimely situation, the rural hospital CEO confirmed, "Recruiting another urologist to suburban North Carolina really doesn't matter. However, one urologist at our community hospital means the difference between 80 000 people receiving care locally or patients having to leave their local community to seek care."

Case Study of Successful Rural Hospital Physician Recruitment

A rural hospital in eastern North Carolina successfully operates a family medicine clinic in a remote rural community of approximately 4000 people located 10 or more miles from the rural hospital. The physician practice served as the only full service primary care clinic in the area. The practicing physicians held hospital privileges and were supported by the rural hospital's existing medical staff structure. After many years of practice, both the physician and family nurse practitioner announced their intent to leave the hospital-supported clinic. The decision left the rural community without immediate access to primary care. The rural hospital immediately began a search to replace the physician and primary care providers.

While the rural hospital is located within an hour and a half drive of 4 major North Carolina physician training programs that focus on primary care, North Carolina's training programs are not the usual resource for recruiting and locating new primary care physicians in this rural community. Of the 10 most recently recruited primary care physicians, only one physician had completed primary care training at a North Carolina-based physician residency program.

The rural hospital was successful in recruiting a husband and wife physician team from Ohio. The key success factors that achieved this recruitment opportunity included:

- Physician interest in the small town setting.
- The appeal of North Carolina as a place to both practice medicine and develop an attractive lifestyle.
- Recruitment support packages offered by the hospital including income guarantees for the practice and assistance with relocation expenses.
- An existing practice with active patient files, well-designed facilities, and readily available office staff.
- Access to a supportive community hospital with a full service compliment of diagnostic capabilities and physician specialists.
- The availability of a weekend hospitalist service, which allows the primary care physicians time off as they develop their practice.

The rural primary care practice is a striking success story. The community has been extremely receptive to the new physicians and their commitment to expand their base of patients. The financial incentives provided by the rural hospital served the practice well during their initial start-up. Financial assistance from the North Carolina Medical Society Foundation proved beneficial to the initial success of the practice as well.

Physician Recruitment and Retention

Virtually all North Carolina rural hospitals are actively and constantly recruiting physicians across many specialties to meet critical physician shortages. Recent surveys from state hospital associations and the American Hospital Association document the recruitment of new physicians to hospitals' medical staffs for small, medium, and large rural community hospitals. Physician recruitment and retention are among the most, if not the most, important issues faced by hospitals today. For rural hospitals, the success of the recruitment process is often termed as a "life and death" objective. The strategic value of the appropriate composition and continued development of the medical staff is critical due to the following factors:

- Each new physician generates incremental, new revenue for the hospital. Physicians with surgical specialties are particularly valuable in creating revenue opportunities for rural hospitals.
- Each new physician expands the market share of the hospital, allowing patients to receive health care services in their rural community.
- Success breeds success. Each new physician recruited to the medical staff improves the image of the rural hospital and the community and, in turn, helps attract more new physicians.

General Lessons Learned

Rural hospitals tend to serve communities whose demographic profiles are more difficult from a health standpoint than the urban hospital counterparts. Typically, communities served by rural hospitals are more elderly and have higher proportions of uninsured residents. Rural community residents also have higher incidence of chronic disease and lower per capita incomes. Recent studies published by the Cecil G. Sheps Center for Health Services Research at the University of North Carolina at Chapel Hill document Duplin County and Sampson County in eastern North Carolina as experiencing the highest uninsured vulnerability rate (approximately 25% of the population) throughout North Carolina. Duplin and Sampson are excellent examples of typical rural North Carolina counties served by rural community hospitals based within the county.

In addition, the specialty mix of physicians and services do not reward rural community hospitals. On average, the hospital service lines that feature tertiary services in cardiology, oncology, and surgical subspecialties are able to generate significantly higher operating margins than the primary and secondary care services characteristically offered at rural community hospitals. Obviously, the key to offering specialty services is linked to the availability of specialty physicians. Unfortunately, many of the medical and surgical specialty physicians tend to be in short supply in rural community hospitals.

Obstacles to recruitment of new physicians to serve communities and rural community hospitals are numerous. Many of the critical issues that impact rural physician recruitment and retention are summarized below.

- Lifestyle—Many physicians and their families prefer the amenities available in larger, more metropolitan or suburban areas. Recruitment to a rural community is particularly difficult when neither the physician nor his/her family has any experience living or practicing outside of an urban area.
- Unintentional medical school bias—Many physicians that choose to practice in rural communities relate that there is an informal, but visible, bias communicated in their medical school and residency training against practicing in rural areas. Most of this subtle bias focuses on the absence of medical technology, lack of research, professional isolation, and fewer continuing education opportunities available in rural areas.
- Call coverage—Call coverage for both the practice and the rural hospital can be a particularly thorny issue for specialty physicians practicing in rural areas. Typically, surgical subspecialties may be solo practitioners or small group practices. It is essential that rural hospitals establish a reasonable call schedule for physicians practicing in specialties with only a few physicians on the call panel.
- Payor mix—As demonstrated earlier, payor mix issues can present a significant financial barrier for both rural physicians and rural hospitals. There is a tendency for well-insured patients to seek care in urban or suburban environments. These patients have the ability to travel easily and bypass their local hospital and physician, leaving behind uninsured patients and poor citizens who are dependent on government insurance to receive adequate health care.

Potential Solutions

Physician recruitment to rural communities is not always a frustrating process. There are certain attractive features for a rural community that the astute physician can understand and may often prefer. For example, there tends to be little or no managed care in rural North Carolina communities due to low population densities. Most rural community hospitals are underserved for physician supply in nearly every specialty, thus, there is very little competition between groups or physicians. In addition, physician productivity is better awarded through seeing and treating a larger number of patients.

Furthermore, the cost of living is usually more reasonable and affordable in rural communities. This is particularly noticeable in the cost of housing and land. The camaraderie of the medical staff tends to be a reinforcing factor in rural community hospitals. There is a great sense that “we are all in this together.” Perhaps the greatest physician recruitment advantage rural community hospitals have is the ability to use financial incentives to attract new physicians to rural communities. Federal and state regulatory guidelines governing inducements offered to new physicians permit hospitals in rural underserved areas to offer financial incentives to attract new physicians in return for their service to the community and hospital. The approved financial inducements may include a start-up bonus, income guarantees, medical school loan repayment, and the marketing of the new physician’s practice in the service area of the hospital. Successful rural hospitals will have to build upon these advantages and work closely with programs throughout the state that offer recruitment and retention assistance. **NCMJ**

COMMENTARY

Location, Location, Location:
North Carolina Faces a Shortage of Primary Care and Specialty Practitioners in Rural and Underserved Counties

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Erin P. Fraher, MPP

It was a downturn in the overall supply of physicians per 10 000 population that prompted the North Carolina Institute of Medicine (NC IOM) to examine the emerging physician shortage in North Carolina. However, what will ultimately matter, and what presents the most pressing policy challenge, is whether we will be able to get the right mix of practitioners in the right places to meet the health care needs of North Carolina's citizens.

Health workforce researchers have long debated how to define a workforce shortage (ie, how many practitioners are too few?), what constitutes the right mix of primary care and specialist physicians to meet population needs, and what is the ideal balance of physician and nonphysician practitioners such as physician assistants, nurse practitioners, and certified nurse midwives in a particular health care setting. While these are important topics to discuss and debate, we must make policy decisions now based on our best understanding of the information currently available. The objective of this commentary is to use data from the North Carolina Health Professions Data System (HPDS) to summarize what we know about the supply and distribution of primary care practitioners, practitioners who deliver babies, general surgeons, and psychiatrists and to suggest what might be done to address shortages and maldistribution of practitioners in these specialties.[a]

> *"Rural counties that have traditionally fared poorly in the competition for practitioners appear to be worse off now than in the past and the existing maldistribution will be exacerbated as the overall physician supply tightens."*

Primary Care Practitioners

Primary care practitioners (PCPs)[b] are those providers who see patients with the most common medical problems. Primary care practitioners serve as the entry point into the medical system for most patients, and they coordinate care for patients requiring specialty services. While there is some evidence that fewer practitioners are selecting primary care specialties,[1] North Carolina continues to have more primary care physicians relative

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a Undoubtedly shortages of other specialty providers exist but data and resource limitations prevent a fuller examination of all specialty areas. For example, although we know that North Carolina's rapidly aging population has increased the demand for geriatric care, in 2005 only 293 physicians reported a primary or secondary specialty in geriatrics or family practice, geriatrics. Physicians in other specialties (ie, internal medicine) are providing geriatric care, but without information on the physician's patient panel there is no way to assess the adequacy of supply.

b Primary care practitioners are defined as physicians, nurse practitioners, and physician assistants who indicate a primary specialty in general practice, family practice, internal medicine, obstetrics and gynecology, or pediatrics. All certified nurse midwives are considered to be in primary care.

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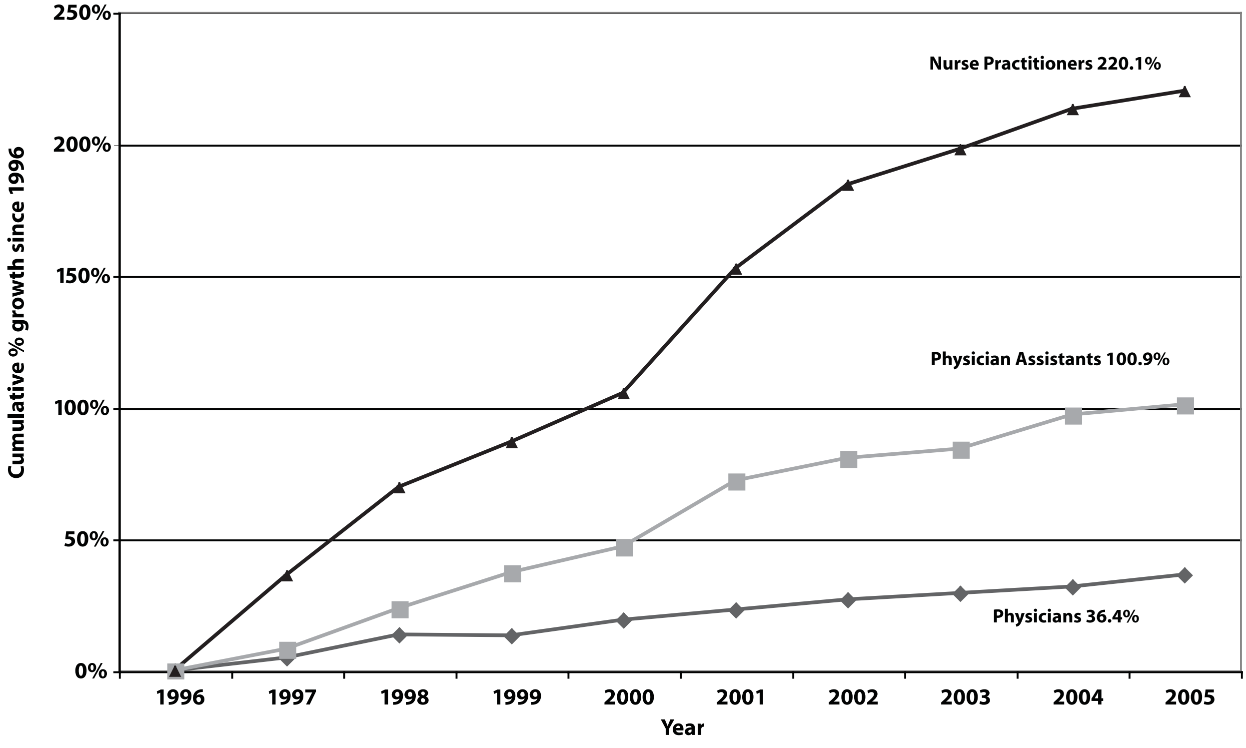
to population size than the United States average.[2] Nurse practitioners (NPs) and physician assistants (PAs) make up an increasingly important component of North Carolina's primary care workforce. Over the past decade, the supply of primary care NPs and PAs outstripped physician growth. While physician supply grew by 36.4% between 1996 and 2005, NPs increased by 220.1% and PAs grew by 100.9%. (See Figure 1.) The rapid growth of PA and NP supply has been especially important in rural areas of the state. Between 2001 and 2005, almost half (47%) of the 264 primary care practitioners gained in rural counties were either NPs or PAs. Despite these gains, North Carolina has faced an increasing shortage of primary care practitioners in the state's most underserved counties. Between 2001 and 2005, 30 counties experienced a decrease in primary care practitioners to population ratios compared to 11 counties between 1996 and 2001. Fourteen of the 30 counties where supply declined relative to population have been designated as primary care health professional shortage areas in 6 of the past 7 years.[1] The net result of these trends is that while the overall supply of primary care practitioners is not yet problematic, there is a maldistribution of practitioners across the state.

Practitioners Who Deliver Babies

An important component of primary care is access to obstetric care services. Despite significant anecdotal evidence that fewer providers are delivering babies in North Carolina due to rising malpractice rates, the number of obstetricians/gynecologists and family physicians who reported delivering babies rose between 2000 and 2005. Concomitantly, the number of births per delivering physician declined from 139.3 in 2000 to 125.7 in 2005.[c] The supply of certified nurse midwives also increased over the period from 167 in 2000 to 195 in 2004. An important caveat to this generally good news about the supply of obstetric care practitioners is that between 2003 and 2004 there was a 12% decline in the number of family physicians (FPs) delivering babies, and of the 101 physicians who stopped providing deliveries between 2003 and 2004, 56 (56%) were FPs. This represents a disproportionate share since family physicians comprise just 10% of total physicians delivering babies. This trend does not bode well for the distribution of obstetric care in rural areas because family physicians provide 26% of delivery services in rural counties. If their numbers continue to decline at such a rapid rate or action is taken on the

Figure 1.
Cumulative Percent Growth in Primary Care Physicians, Physician Assistants, Nurse Practitioners, and Certified Nurse Midwives, Relative to 1996



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[c] There was a slight decrease in the supply of physicians delivering babies between 2004 and 2005, but it is unclear whether this decrease reflects a true trend or a data aberration caused by a change in the way the Medical Board collects this information from physicians.

currently debated question of removing obstetrical training from FP training programs, the supply of practitioners who deliver babies in rural areas may be further compromised. As it is, there are 19 counties in North Carolina without a physician who delivers babies;[d] 12 of these counties have not had a physician deliver a baby in the last 5 years. While there is evidence that the average distance traveled by women delivering babies has not increased,[3] it is not known whether birth outcomes are worse for mothers in counties with no or limited access to obstetrical care.

General Surgeons

Workforce patterns for surgeons echo that of other specialties with an adequate, but poorly distributed, supply. With 0.75 general surgeons per 10 000 population, North Carolina has more general surgeons than the US average (0.60) or other southern states (0.64), but between 2000 and 2005 more than half (53) of North Carolina counties experienced a decrease in the supply of surgeons relative to population, and 5 counties lost all their general surgeons. Seventeen counties had no general surgeons in either 2000 or 2005. General surgeons are a difficult specialty to study from a workforce planning perspective because although they are trained to provide a wide range of surgical services, general surgeons tend to narrow their scope of practice over time in response to the demands exerted by the rapid growth of medical knowledge, patients in their practice, and personal factors.[4] More research is needed to better understand and monitor the supply of general surgery services in the state.

Psychiatrists[5]

North Carolina is currently in the process of redesigning the way mental health services are delivered. As the provision of mental health services is divested from centralized agencies to community settings, it is crucial to know whether there will be practitioners to care for patients at the community level. While a broad range of professionals treat individuals with mental health disorders, a subset of patients requires consultation and pharmacological treatment by psychiatrists. The overall supply of psychiatrists in the state has been keeping pace with population, and North Carolina ranks 20th in the nation with a ratio of 1.05 psychiatrists per 10 000 population. However, two-thirds of North Carolina counties lost psychiatrists relative to population growth or had no psychiatrists between 1999 and 2004.

Examining the supply of psychiatrists relative to primary care physicians is another important perspective from which to examine the issue because in the absence of psychiatrists the burden of diagnosing and managing mental illness will likely fall on primary care physicians who may also be in shortage. In 2004, 19 counties in North Carolina faced a persistent shortage of primary care physicians; 11 of these 19 counties also had a psychiatrist shortage.

Of more concern than the overall supply of psychiatrists is the shortage of child psychiatrists in the state. A recent study of North Carolina pediatricians found that about 15% of children had a behavioral disorder such as attention deficit disorder, anxiety, or depression.[6] While PCPs can diagnose and treat many common childhood mental illnesses, a child psychiatrist is needed for more complex cases. In 1995, the state had 102 physicians reporting a primary specialty in child psychiatry, but this number dropped to 91 in 2005. During the same period, the population 18 years and younger grew by 21%. The net effect of these trends was that the ratio of child psychiatrists per 10 000 population aged 18 years and younger dropped 26% (from 0.55 to 0.41). Distribution is also a problem—in 2004, 43 counties had no child psychiatrists and another 42 counties had fewer than one full-time-equivalent.[e]

So What? Crafting Policies to Address Shortage Issues

The shortage of child psychiatrists is acute and action needs to be taken to increase supply and improve distribution. The long-term ramifications of not taking action will be deleterious for North Carolina's health care system. As children who receive suboptimal or no psychiatric care mature, they are likely to require even more mental health services than if they had been treated earlier. Lack of access to mental health services will also have personal costs that are borne by children and their parents and societal costs if children are not able to reach their potential due to a lack of access to mental health services. Options include increasing the number of child psychiatry positions in North Carolina residency training programs and placing these positions in community-based teaching sites in rural and underserved communities. The thorny issue of reimbursement must also be addressed. Given that many North Carolina rural communities face both a shortage of primary care and psychiatric physicians, private and public payers need to reimburse for face-to-face and telemedicine consultations between the two practitioner groups. Resources also need to be devoted to developing innovative models of interdisciplinary care that do a better job incorporating nurse practitioners and physician assistants with mental health competencies into the psychiatric workforce team.

With the exception of child psychiatrists, North Carolina's current supply of primary care and specialty practitioners is adequate to meet population needs, but there is a maldistribution of practitioners across the state. Rural counties that have traditionally fared poorly in the competition for practitioners appear to be worse off now than in the past, and the existing maldistribution will be exacerbated as the overall physician supply tightens. To reverse this trend, decision makers must focus attention not only on high visibility options such as developing new or satellite medical schools, but must also

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[d] These data include physicians' reported primary, secondary, and tertiary practice locations.

[e] Data include primary, secondary and tertiary practice locations for physicians reporting a primary specialty in psychiatry.

consider a broad range of policy interventions to encourage and support rural practice. Strategies that address the maldistribution by increasing overall supply rely on a “trickle down” assumption that practitioners will diffuse across geographic areas. Although research supports a general diffusion of practitioners from urban to rural areas,[7,8] past experience has shown that more direct policy action is needed to locate practitioners in underserved areas. Resources need to be invested in placing training programs and clinical rotations in underserved areas of the state because practitioners are more likely to settle near where they train. Financial incentives need to be crafted that not only encourage physicians to move to rural areas but to remain there as well. Loan repayment has proven an effective tool in recruiting physicians to rural areas,[9] but longer-term strategies to reduce professional isolation and workload need to be implemented to address rural physician retention. North Carolina has a well-established history of collaborative action between health workforce stakeholders that makes it well positioned to both digest, and act upon, shortages of primary care and specialty practitioners. **NCMJ**

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Increasing Minority Representation in the Health Professions:
One Student at a Time

Patrena N. Benton, MS

Beyond sporadic trips to the clinic for immunization shots, they have limited opportunity to communicate with a physician. A majority of these individuals have never crossed the threshold of a dental office, and they may not understand what the man behind the counter at the local drug store really does. Who are "they" you ask? "They" are the many minority and disadvantaged students who have had limited contact with adequate health care and little to no exposure to any health care practitioners who mirror their image. It is important to understand some of the contributing factors to this harsh reality.

Health Disparities

Many Americans are living longer, and their overall health is improving. However, despite a steady improvement in the overall health of the US population, racial and ethnic minorities, with few exceptions, experience higher rates of morbidity and mortality than nonminorities.[1] This holds true for the citizens of North Carolina. Over the past few decades, enormous strides have been made to enhance the health status and quality of life of all North Carolinians. However, in spite of these gains, a large segment of the state's racial and ethnic minorities, particularly African Americans, American Indians, and Hispanics, continue to experience a disproportionate burden of poor health and premature mortality compared to their white counterparts.[2] Several studies have shown that even with equivalent levels of access to care, racial and ethnic minorities experience a lower quality of health services and are less likely to receive even routine medical procedures than white Americans.[1]

> *"To a great extent, efforts to diversify health care fields have been hampered by gross inequalities in educational opportunities for students of minority racial and ethnic groups."*

In addition to examining this epidemic through national discourse, states are addressing the impact of health disparities on their local home fronts. North Carolina has a long-standing tradition of caring for the health of its citizens. Since 1968, the North Carolina Area Health Education Centers Program (AHEC) Medical Air Operations has transported health science faculty, medical residents, health science students, and university officials to the most remote areas of the state in dire need of health services.[3] In 2001, shortly after Governor Mike Easley appointed her as Secretary of the Department of Health and Human Services (DHHS), Carmen Hooker Odom declared eliminating health disparities a priority for the department. The Secretary charged the Office of Minority Health and Health Disparities (OMHHD) with lead responsibility for developing the DHHS Call to Action to Eliminate Health Disparities.[2] NC OMHHD and the State Center for Health Statistics released the Racial and Ethnic Disparities in North Carolina Report Card 2006. This document reveals some leading health indicators for broad racial and ethnic population groups for the state, provides supporting data for those health indicators, and assigns a letter grade that ranks the health status of those groups. For instance, the 2000-2004 prostate cancer death rate shown for African Americans (73.0) was divided by the prostate cancer death rate for whites (25.1): 73.0 ÷ 25.1= 2.9. This ratio shows that the prostate cancer death rate for African Americans was 2.9 times as high as the rate for the white population. According to the disparity ratio grading scale, this 2.9 receives a grade of "D."[4]

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As the state continues to aggressively focus on this health dilemma, it must also address the shortage of health care practitioners with specific emphasis on increasing the percentage of minority practitioners. Empirical evidence is mounting that compared to whites minorities are more likely to serve the underserved.[8]

Underrepresented Minorities (URMs) Missing from Health Careers

America is experiencing a "browning effect."[5] Due to the rapid increase in minority populations, the country is becoming increasingly more diverse. Unfortunately, the same cannot be said for the diversification of the health care professions. To a great extent, efforts to diversify health care fields have been hampered by gross inequalities in educational opportunities for students of minority racial and ethnic groups. The supply of URM students who are well-prepared for higher education and advanced study in health professions fields has thus suffered.[6] As stated in the Sullivan Commission's Missing Person's Report, increasing diversity in the health care professions will improve health care access and quality for minority patients and assure a sound health care system for all of our nation's citizens. It will also strengthen health care delivery systems at multiple levels, enhance educational experiences for all health professions students, promote relevant research and needed changes in health policy, and prepare our nation for the emerging and culturally dynamic health care challenges of tomorrow.[7] Therefore it is not difficult to surmise that increasing the diversity of our health care professionals is of immense benefit to all citizens. Consequently, health preparation programs are vital vehicles for developing this pool of future practitioners.

Over the years, various academic and enrichment programs have been established at universities across the country to address the shortage of minority and disadvantaged students entering into graduate and health professional programs. These programs have mainly focused on preparing students at the undergraduate and postgraduate levels. However, in order to increase the percentage of matriculants to a more significant level, students must be exposed to health careers at an earlier age.

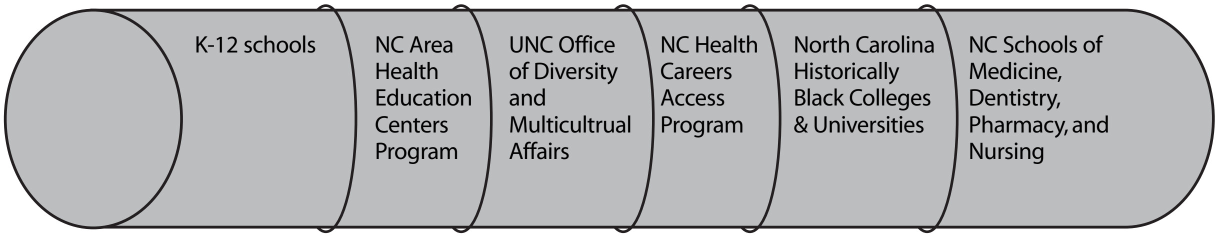
A North Carolina Comprehensive Pipeline Approach

In theory, a pipeline from primary to secondary to postsecondary education and finally to professional training channels the flow of a diverse and talented stream of individuals into the nation's health care workforce. However, in reality, not all students flow equally through the pipeline to the health care professions. Instead, race and ethnicity often substantially influence an individual's forward motion at every stage of the pipeline.[7]

Through years of effective collaboration, many North Carolina institutional partners have worked to create seamless pipeline approaches to increasing opportunities for minority and disadvantaged students pursuing health careers. Collaborators from various sectors of the state such as the K-12 public schools, statewide centers, historically black college and universities, and private and public higher educational schools have created a notable comprehensive pipeline approach.

Over the last three decades, several North Carolina programs were created to address the underrepresentation of minority and disadvantaged students in the health professions. Founded by Dr. Cecil G. Sheps in 1971, the North Carolina Health Careers Access Program (NC-HCAP) is one such program. Together with the North Carolina AHEC Program, NC-HCAP's 4 campus-based centers have exposed thousands of North Carolina's K-12 students to health career offerings. Precollege students also benefit from additional structured programs that AHEC offers throughout the year. As students progress through their undergraduate careers, strong recruitment support is rendered by the University of North Carolina (UNC) Office of Diversity and Multicultural Affairs as well as health science advisors at minority serving institutions within the state. Undergraduate students with interests in various health professions apply for entry into NC-HCAP's Science Enrichment Preparation (SEP) Program. SEP is an 8-week, honors-level academic enrichment program for disadvantaged undergraduate students seeking to increase their level of competitiveness for admissions into graduate/health professional programs. Since its inception in 1979, 834 students have completed the SEP Program. Of that number, currently 86% of these participants are either practicing in a health care field, enrolled in health professions training programs, or completing undergraduate prerequisites for these programs.[9] Freshman and sophomore

Figure 1.
A Comprehensive North Carolina Pipeline Approach



college students interested in medicine or dentistry can apply to the Summer Medical Dental Education Program (SMDEP) at Duke University School of Medicine. For rising seniors and postgraduates with an interest in medicine or dentistry, the natural choice is the Medical Education Development (MED) Program sponsored by the UNC Schools of Medicine and Dentistry. MED offers a structured summer curriculum at the level of professional education to increase the ability of advanced preprofessional candidates, especially those who are disadvantaged, to compete successfully for admission to health professional schools. Since 1974, 88% of the 1886 students who have attended the MED summer program decided to apply to health profession schools. Ninety percent gained admission with 80% matriculating into medical or dental school; the remainder entered other health professional schools.[10] Clearly, this approach has successfully assisted many in becoming the health practitioners they are today. Yet, despite this history of success, the majority of these programs are in constant jeopardy of being eliminated.

Federal Budget Cuts

In addition to the support received by their host institutions, pipeline programs have existed due to the support of federal funding. However, when the federal administration's priorities shift so does the funding. Such a shift occurred in 2006 when the Bush administration enacted drastic cuts to the Health Resources and Services Administration's Title VII Health Professions Education Programs, which supports facilities, initiatives, and individuals engaged in health professions training with an emphasis on recruiting practitioners for rural and other medically underserved areas.[11] The President's 2008 budget has proposed a complete elimination of Title VII and nearly a 30% reduction in Title VIII Nursing Education Programs. This action has dire implications for the future workforce supply. These two funding streams are the only federal programs designed to train practitioners in multidisciplinary settings to meet the needs of special and underserved populations as well as increase the minority representation in the health care workforce. Graduates of these programs are 3 to 10 times more likely to practice in underserved areas and are 2 to 5 times more likely to be minorities.[12]

This federal action has in fact reduced and/or eliminated numerous health professional preparation programs across the country despite their long-standing successes. These programs must recognize their vulnerabilities and the need to validate their continued existence.

Future Direction: Data, Development, Discourse

Pipeline programs have been the saving grace for many minority and disadvantaged students aspiring to be health care practitioners. In light of funding woes, many of these pipeline programs forge ahead, recognizing that in order to create sustainability three areas must become a priority: (1) data collection, (2) development initiatives, and (3) discourse.

Institutional and policy-level strategies for increasing diversity in health professions, however, have been relatively understudied. This lack of emphasis may lead to a void of strategies should future policy changes erode efforts to increase diversity.[6] These programs are attempting to validate their existence through increased efforts to collect data on program graduates. This data collection will assist in demonstrating how many of their program participants completed additional pipeline programs, gained admissions into graduate or health professional programs, and ultimately graduated from these degree programs. Additionally, many of the above programs are striving to evaluate the total impact made not only on increasing the percentage of minority practitioners nationwide but also on how many have remained in North Carolina to serve the people of the state.

With the cyclical nature of federal funding and the economic reality of sparse institutional support, pipeline programs are forced to look in new directions for fiscal resources. One such direction is from their alumni base. The successful impact these pipeline programs have made on the lives of these individuals is evidenced by their willingness to give back. Alumni are demonstrating commitment of support through the development of scholarships and assisting in the creation and funding of program endowments. Additionally, foundations' attention to addressing health disparities and workforce shortages has been unwavering. Historically, they have allocated major funding to support efforts in these areas. As these health disparities and workforce shortages remain on the agenda of the state and nation, philanthropic institutions' interest and dedication to these pressing issues will not dissipate.

Pipeline program accomplishments must no longer be confined within their program walls but shared with the community at large. The disclosing of program outcomes through publications and presentations will assist in creating sustainability and the sharing of best practices and successful models for replication throughout the country.

As North Carolinians, we must continue to recognize that work still remains to be done and continue to be diligent in our commitment to the health of all of our citizens. It is imperative that the pathway to becoming a health professional is open to every student of our great state. Ultimately, we all benefit from a future health care workforce that is reflective of the growing diversity of our society.

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COMMENTARY

The Area Health Education Center's Role in North Carolina's Health Workforce Development

Thomas J. Bacon, DrPH; Samuel Cykert, MD

The North Carolina Area Health Education Centers (AHEC) Program was founded in the early 1970s to address critical shortages of health professionals, with a particular focus on the primary care needs of rural communities in the state. From the outset, AHEC was designed as a comprehensive workforce development program to augment the work of the academic health centers in preparing health professionals to meet the needs of these underserved communities. The AHEC Program was created under the premise that the state would only successfully improve the supply and distribution of health practitioners if it put in place a comprehensive, multidisciplinary set of regionally-based programs to influence all stages of the health professions education and practice pipeline. As a result, AHEC's core services include:

- Programs to recruit young people into health careers, with a special focus on underrepresented and disadvantaged students.
- Comprehensive community-based experiences for health professions students in communities across North Carolina.
- Primary care residencies to prepare physicians to meet the needs of underserved communities in the state.
- Continuing education programs for all types of health professionals to improve the environment for practice and strengthen the quality of health care.
- Library and information services to provide the latest health information for students, residents, and health professionals.

In order to increase the supply of primary care physicians in the state, primary care residency programs were established in 5 AHECs in the state in the 1970s. They were developed in collaboration with the large community teaching hospitals in Charlotte, Greensboro, Asheville, Wilmington, and Fayetteville. In addition, a substantial rotational site for University of North Carolina at Chapel Hill residents was created at WakeMed/Wake AHEC. These residency programs in family medicine, general internal medicine, pediatrics, and obstetrics and gynecology have graduated nearly 2000 graduates since the late 1970s. Of these, over 1100 are now practicing in North Carolina, providing vitally needed primary care services to communities across the state. Without these physicians, a substantially higher number of North Carolina counties would currently be categorized as health professional shortage areas than is currently the case.

In addition to primary care, since 1985 the AHEC Program has partnered with the 4 departments of psychiatry at the medical schools in the state. Through AHEC, psychiatry residents from all 4 schools receive rotations in community settings across North Carolina, many of these in rural and small towns. These rotations are designed to give residents experiences in community and public psychiatry and to expose them to opportunities for practice upon graduation. Although the evidence is antidotal, it appears that these experiences have increased the number of graduates choosing careers in the public mental health field.

> *"The AHEC Program was created ... to influence all stages of the health professions education and practice pipeline."*

The Area Health Education Centers Program has also been a partner in the dramatic growth in the numbers of students and graduates in the physician assistant, nurse practitioner, and

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nurse midwifery programs in the state. The Area Health Education Centers Program's support for community primary care experiences for these students has contributed to the schools' abilities to expand enrollments and further impact the availability of primary care services in the state. The number of primary care nurse practitioners (NPs) and physician assistants (PAs) has nearly doubled during the past 10 years to approximately 1300 NPs and 1100 PAs actively practicing in the state.

The mission to support North Carolina's health care workforce remains active and the North Carolina AHEC Program is addressing the state's primary care practitioner needs in several ways. First, the program continues its support for educational opportunities in the state's communities for medical, physician assistant, nurse practitioner, and nurse midwifery students at every level of training by recruiting preceptors, providing nominal preceptor payments, and arranging housing and library services for participating students from all schools in the state.

Second, AHEC-supported primary care residency programs, with a robust 65% North Carolina retention rate, continue to serve as an efficient reservoir of new primary care doctors in the state. These residencies produce approximately 50 graduates in family practice, 24 in internal medicine, 6 in pediatrics, and 12 in obstetrics and gynecology annually.

Third, AHEC has been working in close collaboration with the Office of Rural Health and Community Care, the Division of Mental Health, Developmental Disabilities, and Substance Abuse Services, the professional associations, and others to develop a series of community-based initiatives to build on the existing infrastructure of primary care with integration of psychiatric clinical care and consultation to simultaneously meet patients' physical and mental health needs. These model programs are being developed in a number of communities across the state by building on the unique characteristics and assets of each community.

Ongoing efforts have been productive, but AHEC will have to do more to address looming practitioner shortages and ongoing concerns of maldistribution and lack of diversity in our health care professions. If we are truly to create a strong and stable primary care workforce for all communities in the state, though, it must be acknowledged that more comprehensive solutions need to be forthcoming. For instance, there will never be an adequate pool of primary care physicians or psychiatrists without payment reform at the national level that narrows the income gap between specialties. Such reform should place appropriate value on primary care as well as other cognitive services. We will not draw large numbers of graduates to rural areas without selectively admitting rural students to medical school, alleviating heavy medical school debt, and providing monetary incentives and systems of care that make rural practice more attractive to future practitioners.

Similar issues and solutions apply to the recruitment of underrepresented and disadvantaged students as well. Our pipeline programs to support students must be better connected at all levels of the educational process. Additional scholarship funding is essential, and strong academic and social support services are critical if all students are to thrive and reach their full potential.

Given these caveats and limitations, what more can AHEC do? One step is to leverage the success of our primary care residencies. We can increase the number of residency slots. By simply maintaining current retention rates, we will produce more doctors in needed specialties for North Carolina. One of the recommendations of the North Carolina Institute of Medicine Primary Care and Specialty Supply Task Force is to create 100 new residency positions in North Carolina, and AHEC is prepared to play a lead role to assure that the state's investment gives us the return we need by producing doctors in specialties most needed by the state's communities.

In the same vein, we are prepared to expand training opportunities for students of all types and to create stronger incentives for moving training into rural and underserved sites. We also must track our pipeline programs better and identify strategies that most effectively direct talented young people to the health professions of our state.

In addition and most importantly, simply adding students and residents to the educational pipeline will not keep pace with the escalation of services needed for the anticipated pace of population growth and aging. Improving and organizing systems of care, especially for chronic illness, will be crucial to improving access to care and health outcomes for North Carolinians. Given AHEC's strong ties to the health profession schools, its faculties on and off campus, and practitioners in local communities, it is in a unique position to coalesce and disseminate novel approaches to care in rural and underserved regions in collaboration with the nationally recognized Community Care Networks across the state. These approaches can use new options for technology support, regional on-call systems, and multidisciplinary teams to create and monitor coordinated systems of care that achieve excellence in health care milestones. With such innovation, we will build teams that make rural health care more rewarding and relieve the imponderable stress on harried practitioners in small practices who want to but cannot muster the resources to provide such comprehensive care. It will be crucial for residents and students to venture away from large medical centers and fully participate in these new styles of care so that they can embrace careers in these communities and serve as leaders in the transition toward innovative approaches.

Increasing the number of trainees at every level will inevitably increase the cost of medical education. We will need new teachers that include AHEC-based faculty and dedicated community preceptors. Sites for comprehensive care models will need to be recruited and created. If we want quality sites and quality teachers, we will need to pay for them. We will also have to finance the informatics systems and other innovative changes required to achieve new paradigms for educational and chronic care work. Finally, residency positions, traditionally supported by the Medicare program, are frozen, so we will have to pay directly for any new AHEC residency slots until federal policy changes. The reward for this investment will be better care for all North Carolinians garnered through prevention of practitioner shortages, improved distribution of care, and use of more efficient, more organized, and more effective systems of care. **NCMJ**

COMMENTARY

The Impact of Primary Care and What States Can Do

Barbara Starfield, MD, MPH; Leiyu Shi, DrPH, MBA

Despite the availability of evidence on the benefits of primary care on population health, little has been done to incorporate this evidence into planning for and evaluation of health services in the United States. In contrast, many industrialized nations have undergone major health system reform to make primary care the essential infrastructure of their health system. Some of these reforms resulted from legislation, as was the case in Spain and Australia, and others have entailed policy decisions to strengthen the practice of good primary care, as has occurred in the United Kingdom (UK) and is now occurring in various aspects of primary care in Sweden, France, and Germany. The reasons the US has not embraced primary care are complex and get to the heart of the characteristics of the US health services system, particularly its increasing dominance by special interest groups such as the academic medical establishment and specialty orientation, medical device manufacturers, and fee-for-service reimbursements that favor specialty practice.[1]

In this paper we briefly review the evidence for the impact of primary care in improving health, increasing equity, and reducing total health system costs; discuss the rationale for benefits of a primary care orientation within health services systems; and conclude with a discussion of needed additional research and policy attention.

Benefits of Primary Care

The first systematic study of the benefits of primary care on health and costs of care consisted of an international comparison of 11 western industrialized nations using data from the mid-1980s.[2] The study was repeated a decade later with 13 countries including Japan.[3] Both studies rated countries on policy characteristics encouraging primary care and practice characteristics reflecting primary care organization: first contact care; person-focused care over time; degree of comprehensiveness within primary care; and coordination of care. The studies were consistent in showing that some countries rated very poorly on primary care whereas others rated better. Those in the former group had poorer health on many population health measures including but not limited to life expectancy at various ages, age-adjusted mortality, and infant mortality (neonatal and postneonatal separately). They also were more costly health systems. These findings were robust and persisted even after controlling for various health-related characteristics of the population (such as extent of risky behaviors in the population). Confidence in the findings was provided by a pooled time series analysis of 18 Organization for Economic Co-operation and Development (OECD) countries that controlled for additional health and health system-related characteristics (such as percent

> *"Analyses of the impact of access to primary care, and to different levels of quality of primary care services, are all consistent in showing that the greater the access to primary care and the better the quality of primary care, the better the health—regardless of the measure of health..."*

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elderly, gross domestic product, and total number of physicians). This analysis showed that life expectancy in countries with weak primary care was lower than that in countries with stronger primary care and that this difference had been widening over time.[4]

Although there is additional evidence of similar benefits of primary care from other studies,[5] in this paper we focus primarily on findings from studies of US states because of the particular interest of North Carolina in the physician workforce. In all studies we included family physicians and general practitioners, general internists, and general pediatricians as primary care physicians because earlier evidence showed that these "specialties" rated higher on primary care characteristics than did other specialties.[6]

Primary Care in US States

In the 1990s, a series of studies examined and found a significant and positive relationship between the supply of primary care physicians and a variety of measures of health including all-cause mortality; mortality from heart disease, cancer, and stroke; infant mortality; low birth weight; and self-reported health. This relationship existed even after controlling for personal and environmental characteristics at the state level including education, income, environmental pollution, unemployment, percentage elderly, percentage urban, minority composition, and lifestyle factors including seatbelt use, obesity, and smoking.[7,8,9]

Consequent to the appearance of new literature on the relationship between income inequality at the state level and some health outcomes,[10,11] a series of analyses was designed to examine the relationship between primary care physician supply and health measures at the state level, while also considering the influence of income inequality in the state. In 1999, Shi and colleagues[12] showed that both income inequality and primary care physician supply had strong relationships with life expectancy, all-cause mortality, stroke mortality, and postneonatal mortality. They also found that smoking rates were related to these outcomes, but the influence of primary care physician supply persisted after controlling for smoking rates.

Subsequent studies refined the analysis to take account of possible other influences on population health levels including the supply of other specialists. In both time-lagged as well as contemporaneous studies, the supply of primary care physicians was associated with lower all-cause mortality whereas a greater supply of specialists was associated with higher rates of all-cause mortality. Furthermore, the beneficial influence of primary care physicians was entirely due to the supply of family physicians (rather than general internists and pediatricians).[13] Additional confirmation of these positive impacts of primary care physicians came from studies of mortality from stroke, using 11 years of state-level data and adjusting for degree of income inequality, educational level, unemployment rates, racial/ethnic composition, and percentage of the population living in urban areas.[14] The benefit on stroke mortality of better access to primary care is consistent with hypothesized mechanisms by which better primary care is associated with earlier and better control of common risk factors for stroke (especially hypertension). Similarly, the reduction in low birth weight and infant mortality (especially postneonatal mortality), even after one-, three-, and five-year lag periods, is associated with primary care physician supply,[15] a finding that is consistent with better maternal health before pregnancy and better availability of resources to deal with infections—a common cause of death in the postneonatal period.

Analyses of the impact of access to primary care and to different levels of quality of primary care services are all consistent in showing that the greater the access to primary care and the better the quality of primary care, the better the health—regardless of the measure of health—whether at the aggregate or individual level of analysis. These benefits have also been quantified. Macinko and colleagues[16] identified 10 studies that met the criteria for adequacy of study of the relationship between primary care physician supply and all-cause mortality; cancer, heart disease, stroke, and infant mortality; low birth weight; life expectancy; and self-rated health. The relationship held regardless of the year studied (from 1980-1995) and geographic level of analysis. Pooled results for all-cause mortality indicated that an increase of one primary care physician per 10 000 population was associated with an average mortality reduction of 5.3%, or 49 deaths per 100 000 population per year.

Additional analyses within some of these studies indicate that the beneficial impact of primary care on African Americans was even greater than for the majority population—evidence of an equity-producing effect of primary care.[5]

A wide variety of other studies conducted at different levels of geographic aggregation (metropolitan, county, urban, rural areas), both in the US and in the UK, support the conclusions of the US state-level analyses, with a few exceptions. For example, Ricketts and Holmes,[17] using pooled 1996-2000 US county data, found that the association between primary care physician supply and mortality was not uniformly observed and that strong regional patterns may explain the lack of a consistent national association based on their county-level data. Primary care physician supply was associated with decreased mortality on the East Coast and in the upper Midwest, but that correlation disappeared or was reversed in the west (with the exception of Washington state) and south central states. Further study is needed to understand these regional differences and the policy alternatives to address them because it is likely that the balance between the supply of primary care and specialist physicians and the influence of major medical centers (with their strong specialty focus) have an influence on people's use of primary care rather than specialty care. Overall, these empirical analyses (particularly at the state level, where there is less of a "cross-over" effect, ie, people seeking medical care across state borders) are consistent with theoretical considerations as to why primary care should have a beneficial impact on population health. Primary care is more accessible than specialty care, and its individual features (first contact care, person-focused care over time, comprehensiveness of care, and coordination of care) have all been shown to produce better outcomes.[5,18] International comparisons of countries show that, of the 4 features just mentioned, comprehensiveness of the package of services offered in primary care practices is the practice characteristic most consistently associated with better primary care overall.[3] That is, the more aspects of health care that are covered in primary care, the better the health outcomes, at least partly due to fewer unnecessary referrals to specialists. Common problems belong in primary care; less common or rare ones belong in specialty care because the training of specialists in tertiary medical centers better suits them to care for people who have been filtered by primary care and thus have a higher likelihood of serious or more uncommon illness. When patients go directly to specialty care, much of their care is inappropriate, as they are suffering from illnesses that are common in the population and thus better dealt with by physicians with training in how illness presents in the community, ie, primary care practitioners. As a result, US studies show that higher ratios of specialists to population are often associated with worse outcomes for common causes of mortality and morbidity.[19]

Popular belief that specialist care is superior to primary care is contradicted by the results of a variety of studies in which the outcomes are generic, ie, not specific to particular diseases. In this category are life expectancy, all-cause age-adjusted mortality, self-reported health, and low birth weight. In fact, for common causes of death, such as acute myocardial infarction, the outcomes are equally good for family physicians as for cardiologists, once a variety of patients' characteristics are taken into account.[20] The fact that generalists' patients are usually sicker than the patients of specialists in studies of this type provides clues about why direct access to specialists leads to worse population outcomes. Because of where specialists are usually trained, they are unaccustomed to seeing patients other than those with problems clearly in their field of specialty; these patients are not representative of patients in the community because the general population of patients has more comorbidity and a more complex pattern of illnesses, even though any given problem seen in a specialty clinic is more likely to be serious than the same problem in the community. Specialists thus learn to do more testing than would be necessary in generalist practice, with consequently more false positive results, adverse effects from the resulting cascade of tests, and with much higher costs.

What Can States Do to Maximize Population Health Through Workforce Policy?

In the absence of federal efforts to reform health care financing and to enable either a single payer system or more uniform health insurance policies through regulation of the many insurance programs, states have a limited number of options to encourage greater and better provision of primary care. At the very least, they can initiate policies to target state funding of medical teaching programs to institutions focusing on primary care training and provide greater financial support (as through loan forgiveness) to physicians who specialize in primary care. They also can encourage or mandate lower payments to specialists for patient visits NOT made by referral from a primary care practitioner. Additionally, they can increase reimbursement rates to providers who demonstrate that they deliver primary care in ways to achieve its benefits; instruments are available to document the primary care orientation of practices.[18]

States could also encourage professional collaboration to develop guidelines for referral or at least to examine the nature of the relative contributions of primary care practitioners and specialists in the care of people with particular health problems or combinations of health problems. The important characteristics of primary care are well known; the same is not the case for specialist practice.[19] As licensing of medical practitioners is in the jurisdiction of states, new licenses could be granted to practice in the state only for areas needing physicians, thus enabling more equitable distribution of both primary care and specialist physicians. Where states have jurisdiction over reimbursement for services, they can use this power to better equalize professional earnings of primary care and specialist physicians. States could also, through their support of medical training programs, require that physicians in training evaluate their own practices with regard to the costs of care that they generate, improvement of the patients' problems (not only biomedical markers for the disease of particular interest) as a result of their interventions, and occurrence of adverse effects consequent to their interventions. And, through the National Governors Conference, states could bring pressure on the federal government to develop a workforce policy that is better informed with evidence on population health needs and maldistribution of the physician workforce.

State efforts to use existing evidence to develop their own workforce policies could be key in improving the poor position of the US, relative to other industrialized countries, with regard to the population's health. **NCMJ**

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Program Description

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- Discuss the relationship between economic development and allied health workforce development efforts in the state.
- Describe the challenges confronting allied health workforce educators and employers.
- Identify best practice models used to meet these challenges.

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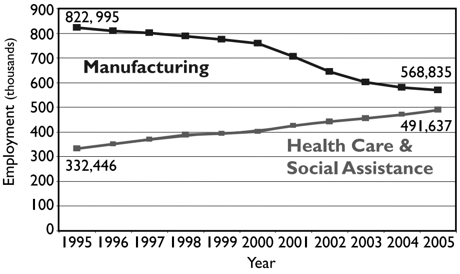

Source: North Carolina Employment Security Commission, 2006.

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COMMENTARY

Critical Connections Between Health Care and Economic Development in North Carolina

Aaron McKethan

This issue of the *Journal* opens with a discussion of how the supply and distribution of health professionals in North Carolina is important to access to care. As the authors point out, policy action is necessary to ensure the right mix of health care professionals in the right locations to meet the state's current and future health care needs. Moreover, current and future health workforce shortages have important implications that go beyond the specific health care needs of individuals and communities. By providing important health care services, health care professionals also play an increasingly important but often underappreciated role in creating and sustaining vibrant economies.

The Health Care Industry as a Growing Source of Jobs

By now every policymaker in North Carolina is keenly aware that the state's economic landscape is changing. This transition is from a largely goods-producing manufacturing-based economy to an economy and workforce increasingly oriented around service industries. A prime example of the latter is the expansion of the number of health service occupations and the number of jobs in those occupations in recent decades.

Job growth in health services at all skill and wage levels has taken place in both rural and metropolitan areas of the state. In 1990, there were about 261 000 health care and social assistance workers in North Carolina, representing about 9% of the state's total workforce. By 2006, that figure had nearly doubled to 509 000 workers, accounting for 13% of the state's total workforce (roughly the same size, in terms of total employment, as the manufacturing industry).[1]

Growth in health service jobs has been particularly rapid in rural parts of the state. As the state's total economy changes, the growing health care industry has helped to sustain local economies, particularly in rural areas where plant closings and business downsizing have eliminated jobs and transformed communities. This growth is likely to continue. As the issue brief points out, growing demand for health care professionals and other workers will be driven by demographic changes, population growth, and epidemiological trends as well as new advances in medicine.

> *"Ensuring an optimal supply of health care professionals to ensure a region's health care needs can also have important spillover effects on a region's attractiveness for new or existing businesses."*

The Flow of Health Care Money

To view the health services industry through the lens of economic development, it is important to understand the health care system's complex (some would say "Byzantine") third-party financing structure. Public and private health care expenditures typically flow not to patients who receive health care services, but directly to health care institutions and medical providers supporting health care jobs. Additionally, some regions are more dependent on government health care spending than others. In Avery County in rural northwest North Carolina, Cannon Memorial Hospital is the largest employer. Cannon receives about 70% of its inpatient revenue from the Medicare program and another 10% from Medicaid. Thus, the county's largest employer receives a substantial portion of its income from federal and state health care programs.[2] This suggests the importance for economic developers and policymakers to

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understand the flow of health care dollars in different parts of the state and to observe how public and private health care dollars trickling through the economy are connected to growth in health care jobs.

Health Care and Business Competitiveness

Ensuring an optimal supply of health care professionals to ensure a region's health care needs can also have important spillover effects on a region's attractiveness for new or existing businesses.

First, businesses seeking new areas in which to locate facilities must ensure, among other things, that the local health care infrastructure is adequate to meet the needs of its employees. *Expansion Management*, a publication that disseminates information for businesses seeking to identify the best locations to establish new plants and other facilities, recently developed a "Health Quotient" ranking of regions. This was done partly in response to business demand for information to evaluate the availability of health care providers and other health-related issues at a regional level. Like information about tax rates, local schools, transportation infrastructure, and crime rates, business executives making site selection decisions may consider health care infrastructure and provider supply measures in their research of prospective regions.

Second, access to health care professionals can also have an important impact on the health and productivity of a region. This may play a role in businesses' site selection decisions as well. Bob Greczyn, chief executive officer of Blue Cross and Blue Shield of North Carolina, has suggested that promoting a healthy population can serve as a competitive advantage for corporations considering relocating to the state. Greczyn argued that a "a healthier work force [would] be more productive, have a significantly lower absenteeism rate and probably generate lower workers' comp costs," which could help North Carolina "stand out from the pack in the competition for new jobs."[3] Of course, regional health care status and worker productivity are also key issues affecting the bottom lines of existing firms as well. This includes some of the state's leading firms in the biotechnology, medical devices, and other health-related industries that are providing an increasing supply of high-tech jobs in the state.

To be sure, healthy regions depend on, among other things, an adequate supply of health care professionals including physicians, physician assistants, nurse practitioners, and others.

Moving Forward

In sum, the growing health care sector has created new jobs in a state undergoing a profound economic transition. Adequate access to health care professionals can increase quality of life and worker productivity through healthier individuals and communities.

Policy choices governing health care supply and provider reimbursement issues should be based on meeting the state's health care needs, not explicitly on job creation or achieving other economic benefits. However, it is important for policy makers and economic developers to understand the numerous connections between health care infrastructure, provider reimbursement, and regional economic attractiveness and productivity.

Of course, the health care community should be willing to embrace change and innovation as well. Given very high health care costs and uneven quality outcomes in the health care arena, health care professionals themselves can play a lead role in improving the economic value their profession confers on individuals and local communities.

On balance, the connections between health care and economic development are indeed critical for North Carolina. **NCMJ**

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Kent E. Moore, M.D., D.D.S. is the founding chairman of the American Association of Oral & Maxillofacial Surgeon's Clinical Interest Group on Sleep-Related Breathing Disorders and Obstructive Sleep Apnea and has served as faculty for the National Sleep Medicine Board Review Course 2002-2005 (sponsored by the American Academy of Sleep Medicine). He is immediate past president of the American Academy of Dental Sleep Medicine and founding board member of the International Society of Sleep Surgeons.

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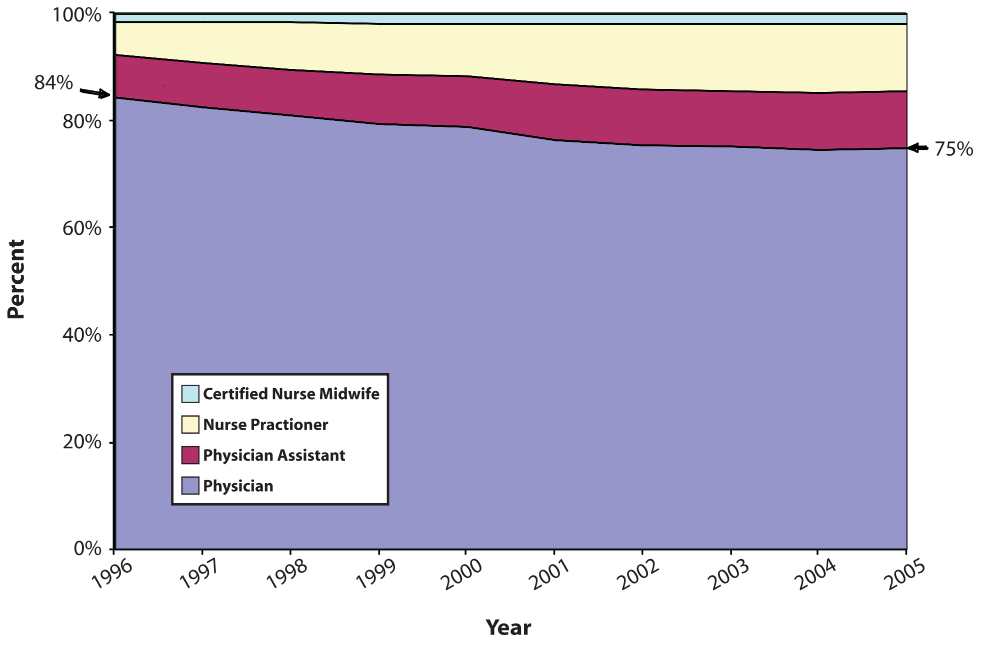
Supply of Primary Care Practitioners by Profession

As highlighted in this issue's commentary by Barbara Starfield and Leyiu Shi, primary care practitioners are important to the overall health of populations. Historically, the primary care practitioner from whom most individuals received care was their local general practice physician. However, over time factors have changed the landscape of primary care practice. Today, many individuals receive primary care from nurse practitioners, physician assistants, and certified nurse midwives as well as from physicians. This section will evaluate how the composition of primary care practitioners has changed over time and may vary in communities across North Carolina. For the purposes of this analysis, primary care practitioners are defined as those practitioners who self-designated in their license application a specialty in family and general medicine, obstetrics/gynecology, pediatrics, or internal medicine. However, specialists also may provide particular aspects of primary care such as blood pressure checks and cholesterol screenings.

Data from the North Carolina Health Professions Data System show the composition of the primary care practitioner supply from 1996 to 2005. In 1996, 84% of primary care practitioners were physicians. By 2005, physicians accounted for only 75% of all primary care practitioners. (See Figure 1.) This indicates the proportion of nonphysician primary care practitioners increased over 50% during that time period, from 16% to 25% of all primary care practitioners.

Figure 1.
Composition of North Carolina Primary Care Practitioner Workforce, by Practitioner Type



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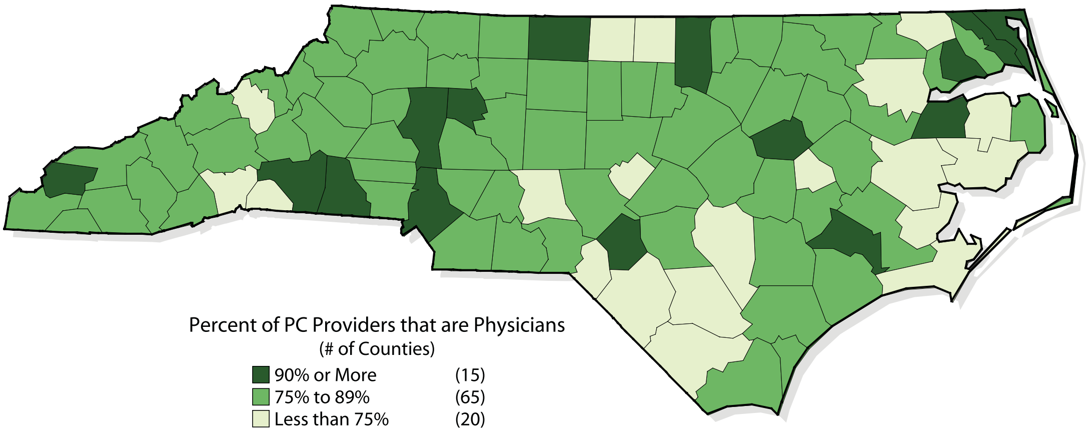
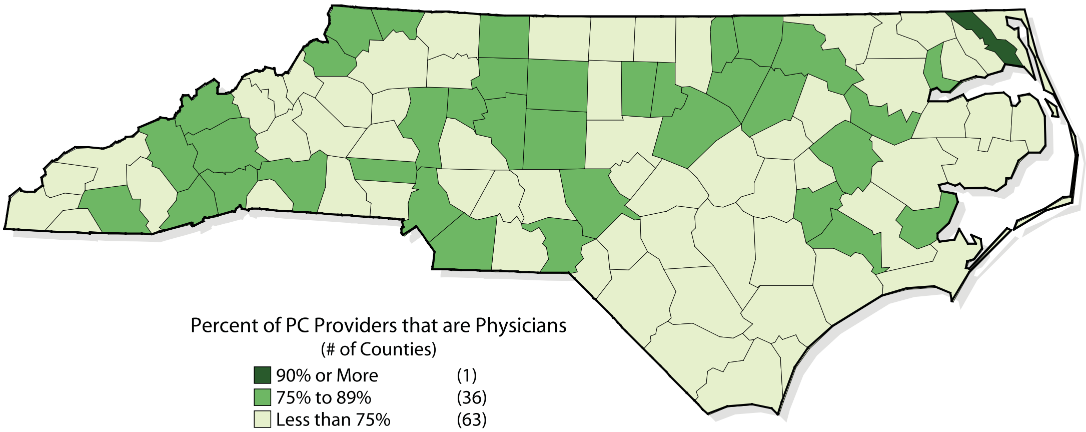
Map 1.
Percent of Primary Care Practitioners that Were Physicians in 1996, by North Carolina County



Data include active, instate, nonfederal, nonresident-in-training physicians, PAs, NPs, and CNMs indicating a primary specialty of family practice, general practice, internal medicine, obstetrics/gynecology, or pediatrics.
Source: North Carolina Health Professions Data System, Cecil G. Sheps Center for Health Services Research, University of North Carolina at Chapel Hill, with data derived from the North Carolina Medical Board and the North Carolina Midwifery Joint Committee.

Map 2.
Percent of Primary Care Practitioners that Were Physicians in 2005, by North Carolina County



Data include active, instate, nonfederal, nonresident-in-training physicians, PAs, NPs, and CNMs indicating a primary specialty of family practice, general practice, internal medicine, obstetrics/gynecology, or pediatrics.
Source: North Carolina Health Professions Data System, Cecil G. Sheps Center for Health Services Research, University of North Carolina at Chapel Hill, with data derived from the North Carolina Medical Board and the North Carolina Midwifery Joint Committee.

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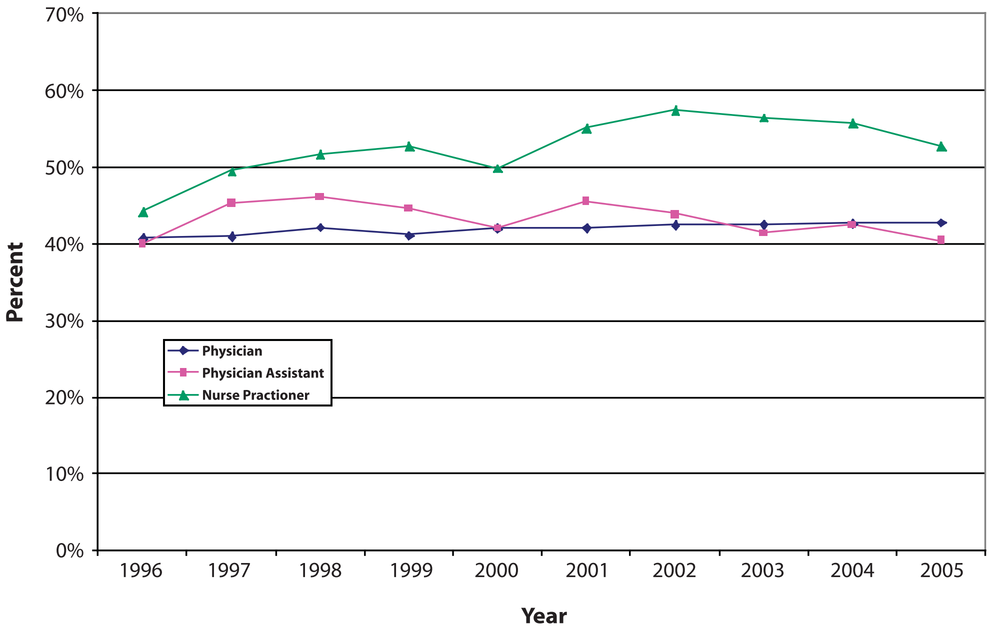
The main factor contributing to this change in the composition of the primary care practitioner workforce is the rapid increase in the number of primary care physician assistants and nurse practitioners relative to the growth in primary care physicians. While the number of primary care physicians grew 36% from 1996 to 2005, the number of primary care physician assistants doubled and primary care nurse practitioners grew 220%.

The distribution of primary care practitioners provides valuable information for policy makers. Data indicate that primary care nurse practitioners, physician assistants, and certified nurse midwives are 50% more likely than primary care physicians to practice in rural areas. Furthermore, these practitioners are playing an increasing role in providing primary care services across the state. In 1996, physicians accounted for 75% or more of the primary care practitioner workforce in 80 of North Carolina's 100 counties. By 2005, the same was true in less than half (37) of those counties. (See Map 1 and Map 2.)

The tendency of each discipline to practice primary care changed slightly between 1996 and 2005 (all certified nurse midwives, using the HPDS definition of primary care, practice primary care). The percent of physicians practicing primary care increased slightly from 41% to 43%. Whereas the tendency of physician assistants to practice primary care increased during the late 1990s, the percent in primary care (40%) was the same in 2005 as it was in 1996. The proportion of nurse practitioners practicing primary care generally increased from 1996 to 2002 but declined in more recent years. (See Figure 2.)

Given the increased reliance of populations in rural areas on nonphysician practitioners for their primary care, trends suggesting a declining tendency of nurse practitioners and physician assistants to practice primary care portend a possible decrease in access to primary care in such communities.

Figure 2.
Proportion of North Carolina Practitioners in Primary Care, by Profession, 1996-2005



Contributed by Katie Gaul, MA, Jennifer King, and Erin Fraher, MPP at the North Carolina Health Professions Data System, Cecil G. Sheps Center for Health Services Research, The University of North Carolina at Chapel Hill

Smart Partnerships: KBR Uses Resources Wisely to Encourage Health Care System Innovations

John H. Frank, MBA; Julie E. Alexander, RN, MSN

In fulfilling its mission to improve the quality of life and health for future generations of North Carolinians, the Kate B. Reynolds Charitable Trust often partners with health care innovators at the local and state level. Last year, the Trust announced a strategy to invest resources in addressing the root causes of poverty and disease, promote innovation through best practices, and increase influence on behalf of those it serves by expanding its role as an educator, convener, and advocate.

The ICARE Partnership, a statewide initiative supported by the Trust, is one example of a collaboration that fulfills KBR's strategy. ICARE represents a broad spectrum of public and private stakeholders committed to integrated care, a collaborative approach that comprehensively addresses physical and behavioral health care needs. ICARE's vision is ambitious—a health care system that is Integrated, Collaborative, Accessible, Respectful and Evidence-Based (ICARE). As a funding partner for ICARE, the Trust is leveraging the support and energies of a broad network of health care leaders and organizations.

The Trusts' strategic plan also includes a commitment to support prevention and provide treatment in several target areas, including mental health services. Integrated care shows promise as an effective approach to care of mind and body, and the Trust has previously funded successful local integrated care projects. ICARE provides an opportunity for the Trust to extend these approaches to more people across North Carolina.

ICARE's vision is being implemented through three projects targeting practice, training, and process and policy. Like a "three-legged" stool, each project supports ICARE's central objectives, which aim to improve patient outcomes by increasing collaboration and communication between primary care and mental health, developmental disabilities, and substance abuse service providers and to increase their capacity to provide appropriate, evidence-based care. Although separate, ICARE's three projects interact to create a whole greater than the sum of its parts.

The Local Model Development Project addresses practice by developing replicable integrated care systems in four North Carolina pilot sites. Local implementation partners, representing different facets of the health care community, advise and support each site's model development. Each pilot uses a common approach to organize, but has chosen a locally-relevant focus area.

The Trust is funding two pilots in the western and eastern regions of the state. The western site (Buncombe and Henderson counties) is focusing on care for citizens with severe and persistent mental illness. The eastern site (New Hanover and Pender counties) is expanding community capacity by placing part-time psychiatrists in four primary care practices and promoting the use of patient care algorithms for anxiety and attention-deficit/hyperactivity disorder. Two additional pilots, a northcentral site (Vance, Warren, and Granville counties), and a southeastern site (Robeson County) are targeting addictive disease and crisis management, respectively.

The Statewide Education and Assistance Project addresses training by developing provider tools, education, and opportunities for relationship building across the state. Based on an initial needs assessment, a variety of training venues are offered including regional conferences, office-based training and technical assistance, and web-based resources. Among others, collaborators included the North Carolina Area Health Education Centers Program, North Carolina Academy of Family Physicians, and North Carolina Association of Psychiatry. A website (www.icarenc.org) serves as a clearinghouse of information on integrated care in North Carolina. As ICARE progresses, the training component will disseminate new information and best practices through its programs.

The Process and Policy Change Project addresses the final component of ICARE. The project aims to remove barriers and promote implementation of integrated care. Key process and policy change targets have been identified and are being tracked by two groups including public and private health care leaders. As these groups advocate for a more favorable environment, their efforts will be informed by feedback from participants in ICARE's local pilot sites and training programs.

The ICARE Partnership represents a broad collaboration between public and private stakeholders dedicated to creating a new paradigm for health care in North Carolina. The Kate B. Reynolds Charitable Trust, through its strategic investment, is a key partner in fulfilling this bold vision. **NCMJ**

John H. Frank, MBA, is director of the Health Care Division for the Kate B. Reynolds Charitable Trust.

Julie E. Alexander, RN, MSN, is a health care consultant. She coordinated the development and initial launch of the ICARE Partnership on behalf of the NC Foundation for Advanced Health Programs.

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Coming in the July/August 2007 issue of the
North Carolina Medical Journal
a look at:
Emergency Medical Services

Index of Advertisers

Spotlight on the Safety Net

A Community Collaboration
Kimberly M. Alexander-Bratcher, MPH

Gaston County Collaboration

Gaston Family Health Services (GFHS) was created by the Gaston County Health Department (GCHD) to help provide comprehensive medical care to indigent citizens. Today the two organizations collaborate to ensure the Gaston County safety net remains intact. Together, they provide primary care for adults, children, and special populations including HIV positive and mentally ill patients; pediatric and adult dental services; hospital care; reproductive health services; immunizations; behavioral health services and case management; and access to specialty providers.

The Gaston County collaboration, developed in 1989, brought these two safety net health care providers, under the same roof. This proximity allows them to share many of the same resources such as lab and billing staff and enables the provision of unduplicated comprehensive health care to the uninsured, low-income community. The GCHD primarily serves women and children whereas GFHS tries to fill in the gaps by providing primary care, acute care, and treatment for chronic diseases in populations who do not receive care at the health department.

Both GFHS and GCHD have physicians on staff to care for patients. In addition, GFHS has volunteer clinics staffed by specialists, such as ophthalmologists and podiatrists, as well as volunteers who work on pharmaceutical medication assistance programs for patients. Case management also is provided and is primarily targeted to chronic disease or HIV positive patients. There are no eligibility criteria for patients desiring to be seen by GFHS or GCHD; however, patients must reside within county lines for some health department programs. Both GFHS and GCHD use a sliding fee scale, although some services at the Health Department are provided free of charge. Together, the Gaston County collaboration sees about 78 000 patients annually—60 000 through the health department and 18 000 through GFHS. Approximately 55% of the patients seen at GFHS are uninsured, while the remaining 45% are covered by Medicaid (22%), Medicare (18%), or private insurance (5%).

Colleen Bridger, MPH, Gaston County Health Director, shared several valuable lessons for other communities considering this type of collaboration. Colocation is ideal because it facilitates the flow of information and communication between providers and patients. Preventing duplication of services is important because competition for insured patients can weaken care to uninsured, indigent consumers. Collaborations should utilize the strengths of each collaborating organization to best serve the patients' needs. By working together, organizations can fill in gaps in the services that are provided and the populations that are reached—frequently neither organization receives enough funding to provide all needed services to indigent patients. Collaborators should advocate for one another because doing so can build confidence in the community and in the collaboration. Finally, partners should communicate openly and honestly. Incorporating these lessons can help develop a tight knit environment for the collaboration and strengthen the work and success of both organizations.

Contributions from Colleen Bridger, MPH, Gaston County Health Director, and Morgan Jones, MSPH, North Carolina Institute of Medicine Research Assistant.

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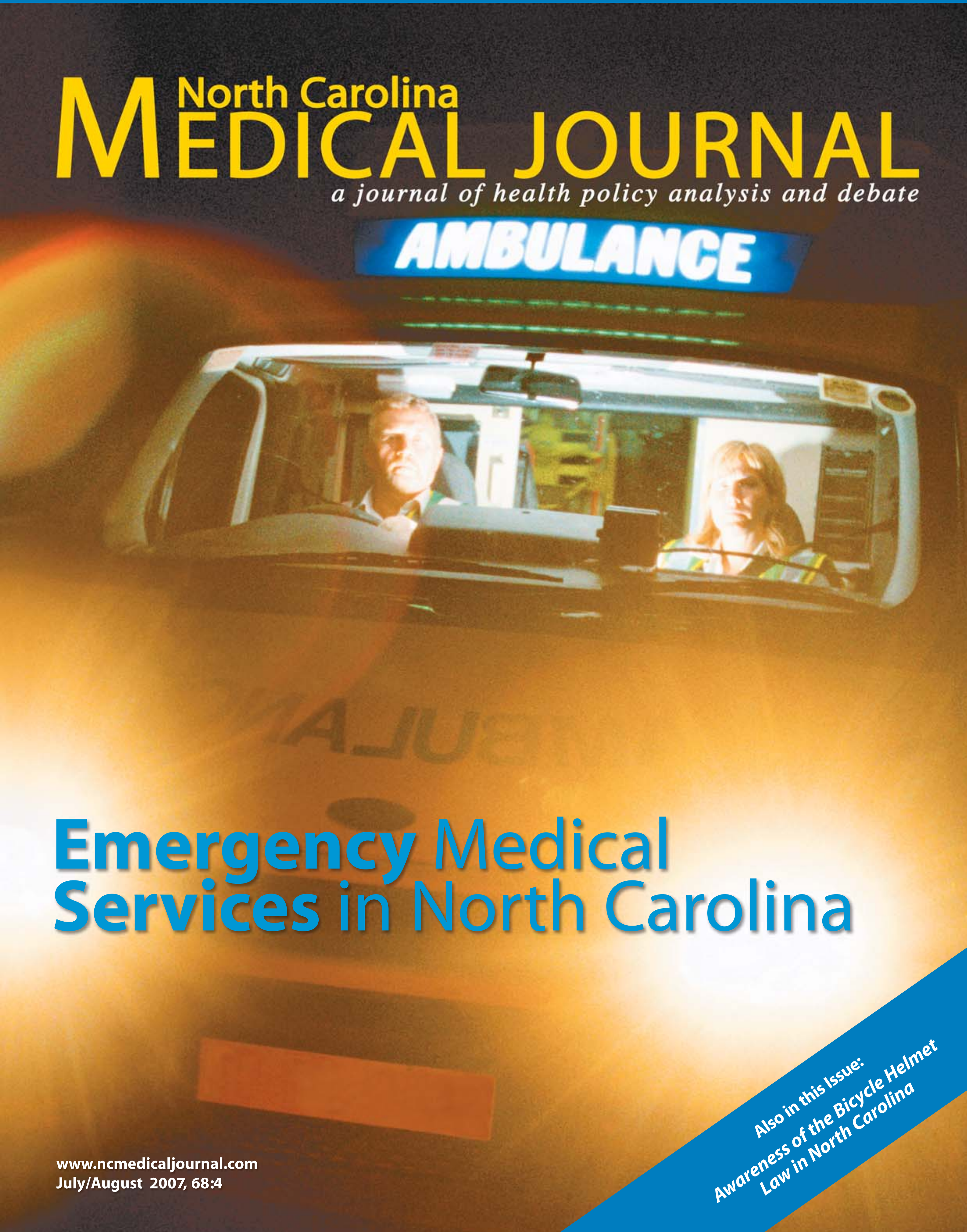

Emergency Medical Services in North Carolina

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Awareness of the Bicycle Helmet Law in North Carolina

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Working together, Pitt County Memorial Hospital and Brody School of Medicine surgeons have been performing and studying gastric bypass surgery since 1978. To watch a live web cast of bariatric surgery at Pitt County Memorial Hospital or learn more about bariatric surgeons at the Brody School of Medicine and Southern Surgical Associates, visit www.bariatric.uhseast.com.

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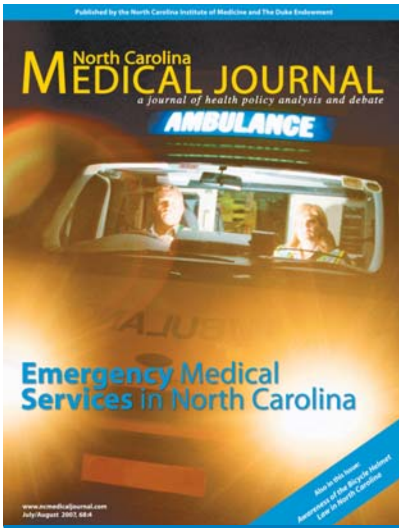

North Carolina
MEDICAL JOURNAL
a journal of health policy analysis and debate

July/August 2007, Volume 68, Number 4 **Published by the North Carolina Institute of Medicine and The Duke Endowment**

ARTICLE

POLICY FORUM

Emergency Medical Services in North Carolina

COMMENTARIES

DEPARTMENTS

"On November 16, 1973, Congress approved the Emergency Medical Services Systems Act of 1973 ... which funded and authorized the US Department of Health, Education and Welfare to help develop EMS programs throughout the country."

Tarheel Footprints in Health Care

Recognizing unusual and often unsung contributions of individual citizens who have made health care for North Carolinians more accessible and of higher quality

Stanley Wardrip

Stanley Wardrip is what many would consider a model emergency medical services (EMS) professional. Mr. Wardrip started his EMS career at the age of 15 with the Jacksonville Volunteer Rescue in Jacksonville, North Carolina. During his tenure at Jacksonville Rescue, he and his fellow rescuers received recognition for their superior service and performance delivering EMS care. Throughout high school, Mr. Wardrip worked in EMS and in 1987 he won the North Carolina Governors Award for Youth Rescuer of the Year. Mr. Wardrip went on to graduate at the top of his paramedic class and graduated with an Associate Degree in Emergency Medical Science from Catawba Valley Community College.

Mr. Wardrip has worked for New Hanover EMS for 17 years. He is a senior paramedic, public relations coordinator, and field training officer. As a member of the New Hanover County Board of Health and the New Hanover County Public Health and Safety Committee, Mr. Wadrip has worked hard to help promote the health and safety of New Hanover's citizens. He has a strong appreciation for the role EMS plays in community health which is why he also started a Boy Scout Explorer Post for New Hanover Regional Medical Center EMS to help encourage younger people to get involved in EMS. His community-based efforts have been well-received and have positively impacted eastern North Carolina.

As an advocate for EMS, Mr. Wardrip identified a gap in representation for eastern North Carolina EMS professionals at the state and national level. To address this gap, he helped start the Eastern Carolina EMS Association, a professional organization of individuals within eastern North Carolina who are engaged in EMS and who wish to make an impact upon the health and welfare of the public and also promote, represent, and provide guidance for the practice of prehospital care. This association is open and free to all emergency responders in eastern North Carolina. The association offers first aid instruction and CPR classes to the public at a low or no cost. Other safety topics promoted by the association include child bike and gun safety.

Currently, Mr. Wardrip works for Pender EMS as a paramedic and member of the North Carolina State Medical Assistance Team. Friends feel he is one of the top paramedics in the state due to his great patient care and his kind heart. He always finds time for his family and friends, something that is very difficult to do in EMS.

Besides being a tireless advocate for EMS and community health and being family man, Mr. Wardrip works with Medical Missions to help others in times of need. In 2007 he plans to work with Wrightsboro United Methodist Church Medical Mission to provide medical assessment and treatments to those who cannot afford medical care in St. Anne's Bay, Jamaica. The *North Carolina Medical Journal* would like to recognize Stanley G. Wardrip Jr. as a model EMS professional and offer appreciation to EMS professionals across the state who offer their time and talent to help improve prehospital care in North Carolina.

Contributions from Doug Strickland, NREMT-I

Readers' Forum

To the Editor:

In the March/April 2007 issue of the *North Carolina Medical Journal*, Roche et al wrote about the importance of screening for intimate partner violence (IPV) after a study of 321 adult female patients were surveyed in an urban medical center in North Carolina. Respondent characteristics of the women screened are offered in the article.

I agree wholeheartedly with the authors' assertion that IPV is a very common and serious problem that is perhaps underinvestigated by health care providers. Teaching medical students and residents how to appropriately screen their patients in the outpatient and inpatient settings as well as the emergency department is essential. However, as much as a history of IPV is frequently not obtained by health care practitioners, more often than not a sexual orientation history is not obtained either. I commend the authors of this study for using the inclusive and nonjudgmental term "partner" repeatedly in their article. However, in the authors' survey they address their patients' marital status. Because same-sex marriage is legal in very few places, they therefore do not specifically address IPV in same-sex relationships. Data shows that IPV in lesbian couples occurs at a frequency similar to that in heterosexual couples. In a 2005 study published by the Centers for Disease Control and Prevention (CDC), 11% of women aged 15 to 44 reported having been in same-sex relationships—not an insignificant number. Perhaps a number of the 43.9% of patients claiming to be "single" in this study include some of these patients.

One may ask why obtaining a sexual orientation history is important. Studies show that victims of IPV by a same-sex partner find it more difficult than their heterosexual counterparts to seek help for their problem. This seems to be largely out of fear of homophobia by the organizations offering assistance or fear of being "outed" if they seek help. Perhaps if they are asked about who their partner is in a way that is supportive and nonjudgmental (ie, not "are you married or single?"), they will feel safer in divulging the violent situation they are trapped in. Instead of asking "Are you married," simply ask "Are you in a relationship? With whom?" Those questions are simple to ask, even for the provider not completely comfortable with addressing specific questions about sexual orientation.

I urge the authors of this study and interested readers of this journal to see the CDC-sponsored National Violence Against Women Prevention Research Center website on this particular topic (http://www.vawprevention.org/lesbianrx/factsheet.shtml). Several references are offered on the website for further information. With careful screening for IPV by caring and nonjudgmental health care providers, we can hopefully better address the needs of all patients trapped in destructive relationships.

John E. Snyder, MS, MD

Editor's note: In the May/June 2007 issue of the *Journal*, the article *Issue Brief: Weathering the Practitioner Workforce Shortage* inadvertently omitted reference to the central role the Kate B. Reynolds Charitable Trust (KBR) played in the formation, funding, and deliberation of the task force. The original impetus for the task force grew out of a meeting convened by KBR that focused on trends in provider supply. In addition, KBR provided the funding for the task force, and shared its experience in this area through task force participation. The Kate B. Reynolds Charitable Trust has a long history of grant making to improve access to practitioners in rural and underserved areas. The editor and authors apologize for the oversight in failing to reference the important role that KBR played in the task force's work. This oversight is corrected in an online version of the article available at: http://www.ncmedicaljournal.com/may-jun-07/toc0607.shtml.

Awareness of the Bicycle Helmet Law in North Carolina

Kelly A. Carter, MD; Kori L. Brewer, PhD; Herbert G. Garrison, MD, MPH

Abstract

Background: *One in 3 bicyclists killed in North Carolina is under the age of 16. Since enactment of a mandatory bicycle helmet law for children in 2001, there has been no observed increase in helmet use in North Carolina. The goal of this study was to assess perceptions of helmet effectiveness and the level of awareness of the North Carolina bicycle helmet law.*

Methods: *A written survey was distributed to parents, physicians, teachers, and emergency medical services (EMS) personnel throughout Pitt County, North Carolina, to ask their knowledge of the bicycle helmet law, the frequency of their helmet use, their perceptions of the effectiveness of helmets, their opinions of who should be providing education about bicycle helmets, and their knowledge of proper bicycle helmet use.*

Results: *The survey response rate was 72% (n= 413). Seventy-five percent of teachers and EMS personnel, 69% of parents, and 58% of physicians were aware of the North Carolina helmet law. Nineteen percent of parents responded that their children wore helmets "always," 21% answered "often," and 18% answered "never." The effectiveness of helmets in preventing head injuries was underestimated by many respondents with 49% estimating 50%-75% effectiveness.*

Limitations: *This survey was distributed only in Pitt County and does not reflect helmet awareness for the state as a whole.*

Conclusions: *The majority of parents, teachers, physicians, and EMS personnel in Pitt County, North Carolina, are aware of the mandatory bicycle helmet law for children. Enforcement of and education about the bicycle helmet law should be increased.*

The North Carolina Division of Transportation reports that a bicyclist is injured or killed in the state every 6 hours, with one in 3 bicyclists killed in North Carolina being under the age of 16.[1] Among bicycle injuries, one-third of emergency department visits, two-thirds of hospital admissions, and three-fourths of deaths are due to head injuries.[2] Bicycle helmets have been shown to reduce the incidence of head injury by 85% and the risk of traumatic brain injury by 88%.[3] Because head injuries from bicycle crashes are such a significant problem, 20 states have implemented statewide mandatory helmet laws and another 16 states have counties with helmet use laws.[4] In October of 2001 North Carolina passed a law requiring all children younger than 16 years of age to wear a helmet while riding a bicycle. This law holds the parent or legal guardian responsible for the child's helmet use with a penalty of a civil fine of $10.[5]

A 2002 study[6] conducted by the University of North Carolina Highway Research Center concluded that the mandatory helmet law had little impact on the use of helmets by children under the age of 16. The study observed helmet use in the same randomly picked cities in 3 regions of the state in 1999 and 2002. They found that on-street helmet use by children under the age of 16 increased from 12% to 16% (reported Law Effect, p =0.5627), and one-fifth of helmets observed in 2002 were misused. Weighted estimates of total helmet use (including adults) found that the coastal region of North Carolina, which includes Pitt County, had the lowest observed helmet use and no observed increase in overall helmet use after the law was implemented (9.5% pre-law, 9.2% post-law, with a state average of 17.8% and 24.3% respectively). In support of these findings, a database from the North Carolina Department of Transportation[7] on bicycle-car crashes also found no reported

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Kori L. Brewer, PhD, is an associate professor and associate chief of the Division of Research at the Department of Emergency Medicine of the Brody School of Medicine at East Carolina University.

Herbert G. Garrison, MD, MPH, is a professor of Emergency Medicine at the Department of Emergency Medicine of the Brody School of Medicine at East Carolina University and director of the Eastern Carolina Injury Prevention Program at the University Health Systems of Eastern Carolina.

increase in helmet use in children under the age of 16 after the law was implemented. In the 4 years prior to the law, 42 of 1303 (2.3%) children involved in bicycle-car crashes wore helmets; in the 4 years following implementation of the law only 22 of 849 (1.3%) children were documented to be wearing helmets.

The purpose of this study was to determine if the ineffectiveness of the mandatory helmet law is due to a lack of awareness of this law or a lack of knowledge of the utility of helmets in preventing head injury. We assessed these factors by surveying parents, teachers, physicians, and prehospital emergency medical services (EMS) personnel in Pitt County, North Carolina, a geographically distinct area that included communities with bicycle helmet ordinances in place before the statewide law. Ultimately, our goal was to define areas of focus that will improve bicycle helmet use among children.

Methods

All protocols were reviewed and approved by the University Medical Center Institutional Review Board. The study was conducted in Pitt County, North Carolina. Pitt County is mostly rural with a year 2000 population of 138 690. It is located in the eastern region of the state and is comprised of approximately 650 square miles.

A written survey was distributed to the following groups: a convenience sampling of Pitt County public school district parents of school-aged children (n=150); a convenience sampling of Pitt County public school district teachers from elementary to high school, both rural and urban (n=210); pediatricians, emergency physicians, and family physicians (n=88); and EMS personnel (n=124). We used the following strategies to recruit survey participants: (1) to obtain a survey of parents, Parent Teacher Associations (PTAs) in Pitt County were contacted and surveys were given to interested PTA leaders which were then distributed to parents and collected by the PTA leaders for return; (2) principals from Pitt County public elementary, middle, and high schools were contacted and those interested in the project distributed surveys to their teachers and returned them by mail; (3) all pediatricians, emergency physicians, and family physicians in the Pitt County Medical Society were mailed surveys with response envelopes; and (4) all Pitt County EMS personnel were given surveys to be mailed in when completed. These groups were chosen since they are most likely to interact with children on a daily basis or to see the results of a bicycle crash when it occurs. The survey was distributed between October and December of 2006. All surveys included in the study were returned by January 2007.

Table 1.
Survey Questions

Is there a North Carolina law requiring bicycle helmet use in children younger than 16 years old?
Yes____ No ____ Don't know____
If not, should there be a law?
Yes____ No____ Don't know____
How often does your child (age 5-15) wear a bicycle helmet? *
Always____ Often____ Sometimes____ Rarely____ Never____
How often do you wear a bicycle helmet?
Always____ Often____ Sometimes____ Rarely____ Never____
What percentage (%) of head injuries due to bicycle accidents can be prevented by wearing a helmet?
0%-25%____ 25%-50%____ 50%-75%____ 75%-100%____
Who do you think is responsible for providing education about bicycle helmets?
EMS Personnel____ Doctors____ Teacher____ Internet____
Parents____ Police Officers____ Other: ____________________
Who do you think parents expect to provide education about bicycle helmets to children? **
EMS Personnel____ Doctors ____ Teachers____ Internet____
Parents____ Police Officers____ Other: ____________________
How would you rate your understanding of proper helmet fit and helmet use?
Very good____ Good____ Okay____
I don't know anything about helmets____

* Asked only to parents
** Asked only to physicians, teachers and EMS providers

The survey included questions about: (1) the presence of a mandatory helmet law for children; (2) helmet use among respondents and use among the children of the parent group; (3) perception of helmet effectiveness in preventing head injuries; (4) perceptions of who should be providing education about proper helmet use and laws (more than one answer was allowed for this question); and (5) familiarity with the proper use and fit of helmets. (See Table 1.)

Responses were recorded in a database and response percentages were calculated. Differences in response rates between groups (eg, teachers vs. parents) were analyzed using chi-square analysis with $p<0.01$ indicating statistical significance. The use of $p<0.01$ to indicate significance is a more stringent criterion than $p<0.05$ and helps adjust for the necessary multiple testing. The relationship between helmet use and knowledge of the helmet law and perceived effectiveness of helmet use was assessed using logistic regression. Helmet use and perceived effectiveness were each used as the dependent variable and assessed using simple logistic regression (LR) to produce a coefficient of determination (r-squared calculated using STATVIEW by SAS, Inc). The adjusted r-squared was calculated based on the following equation: Adjusted $r^2 = 1-(1-r^2)\ ((n-1)/n-k-1))$ where n = # of observations and k = # of independent variables.

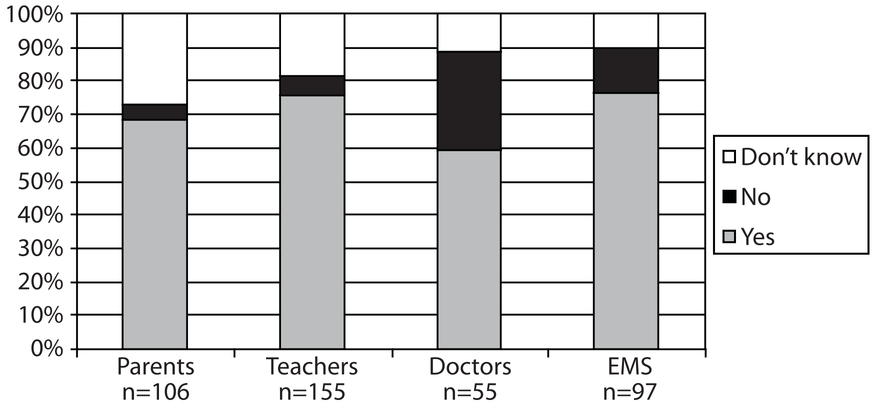
Results

The overall response rate for this survey was 72.2%. One hundred six of 150 parents (71%), 155 of 210 teachers (74%; 61/88 elementary school, 16/22 middle school, 78/100 high school), 55 of 88 physicians (63%; 14/27 emergency physicians, 16/20 family physicians, 25/41 pediatricians), and 97 of 124 (78%) EMS personnel returned surveys.

Awareness of the Helmet Law

Four years after the implementation of the bicycle helmet law, 69% of parents, 75% of teachers, 58% of physicians, and 75% of EMS personnel surveyed were aware of the law. (See Figure 1; p=0.06). Of those who answered "no" or "don't know," most (91/115 or 79%) thought there should be a law.

Figure 1.
Knowledge of Helmet Law: Is There a Law?



Among teachers, elementary teachers were most aware of the law (80%) followed by middle school teachers (75%) and high school teachers (72%). These differences were not statistically significant (p=0.049). Knowledge of the law was not associated with physician specialty (p=0.098). However, pediatricians had the highest awareness of the law (68%); only 57% of emergency physicians and 47% of family physicians were aware of the law.

Helmet Use

When asked how frequently their children wore their bicycle helmets, 18% of parents with children ages 5 to 15 responded "never" with 5% adding that their children do not ride bicycles. Nineteen percent of parents stated their children "always" wear a helmet. Among the respondents themselves, 21% reported "always" wearing their helmet when riding a bicycle. Physicians were statistically more likely to report "always" wearing a helmet (46%) compared to all other groups (12% of EMS personnel, 11% of teachers, and 8% of parents; p<0.001). Parents (65%), teachers (65%), and EMS providers (57%) most often reported "never" wearing a bicycle helmet.

There was no relationship between helmet use and knowledge of the law (adjusted $r^2 = 0.020$), perceived effectiveness of helmets (adjusted $r^2 = 0.008$), or knowledge of proper helmet fit (adjusted $r^2 = 0.050$).

Knowledge of Proper Helmet Use

The respondents' understanding of proper helmet use and fit was reported by them to be "okay" for the majority in all groups. Ten percent of parents, 20% of teachers, 7% of physicians, and 8% of EMS personnel answered that they "don't know anything about helmets." Sixty-four percent of those responding that they "don't know anything about helmets" answered "no" (17%) or "don't know" (47%) when asked about the existence of the helmet law.

Perceived Effectiveness of Helmet Use

All groups underestimated the effectiveness of helmet use in preventing injuries with the majority of teachers (53%), physicians (64%), and EMS personnel (57%) perceiving that 50%-75% of head injuries could be prevented by a helmet. Thirteen percent of all responders answered that less than 50% of head injuries could be prevented. The perceived effectiveness of the helmet was independent of their knowledge of the law (adjusted $r^2= 0.17$). Forty-nine percent of those who knew there was a law and 51% of those who stated there was not a law thought that helmets prevented 50%-75% of head injuries.

Education

A majority (80%) of respondents indicated that the burden of educating children about bicycle helmets should fall on parents, a finding that was consistent across all groups of respondents. Fewer expected that teachers (60%), physicians (46%), law enforcement officers (34%), and EMS personnel (22%) should provide education.

When asked "Who do you think parents expect to provide education about bicycle helmets to children?" only 18% of teachers, 26% of physicians, and 26% of EMS personnel responded "parents." The majority of respondents (61%) responded that parents expected teachers to provide education on bicycle helmets.

Discussion

This study demonstrates that while there is general awareness of the North Carolina bicycle helmet law, there is a lack of knowledge about helmet effectiveness and proper fit and a limited use of helmets by those with frequent contact with children. Based on the responses from parents, a substantial portion of children do not wear helmets while riding bicycles despite their family's awareness of the law.

Mandatory helmet use legislation in Canada and New York has been shown to increase helmet use among children by observing helmet use among those admitted to the hospital for bicycle crashes.[8,9] An international systematic review of published observational studies relating to mandatory helmet use legislation also showed an increase in helmet use; however, it did not control for time since law enactment, enforcement, or education about the law.[10] In contrast, the observational study performed in North Carolina 6 months after the passage of its helmet law failed to show an increase in helmet use among children younger than 16.[6] There were no educational programs associated with the North Carolina bicycle helmet law prior to this study. This provides an opportunity for improvement because research has shown that helmet use in communities where bicycle helmet legislation is combined with educational programs is greater than in communities without these programs.[11,12]

The results of our study suggest that education is necessary among parents, teachers, physicians, and EMS personnel in North Carolina in order to improve the number of children wearing helmets and decrease the number of bicycle-related head and brain injuries. The survey results suggest that most people expect parents to be the main educators of children about bicycle helmets. Reaching parents could provide the greatest impact. The survey participants are potential role models for children. Only 21% reported "always" wearing a bicycle helmet, suggesting that an educational campaign should also be extended to adult use.

This education should also include instructions on proper fit of the bicycle helmet. Of the 21% of improperly used bicycle helmets observed among children aged 5-15 in the 2002 North Carolina study,[6] the most frequent misuse (40%) was due to the helmet being tipped back, exposing the forehead. The next most frequent (31%) mistake was a helmet that was too large or a chin strap that was loose. (See Figure 2 for details of proper helmet use.)

Many methods to educate about helmets as well as increase the use of helmets among children have been studied including free helmet giveaways,[13,14] requiring the purchase of a helmet with a bike,[15] police enforcement of legislation,[16] physician involvement in behavior change counseling and education,[17] and community programs.[18] A 2005 Cochrane Review of nonlegislative interventions aimed at increasing helmet use among children found that the most effective method is a community-based education program along with free helmet distribution with some evidence supporting interventions in the school setting.[19]

Bicycle helmet use and legislation is comparable to seat belt use and legislation. North Carolina was the pilot state for enforcing seat belt use. In 1985 the North Carolina General Assembly passed a law requiring all front-seat passengers to wear seat belts. An initial rise in seat belt use followed, but by 1993 the seat belt use returned to near prelaw levels at 65%.[20] The *Click It or Ticket* campaign started in October of 1993 with a month of public education and high-visibility enforcement. Seat belt use rose to 80%, but by May 1994, just 7 months later, it had dropped to 73%. A return of enforcement and education in July of 1994 brought seat belt use back to 81%.[21,22] According to the National Highway Traffic Safety Administration (NHTSA), seat belt use in North Carolina was reported to be 86.7% in 2005.[23] This shows that coupling education and law enforcement increased seat belt use in North Carolina. A similar strategy may increase bicycle helmet use among children.

Limitations

The data from this study was collected by survey which introduces nonresponder bias. It is possible that those recipients of the survey not interested in or educated about helmet use may have been less inclined to complete and return the survey, creating a bias towards awareness of the law or helmet use.

The question about knowledge of the law may have been misinterpreted. The survey asked about the state law (enacted 2001) when there also was a citywide law in place in Greenville, North Carolina (roughly half of the population of Pitt County) since 1998 requiring bicycle helmets in children under the age of 16. This could create a bias towards knowledge of the law. Also, for the question asking how frequently helmets were worn, an option was not given stating "do not ride a bike." This response was written in on some surveys, and it is possible respondents answered "no" to this question when in reality they do not ride a bike. Furthermore, frequency of and reason for bicycle use was not addressed, and this may also impact helmet use. Respondents who frequently use their bicycle for exercise could be more likely to wear a helmet than those who infrequently ride their bicycle. Some responders did not answer all questions on the survey; however, this was limited to the follow-up item to the question asking about the need for a law. This question was "If not, should there be a law?" Results were reported only on the respondents who answered "no" to the initial question, all of whom answered the follow-up question.

Further limitations provide areas for continued research. This study did not include an observational component and therefore only shows the opinions of the respondents, not actual helmet use. The survey was distributed only in Pitt County, North Carolina, and does not reflect helmet awareness for the state as a whole. A state-wide observational study should be repeated.

Conclusion

Helmets have been shown to be effective in reducing head and brain injuries among children which is the basis for the mandatory helmet law for children in North Carolina. A majority of surveyed parents, teachers, physicians, and EMS personnel in North Carolina were aware of the helmet law, yet they underestimated the effectiveness of helmets and felt uncomfortable with their level of understanding about proper helmet use and fit. Education aimed at parents and teachers may improve the overall understanding of helmets. However, awareness is not enough. Enforcement of and education about the helmet law is necessary to improve helmet use among children. **NCMJ**

Table 2.
Proper Bicycle Helmet Fit[24]

Step 1: Size	With the helmet sitting flat on top of your head, make sure it doesn't rock side to side. Sizing pads come with new helmets; use the pads to securely fit the helmet to your head.	
Step 2: Position	The helmet should sit level on your head and low on your forehead —one or two finger-widths above your eyebrow.	
Step 3: Buckles	Center the left buckle under the chin by shortening and lengthening the straps.	
Step 4: Side strap	Adjust the slider on both straps to form a "V" shape under, and slightly in front of, your ears.	
Step 5: Chin strap	Buckle your chin strap. Tighten the strap until it is snug, so that no more than one or two fingers fit under the strap.	
Step 6: Final fitting	A. Does your helmet fit right? Open your mouth wide…big yawn! The helmet should pull down on the head. If not, refer back to step 5 and tighten the chin strap. B. Does your helmet rock back more than two fingers above the eyebrows? If so, unbuckle, shorten the front strap by moving the slider forward. Buckle, retighten the chin strap, and test again. C. Does your helmet rock forward into your eyes? If so, unbuckle, tighten the back strap by moving the slider back toward the ear. Buckle, retighten the chin strap, and test again.	

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North Carolina
MEDICAL JOURNAL

POLICY FORUM

Emergency Medical Services in North Carolina

COMMENTARIES

> *"Groundbreaking ideas and advances in EMS research and education are incubated and cultivated in North Carolina ... State officials are tackling the most pressing challenges—recruitment and retention—by describing the extent of the problem and offering alternative solutions."*

INTRODUCTION

Policy Forum:
The North Carolina System of Emergency Medical Services

Running on adrenaline and altruistic motives, nearly a million first responders, emergency medical technicians (EMTs), and paramedics across the US perform life-saving procedures every day. They do this under stressful and dangerous work conditions, for very little pay, and with little recognition. Funding and support for maintaining readiness is limited. Reimbursement for services rendered is often below actual costs. Low patient volumes, limited billing capacity, high turnover, and reliance on volunteers force many rural-based emergency medical services (EMS) systems, including some in North Carolina, to close or convert to a different type of EMS model.

Current research and policy reviews indicate that we possess very little knowledge and understanding of EMS; how it works today, how it is supported, how the personnel are trained and educated, what professional issues emergency responders face, and what operational and political obstacles prevent timely and high quality EMS care.

The public's visibility of the current status of EMS was raised recently by the Institute of Medicine of the National Academies (IOM) report on the status of EMS. The report pointed to inefficiencies, workforce problems, and other systems-level challenges. The overarching recommendation from the IOM was for the establishment of a permanent federal lead agency within the US Department of Health and Human Services dedicated to EMS. This issue of the *North Carolina Medical Journal* follows the IOM's footsteps by focusing attention to the challenges and needs of North Carolina's EMS system.

Lifelong EMS professionals in North Carolina feel the state has been on the forefront of the EMS evolution. Many national and internationally recognized EMS leaders live in North Carolina and have contributed to this issue of the Journal. Groundbreaking ideas and advances in EMS research and education are incubated and cultivated in North Carolina institutions of higher learning. State officials are tackling the most pressing challenges—recruitment and retention—by describing the extent of the problem and offering alternative solutions.

All of health care delivery is under scrutiny as we seek ways to provide the best possible care at a reasonable cost. However, we often don't look at this problem in a fully systematic way—largely because we do not have a uniform system of care. A uniform health care system would link and coordinate its many parts, including the emergency services components that have immediate and important roles to play in keeping our citizens healthy and bringing them quickly to definitive care.

This issue of the Journal seeks to highlight this part of the system by describing its origins and development and outlining the future organization and operation of EMS. There are decisions to be made at the local and state levels regarding how we can keep this important part of health care delivery functioning effectively for the citizens of North Carolina and the nation.

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ISSUE BRIEF

Overview of Emergency Medical Services in North Carolina

William K. Atkinson II, PhD, MPH, MPA

The emergency department is an integral part of our nation's health care safety net. Emergency medical services (EMS) are the integral thread in the safety net.[1] The position EMS care has in health care is significant and the services it provides are unique. There are more than 18 000 EMS systems in the United States[2] and approximately 800 separate service units operate in North Carolina. Coordinated at the county level, giving North Carolina 100 local "systems," North Carolina EMS systems incorporate local rescue squads and hospital, public health, and public safety personnel.[3] In many rural areas of the US, there may be a single volunteer rescue squad that serves as the only form of health care for miles.[4] Spread across almost every community in the US, there are nearly one million paramedics, emergency medical technicians (EMTs), and emergency first responders.[5] An estimated 33 000 EMTs and paramedics are currently certified in North Carolina and most are volunteers.[6]

In most communities, EMS care is available to anyone, for any reason, at any time. On average, individuals use EMS care twice in their lifetimes.[4] The likelihood of using EMS care increases as an individual ages.[7,8] In some communities, demographic and socioeconomic factors associated with EMS utilization include lower income (poverty), minority race, female gender, and Medicaid or health maintenance organization insurance coverage.[9-15]

It is unclear exactly how frequently EMS care is accessed on a national scale. A recent Institute of Medicine of the National Academies report estimated 16 million EMS transports to emergency departments (EDs) in 2002.[16] Other publications cite much higher frequencies with as many as 28 million EMS encounters.[17] Thousands of other EMS encounters involve interfacility transports or transports to clinics, physicians' offices, or other institutions. North Carolina citizens use EMS over 1 million times each year.[18]

Emergency medical service systems are well known for their ability to handle cardiac emergencies and traffic-related trauma, but much of the medical care EMS provides is nonemergent in nature.[14,19-22] Research shows that an overwhelming number of visits to the ED are nonemergent[23] and, in fact, are unnecessary,[19,24,25] and use life-saving and expensive health care services needed by others.

A Call to Action

There are things in life and in health care that move along at yesterday's pace for seemingly no good reason. Many aspects of today's system of EMS care vary little from what was seen in the 1970s. In the 1950s and 1960s in North Carolina and across the nation, ambulance services provided little more than "scoop and run" transport.[26] Untrained personnel in hearse-type vehicles sped to an emergency scene, "scooped" up the patient with no regard to injury, illness, or care and raced—sometimes with both the driver and an attendant (if present) riding in the cab—to an ill-equipped and poorly staffed emergency room. Such was the case in almost every community across this nation.

> *"Before the 1960s, ambulance transportation was often provided by volunteer rescue squads or through local funeral homes."*

Before the 1960s, ambulance transportation was often provided by volunteer rescue squads or through local funeral homes. It was the norm and something that was accepted. Funeral home ambulances were solely for convenient, horizontal transportation. As of 1959, local governments were also authorized to help finance rescue squad operations.[31] At that time, North Carolina's volunteer emergency squads were structured and

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funded in a haphazard way. These volunteer squads were mostly dependent on local donations to fund their activities. Rescue squads were sometimes formed through local fire departments, police departments, or civil defense units. Regardless of affiliation, the availability and quality of rescue and ambulance services across North Carolina was generally questionable. North Carolina wasn't alone; emergency services across the country were much the same.

Physicians and other health care providers insisted we could do better. In 1965, the National Academy of Sciences (NAS) published a report entitled *Accidental Death and Disability: the Neglected Diseases of Modern Society*.[27] The report forced public officials to take concrete steps to establish standards for ambulance design and construction, EMS equipment and supplies, and training programs and protocols for personnel. The NAS, drawing on lessons learned in the military in Korea and Vietnam, reported 52 million accidental injuries in the US, with 107 000 deaths. Of those who survived their injuries, more than 10 million were temporarily disabled and another 400 000 permanently disabled, all at a cost of $18 billion. The report described accidents as the "neglected epidemic of modern society" and "the nation's most important environmental health problem."

The report stimulated the passage of the National Highway Safety Act of 1966, which called on the US Department of Transportation (DOT) to develop minimum standards of care for accident victims. It also gave the federal DOT the right to withhold 10% of its highway design, construction, and operation funds to states that did not comply. This risk equated to millions of dollars annually for each state and, as intended, quickly drew the attention of state governments.

Between the DOT and the National Highway Traffic Safety Administration (NHTSA), model EMS systems were developed. The appropriations for each agency included more than $48 million for national training standards for emergency medical training. This structure provided for multiple levels of training to include emergency medical technician-basic (EMT-Basic), EMT-Intermediates, and EMT-Paramedics.[28]

On November 16, 1973, Congress approved the Emergency Medical Services Systems Act of 1973 (PL 93-154)[29,30] which funded and authorized the US Department of Health, Education and Welfare to help develop EMS programs throughout the country. Funding allocated $30 million for the fiscal year ending June 30, 1974, $60 million through June 30, 1975, and $70 million through June 30, 1976. The act identified 15 "key elements" of an EMS system including manpower, training, communications, transportation, facilities, critical care units, mutual aid, consumer participation, accessibility to care, transfer of patients, standard record keeping, consumer information and education, review and evaluation, disaster linkage, and use of public safety agencies. Because PL 93-154 called for the development of a comprehensive system with a minimum of 15 complex components, an EMS system built around the federal model actually became many different innovations rolled into one umbrella known as EMS.

North Carolina as a Leader in EMS Innovation

North Carolina was one of the first states in the nation to address EMS development through state government involvement and on a statewide basis. National and state-level legislation led the way in the formation of modern EMS programs across the country. But while many states approved EMS development on an element-by-element basis, North Carolina approached EMS from a comprehensive system development perspective. Considerable federal and state resources were applied to system development and talent was drawn from both in-state and out-of-state to support the overall program and its implementation.

North Carolina adopted the federal 15-element model and actively pursued implementation of EMS across the state. The central theme and intent of the EMS Systems Act was to develop systems of emergency medical care that would significantly decrease death and disability rates. However, implementation is often far more complicated than planning. In North Carolina's case, some volunteer emergency squads were just as ready to block federal intervention then as other types of North Carolina volunteers were ready to block Union troops in the American Civil War. Federal ambulance and training standards, even though they were to be administered through state government, were viewed by many local rescue volunteers as an intrusion on their rights, values, and way of life. This set the stage for another battle. This time it was state regulators, armed with federal standards and an innovative concept called emergency medical services, squaring off with community volunteers from across the state.

Due to many factors, by August 1966, 56 counties in North Carolina were threatened with the loss of ambulance service. Some municipalities stepped up to the plate to offer services that were lost, and some commercial providers began operation, but those services were normally of poor quality and limited financial means. Some commercial providers were allocated subsidies from local governments, but even with that, most still failed. By 1967, the lack of a sound approach to ambulance service was more visible than ever before. Many public and private interest groups, along with a growing list of medical professionals, began to focus on the statewide ambulance issue. Funeral directors began to withdraw from the delivery of the service, in part driven by the cost of labor due to newly introduced federal labor standards. The North Carolina General Assembly responded by passing the Ambulance Act of 1967. The act placed the legal responsibility for ambulance availability on county governments as an extension of public health.

In North Carolina, the Ambulance Act of 1967 represented the first major step for ambulance legislation in the state. More states across the country were taking advantage of federal dollars for technical assistance and funding in support of ambulance improvements and model projects. With money from the US Department of Transportation, the Jacksonville, Florida, fire department began efforts to reduce traffic related deaths by implementing a citywide EMS system.[32] Overnight, the city government became involved in ambulance service. All of the community funeral homes and commercial ambulance services quit providing the service during a strike. In 1968, a similar situation occurred in North Carolina's Guilford County. The county had to step in and assume immediate responsibility for ambulance service when the only local, private service went on strike. Incidents like these were not isolated and occurred in numerous locations across the nation and throughout North Carolina.

State government, with limited funding, began to oversee North Carolina's ambulance and rescue services. For the first time in the state's history, minimum training standards, very minimum by today's rules, were established. Ambulance "attendants" were required to complete a 24-hour course in standard first aid through the American Red Cross or other training source. The North Carolina Board of Health also established equipment standards for all ambulances, based on recommendations from the American College of Surgeons' Committee on Trauma. Even with the minimal requirements, some rescue squads still refused to participate because they were wary of government intervention and they resisted change.

The North Carolina Board of Health was designated to inspect ambulances, but again, the quality of this oversight process was poor. Staff was assigned to monitor a system that truly didn't exist. F. O'Neil Jones, a freshman senator from the 24th district (Anson County), learned of the problems from Dr. Bill McKennon, a friend and physician, who said that something needed to be done. Armed with McKennon's advice and help from David Warren at UNC-Chapel Hill's Institute of Government, Jones created a research commission to examine statewide issues in emergency care and transportation. The results of the commission were outlined in the 1972 report *Emergency Medical Services in North Carolina: Transportation, Communication and Personnel*. The report stated:

> North Carolina has approximately 400 organizations with 927 vehicles and 6,300 persons providing ambulance and/or rescue services. About one half of these providers is volunteer agencies and one-fourth is funeral home operators. Though volunteer and funeral home units represent almost 75 percent of the providers, they respond to only 43 percent of the calls. Governmental and commercial responders, who constitute less than 20 percent of the providers, respond to 52 percent of the calls. Other providers, such as hospitals, respond to the remaining calls.… It is estimated that only 202 service units meet the minimum requirements. (RTI, 1972:3)[33] … The presumption is that people are dying needlessly at the hands of ambulance attendants who are so medically under skilled that they do not know how to deal effectively with many common medical emergencies.

Jones' work and the report of the commission resulted in the North Carolina EMS Act of 1973 and the creation of the North Carolina Office of Emergency Medical Services (NC OEMS) in the North Carolina Department of Human Resources. Subsequently, North Carolina was one of the first states in the country to begin a statewide effort to establish an EMS system in every community.

This lead agency, under the secretary of the North Carolina Department of Human Resources, established broad powers and responsibilities to create, maintain, and oversee prehospital EMS operations and hospital-based trauma and helicopter ambulance services in the state. David Warren was appointed as acting chief of NC OEMS with instructions to get the office organized and do a national search for the best person to become permanent chief. That led to the hiring of a man who many emergency service professionals across the globe now describe as an emergency medical services pioneer—James (Jim) O. Page.

Jim Page, an attorney and a Los Angeles County fire battalion chief, was a leader of one of the first agencies in the nation to train paramedics and provide advanced prehospital care. Page, at the time, was also technical advisor to the NBC hit show "Emergency!" This program and Page's leadership brought him to North Carolina to lead the new agency after he came to the state for a speaking engagement and was enticed to apply for the newly created chief's position. He assumed the role as chief of North Carolina OEMS on December 19, 1973.

Page and the talented OEMS team he developed found it straightforward to upgrade vehicles and equipment through federal funding and new national standards in ambulance design and construction. Funds were also available to assist with the initial development of local and statewide EMS communications systems and air ambulance services. Likewise, the designation of hospital trauma centers was also a duty assigned to NC OEMS.

Implementing training standards and working with the hundreds of emergency service providers across the state proved to be another challenge—one that would eventually cost Page his job. The task of training and certifying basic EMTs was monumental. Urban areas rapidly accepted and adopted the new training standards while eastern and western parts of the state resisted implementation. Specifically, major pockets of opposition quickly built within the volunteer squads in and around Wayne County in the east and Gaston County in the west. The resistance was "organized, highly vocal, media intensive and politically active."[34]

Rescue squads and funeral homes saw the training as an extra burden that was too much to ask of their members or employees. Page's support for training and education set him up as a political lightning rod. A number of state senators were complaining to the secretary of the Department of Human Resources that their local rescue squads were angry and putting significant political pressure on them about Page and NC OEMS.

Another looming problem and one that hints at reasons why some squads resisted initial training was illiteracy. For the first time, ambulance personnel would be required to attend formal training, read an EMT textbook, and pass written and practical exams. At the time, illiteracy was a problem plaguing squads from the mountains to the coast. Political pressure mounted to extend the basic EMT certification deadline, which Page was willing to do, and allow for oral examination for EMT candidates, which he was not. Giving in to "voter pressure," Page was asked to resign by the secretary, but he refused to do so. Page was then terminated. He was at the helm less than two years.

Page was replaced with Colonel Charles A. Speed, former commander of the North Carolina Highway Patrol. Speed was a highly principled man who also refused to compromise on the training standards. Although the road remained rocky for some time, the statewide training program moved forward; by 1977 all 100 counties had adopted basic EMT training, and by 1984 the number of certified EMTs had climbed to more than 50 000.

Following Colonel Speed's retirement, strong leadership continued to be a characteristic of NC OEMS. Under each chief, including the current chief, Drexdal Pratt, the implementation of all 15 key elements and many more add-on components and policy advances of the state's EMS system have continued to take place.

EMS Today

Today no one debates the merits of a 9-1-1 system, skills certification for paramedics, or the need for understood "levels" of care whether those be in the hospital-based trauma program or the neonatal intensive care unit. As September 11, 2001 taught us, the ability to communicate is essential in order to protect lives. When terrible things happen, people turn to their hospitals for help. As the recent tragic events at Virginia Tech also showed us, a level III trauma center handled more than 20 wounded students, many of them in critical condition, with skills and processes that make us all proud.

Are all of our hospitals in North Carolina and all of our first responders ready to handle such a terrible event? What should be the level of care we expect of any hospital in our state that has an emergency department? Many of our state's original emergency services physicians, nurses, physician assistants, and paramedics have or are approaching retirement. How will we replace their skills and expertise?

These are important questions the state's hospitals, physicians, policy makers, and their partners in emergency medical services are considering and debating. Once again, it will be surprising if North Carolina does not lead the way in finding solutions.

Essential Components of EMS: A Status Report

Over time, EMS systems in North Carolina and in the nation have evolved into sophisticated and mobile medical care units with highly trained medical professionals. In this special issue, local, state, and national experts and leaders in EMS provide detailed discussions and commentaries on the essential components of EMS.

Recruitment and retention of EMS personnel at all levels is perhaps the most visible challenge for EMS systems in North Carolina and nationally.[35] The EMS industry is in a struggle at the moment with advancing the profession while sustaining the existing workforce to meet rising public need and demand. Dr. Daniel Patterson comments on the nature of the manpower challenge for our state and the nation. Although research is limited, many states, local leaders, and colleagues in foreign nations are experimenting with a variety of approaches to ensure every citizen has access to the emergency care they need. We in North Carolina should monitor these trends and adopt emerging and innovative approaches to sustaining the EMS workforce.

In most locales, EMS professionals are first trained at the basic level of certification to deliver essential life saving care. With additional training, professionals are certified as intermediate technicians, paramedics, or critical care professionals. The bulk of the nation's and North Carolina's EMS professionals are trained in the community college system. Studies of EMS professionals show that many would prefer a degree over certification only.[36] In several commentaries, national and state leaders in EMS education and training discuss the role of community colleges, universities, and national registration organizations in the training of EMS professionals.

EMS communications include the transmission of information between EMS professionals, members of public safety (ie, police), and others. Cell phones and text messaging are increasingly being used to facilitate EMS communications. Much consideration has been given to gaps in communications due mostly to the communications challenges experienced during September 11, 2001 and during recent natural disasters. Communications experts Carl Van Cott of North Carolina and Kevin McGinnis of the National Association of State EMS Officials outline EMS communications in North Carolina, the challenges we face, and what is on the horizon in terms of new communications technologies and how they can help prevent miscommunication.

Data are the foundation for research that advances knowledge and even a profession. While we know that our nation's emergency departments receive over 100 million visits annually, we have no true sense of how many EMS responses and transports are made in America. Nor do we know very much about the details of EMS utilization or how best to go about reducing unnecessary use and improving the quality and safety of care for those who need EMS assistance. Sporadic record keeping in EMS is partly to blame. A lack of data has in many respects stalled the advancement of EMS as a service to our citizens. Work performed right here in North Carolina with support from a variety of federal agencies has helped to construct a national EMS information system, NEMSIS. Dr. Greg Mears of the University of North Carolina at Chapel Hill describes NEMSIS and what it can do for the state of North Carolina and EMS nationally.

EMS has evolved such that it works in concert with public safety and health care while standing on the outside looking in. EMS is a very fragmented system where it is difficult to make the vertical and horizontal connections between EMS and many of its partners in public safety or health care. Poor integration impacts patient transportation and transfer (by air or ground) to different facilities such as critical care units. It also impacts how one EMS system communicates and works with other EMS systems. Several commentaries included in this issue touch on these components from a variety of vantage points.

Emergency medical service was founded under the umbrella of traffic safety. Over time, various federal and state agencies have assumed responsibility for some or all aspects of providing EMS care. Identifying who or what agency is responsible for EMS can be difficult. Bob Bailey, a former chief of the NC OEMS, describes federal EMS legislation and what the legislation is intended to do. Drexdal Pratt, the current chief of the North Carolina Office of EMS, describes North Carolina's EMS legislation.

Financing EMS services is a very complex and often contentious issue. Many EMS systems receive some support from federal, state, and local governments. This funding usually represents a very small component of total system revenues or capital. In many instances, EMS systems must bill for services rendered which means transportation. If an EMS system responds to a scene and the patient is not transported, most systems are not reimbursed for the costs incurred. Todd Hatley, a former North Carolina local EMS training officer and EMS quality consultant, describes the EMS financing system, financial challenges, and experiences.

When one compares the amount of published research on topics specific to EMS to the amount published on non-EMS topics or in other disciplines, one word comes to mind: paucity.[37] Some our nation's most recognized leaders in EMS research are located right here in North Carolina. Two leaders, Dr. Herb Garrison of East Carolina University and Dr. Jane Brice of the University of North Carolina at Chapel Hill, discuss research and evaluation in EMS, focusing their attention on gaps in EMS research and where we need to be in terms of advancing the profession.

A survey of some Eastern North Carolina residents found that many have very little idea what their local EMS system provides in terms of medical care.[38] This lack of understanding also extends to many medical professionals. EMS professionals are designated agents of a physician.[39] In other words, EMTs and paramedics provide medical care under the license of a physician. With supervision and guidance, EMS professionals administer medications and perform many cognitively complex medical procedures outside of the hospital setting. Added to the list of 15 essential components of an EMS system after the 1973 legislation was written, medical oversight is an extremely important element of EMS care and delivery.[40] Local EMS systems, their chiefs, and their personnel must overcome many challenges in order to access and receive the medical oversight they need to perform their duties. Rural areas are known to have limited access to adequate medical oversight.[41] The National Association of EMS Physicians (NAEMSP) and others have published a list of duties all physicians engaging in medical oversight activities must provide a local EMS system.[42,43] Dr. Brent Myers, the medical director for Wake County EMS and WakeMed's Emergency Services Institute, comments on medical oversight in North Carolina and in the nation.

Providing a very in-depth look into one of the most controversial medical procedures performed in the prehospital setting is Dr. Henry Wang of the University of Pittsburgh. Endotracheal Intubation (ETI) is the insertion of a plastic tube into the mouth and throat of a patient in order to establish or maintain an open airway. For many reasons, performance of this procedure by EMTs has attracted a great deal of scrutiny from the medical community. Dr. Wang comments on the origins of ETI, outlines some of the controversies, and speculates on the future of ETI in EMS.

Threats of terrorism and natural disasters are prominent on the minds of most citizens and policymakers. Regardless of the type of event, EMS must be prepared for mass casualties. Drs. Roy Alson and Jane Brice are intimately involved in EMS preparedness activities and planning. They comment on preparedness in North Carolina.

Conclusion

At some point in time, virtually every North Carolinian and every American will require the assistance of EMS. One Congressionally supported report published in the late 1980s anticipated that every American could anticipate a minimum of two EMS encounters in his/her lifetime.[4] The importance of our state and nation's EMS system should not be understated. When EMS is needed, we expect them to get there as fast and safely as possible. It is only at that point in our own history that we can truly appreciate the significance of our local EMS system, the training EMTs and paramedics go through, and the challenges they encounter while tending to our emergency needs.

Unfortunately, while we may all voice our appreciation for EMS in our community, the state's system of prehospital care, and that of the nation, is in jeopardy. In the recently released *Rural and Frontier EMS Agenda for the Future*,[44] the authors noted that the infrastructure upon which EMS was built is crumbling. More recently, our nation's emergency care system received an overall grade of C- in the first ever National Report Card on the State of Emergency Medicine.[45] Overcrowding, poor access to emergency care, and liability issues were identified as prominent factors. The nation's leading independent health policy body, the Institute of Medicine of the National Academies, released three scathing reports on the state of emergency departments, EMS, and pediatric emergency care in 2006. The reports focused on the lack of federal leadership in the development of EMS systems as the most critical of factors in the delivery of EMS care today.[16]

Throughout its 50-year history, North Carolina's modern EMS system has played a prominent role in the evolution of EMS health care nationally. While there are many obstacles and many challenges, as the reader will learn in the pages that follow, North Carolina EMS authorities are well positioned to lead efforts in innovation and improvement. With recognition from state policymakers that EMS is a vital component of health care, public safety, and public health, our state's EMS system can continue to improve and serve as the EMS model for the nation. **NCMJ**

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COMMENTARY

Emergency Medical Services Legislation in North Carolina

Drexdal Pratt

North Carolina's history of emergency medical services (EMS) legislation dates back to 1967. The study commission and subsequent legislation in the state was a result of the federal National Highway Safety Act of 1966. This federal act created the National Highway Safety Administration and directed each state to develop a regional EMS system. The North Carolina Governors Highway Safety Program was charged with assisting in the funding of such a program in our state. Soon after the enactment of this act the US Department of Transportation released national standards for the design and equipment of ambulances and training for ambulance attendants.

In 1967 the North Carolina General Assembly passed the Ambulance Services Act under Chapter 130, Article 26, Regulation of Ambulance Services. This act placed the regulatory responsibilities of EMS under the North Carolina State Board of Health and provided the board authority for adopting standards for equipment, inspection of medical equipment, and supplies required for ambulances. In addition, the law required that ambulances have permits and the board adopted regulations setting forth the qualifications required for certification of ambulance attendants.

The 1967 law also created an Advisory Committee on Ambulance Service to assist the North Carolina State Board of Health in developing standards for use in Article 26. The advisory committee consisted of 9 members and representative of the North Carolina Funeral Directors Association Inc., Funeral Directors and Morticians Association of North Carolina Inc., North Carolina Ambulance Association Inc., North Carolina Medical Society, North Carolina Hospital Association, American Red Cross, North Carolina State Association of Rescue Squads Inc., North Carolina Association of County Commissioners, and North Carolina League of Municipalities.[1] This advisory committee still exists today and has expanded in membership to represent the many EMS stakeholders. The committee's name has changed to the North Carolina EMS Advisory Council, and it continues to offer a valuable service to the state and the citizens of North Carolina.

In 1971 Senator F. O'Neil Jones sponsored Senate Resolution 827 authorizing a Legislative Research Commission "to study and investigate the problem of emergency care in North Carolina and to plan and develop an adequate system of providing comprehensive emergency medical care throughout the state with sufficient resources to save human lives and diminish the immeasurable emotional burden and vast economic losses of avoidable disability."[2] The Commission was instructed to report its findings and recommendations to the 1973 session of the General Assembly. Senator Jones chaired the commission and provided its report and recommendations to the General Assembly in January 1973.

> *"North Carolina's history of EMS legislation dates back to 1967. The study commission and subsequent legislation in the state was a result of the federal National Highway Safety Act of 1966. This federal act created the National Highway Safety Administration and directed each state to develop a regional EMS system."*

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One of the recommendations of the commission was the establishment of the Office of Emergency Medical Services within the Department of Human Resources (now Health and Human Services). In addition, the agency should be adequately funded and empowered to coordinate and control all state EMS programs and have the ability to pursue federal and private funding and make allocations to both governmental and private local EMS systems. There were several other recommendations to increase the minimum standards for EMS training and to change the name of the Advisory Committee to the EMS Advisory Council and increase its membership to better reflect all of the state's EMS stakeholders.

As a result of the study commission's work, the Office of Emergency Medical Services was established in 1973 and placed in the Division of Facility Services. Funding was appropriated to the agency to improve training, transportation, hospital emergency rooms, and communications consistent with the 15 federally recognized components of an EMS system. Chapter 224 of the law consolidated the rule-making authority over ambulances and personnel in the Medical Care Commission. In Chapter 1121 the law authorized training emergency medical technicians to perform advanced first aid and limited medical procedures under the rules and regulations of the Board of Medical Examiners.

Over the next 20 years some minor changes were made to the EMS statutes and many administrative rule changes were made. In 1976 the North Carolina Medical Care Commission published a document entitled "Rules & Regulations Governing Ambulance Services," thus creating the state's basic life support rules. Also in 1976 the North Carolina Medical Board adopted rules to allow advanced skills for EMTs under the certification of Mobile Intensive Care Technicians.

In 1993 G.S. 131E-162 was passed and required the department to develop a Statewide Trauma System and, in 1995, G.S. 131E-155.1 was enacted to require the licensing of EMS providers. This legislation served EMS in our state well for many years and established a solid foundation to build on for the future.

North Carolinas EMS Legislation Rewritten in 2001

In 1999 the NC Office of Emergency Medical Services embraced the National Highway Traffic and Safety Administration's plan entitled *Emergency Medical Services, Agenda for the Future*. The agenda listed 14 attributes of an EMS system much like the previous 15 components but revised to meet the needs of a more expanded and developed profession. Realizing that EMS continues to be a local community based system, the new vision brings clarity and places emphasis on the fact that EMS is truly a port of entry to the overall health care system. Integration of health services are needed with such partners as public health, social services, community agencies, and academic institutions as part of the new vision.[3] The new attributes address areas such as EMS research, system finance, prevention, information systems, evaluation, and others requiring additional statutory authority for implementation and funding. Those of us that have worked in the EMS system since its inception realized that North Carolina needed to rewrite its laws and rules governing EMS to fully embrace and implement the agenda.

Therefore, in 1999 we began the process to educate EMS stakeholders on the National EMS Agenda for the Future and rewrite the existing EMS laws. With help and support from the secretary of the Department of Health and Human Services, the director of the Division of Facility Services, the North Carolina EMS Advisory Council, 18 EMS stakeholder groups, and the dedicated staff of the Office of Emergency Medical Services, Representative Thomas Wright, New Hanover County, agreed to introduce House Bill 452, An Act to Revise and Update the EMS Act of 1973, and House Bill 453, Regulation of Emergency Medical Services, two of the most comprehensive EMS system bills in the country. The bills were passed in the 2001 session of the General Assembly and became law on January 1, 2002. The North Carolina Medical Care Commission adopted temporary rules to coincide with the legislation's enactment.

The new legislation required many changes to the structure of EMS in the state. Since most EMS providers in the state had progressed using the previous enabling legislation to provide advanced life support, it was apparent that EMS rule making needed to reside under the authority of one entity, either the NC Medical Care Commission or the NC Medical Board. After much discussion with the stakeholders it was decided to move all rule-making authority under the authority of the NC Medical Care Commission. The NC Medical Board retained statutory authority in G.S. 143-514 for defining the scope of practice for all levels of EMS personnel.[4]

The law now defines emergency medical services in G.S. 131E-155 (6) as: "services rendered by emergency medical personnel in responding to improve the health and wellness of the community and to address the individual's need for emergency medical care within the scope of practice defined by the North Carolina Medical Board in accordance with G.S. 143-514 in order to prevent loss of life or further aggravation of physiological illness or injury." The law also defines the Statewide Emergency Medical System in G.S. 143-507 (b).

Another major change in the law clearly places the responsibility of ensuring that every citizen has access to EMS to the Board of County Commissioners for each county. The new law establishes local EMS systems with no more than one system per county. New rules require that all counties submit a comprehensive EMS system plan to the Office of EMS and that all EMS providers licensed to operate in the county function as part of the county's EMS system. These requirements help standardize and coordinate the EMS care provided by the more than 850 EMS agencies operating in the state.[5]

New rules enacted by the NC Medical Care Commission enable counties to advance their systems to earn the designation of "Model System."[a] Model System designation far exceeds the minimum system requirements, is voluntary, and allows counties less regulatory oversight by the state. Less regulatory oversight includes self inspection of vehicles with appropriate documentation and more flexibility in all areas of their program management. In order to obtain the designation, counties must provide documentation that all system components of medical oversight, peer review, continuing education, and emergency medical dispatch are met and ensure the same high level of care is being provided to its citizens 24 hours, 365 days per year. The OEMS reviews the documentation then verifies through an on-site visit with the county before awarding the designation. The designation is awarded for a six-year period. Currently there are 12 counties in North Carolina that have obtained this designation.

Although air medical services were included in the previous rules, the new rules changed the terminology to include Specialty Care Air and Specialty Care Ground to address the interfacility patient transport. The term specialty care also assists EMS systems with reimbursement issues because this is a recognized term for Medicare and Medicaid. The law also provides liability protection for local and regional peer review meetings and requires electronic patient records to be submitted to the department on a daily basis. The data provides valuable information to assist the counties and state in assessing needs and looking at statewide patient outcomes for prehospital care.

The law also expanded membership on the EMS Advisory Council to be more representative of today's EMS system and created a 7-member EMS disciplinary committee that reviews all EMS personnel disciplinary cases and provides recommendations to the Office of EMS for possible action.

Throughout North Carolina EMS history the General Assembly, the Department of Health and Human Services, and the Division of Facility Services have supported efforts to improve the state's EMS system and have been proactive in passing legislation and rules to meet the needs of an ever expanding North Carolina EMS system. **NCMJ**

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[a] The requirements for Model System designation can be found in the North Carolina Administrative Code 10A NCAC 13P .0202.

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COMMENTARY

Federal Policy Leading the Way in Emergency Medical Services

Bob W. Bailey, MA

The most influential piece of federal legislation during my 30-year tenure with the North Carolina Office of Emergency Medical Services (NC OEMS), the last 15 as the state Emergency Medical Services (EMS) director, was creation of the EMS program at the National Highway Traffic Safety Administration (NHTSA). Since then, federal EMS legislation, programs, and agencies have profoundly impacted the evolution of EMS throughout our nation and my personal career in North Carolina.

Federal EMS legislation permitted NHTSA to 1) assist states and local communities with the purchase of ambulances; 2) fund for automobile extrication courses; 3) provide national-level guidance and support to evolving EMS systems; and 4) standardize emergency medical technician (EMT) training across the nation. The NHTSA also made the term EMT a household word and created a universally recognized symbol for EMS, the blue "Star of Life."

The 1973 National EMS Systems Act helped shaped state legislation including that of North Carolina. The NHTSA state EMS assessments and reassessments program, a program supporting expert team evaluations of state EMS systems, continues to help guide the development of state EMS systems. NHTSA publications, such as the *EMS Agenda for the Future* and its various spin-off documents including the *EMS Education Agenda for the Future: A Systems Approach*, the *EMS Research Agenda for the Future*, and others, encouraged the nation to adopt a collaborative, consensus-based, and forward-thinking approach to EMS issues.

The passage of the Emergency Medical Services Systems (EMSS) Act of 1973 brought positive changes to EMS. Health care provided in the hospital could now be extended into the community[1] and mechanisms were now available for funding the development of regional EMS systems.[2] The EMSS Act brought much needed recognition to emergency medicine as a field of medicine.[3] It also placed substantial obligations on hospitals which compelled them to provide new funding for emergency and trauma facilities including adding laboratory, imaging, and other services as resources for emergency departments.[4]

Under the EMSS Act of 1973, requirements for medical direction were nonnegotiable, which in turn stimulated the involvement of prominent physicians in EMS. Hospitals, specialty care centers, and rehabilitation facilities became recognized as essential components of an effective EMS system. The EMSS program and the North Carolina 1973 EMS legislation fundamentally changed the North Carolina EMS system for the better. Unfortunately, the federal program was discontinued in the early 1980s when the funding was incorporated into the Preventive Health and Health Services Block Grant program.

> *"The EMSS Act brought much needed recognition to emergency medicine as a field of medicine."*

Since 1984, the Emergency Medical Services for Children (EMS-C) program at the Health Resources and Services Administration (HRSA) within the Department of Health and Human Services (HHS) has provided national leadership in the improvement of emergency medical care for children in both prehospital and hospital environments. The program helps ensure that each state EMS office has someone dedicated to the emergency medical care needs of children, has utilized special projects or "targeted issues grants" to develop pediatric products and tools, and has promoted research in pediatric care. Although the EMS-C program is primarily intended to improve EMS care for children, HRSA recognizes that emergency medical

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care for children cannot be built on the foundation of a crumbling EMS system. As a result, the program also plays a prominent role in promoting comprehensive EMS system development overall. Through this and other programs, HHS coordinates extensively with all federal agencies involved with EMS.

In 1990, the Trauma Care Systems Planning and Development Act, which focused on improving emergency care of the seriously injured patient, became law. The resulting federal trauma program was located at HRSA. Some of the program successes include creating a Model Trauma Systems Plan for states to use as a template to develop inclusive trauma systems, providing limited grant funding for states to develop trauma systems, and stimulating national interest in and attention to trauma systems. As a state EMS director, we used federal highway safety funds through the NC Highway Safety Office and later the federal Trauma Program grants to convene trauma system stakeholders, develop a trauma system for North Carolina, and initiate a state trauma registry. Ultimately, this resulted in comprehensive state trauma system legislation. Although program authorization and funding for the federal program has lapsed several times, this program has demonstrated strong leadership and the wise allocation of limited federal resources to further the development of trauma systems. The program has again been reauthorized, but not yet funded.

Several years ago Drew Dawson, the Montana State EMS director for 20 years became the head of NHTSA's EMS program. Under Drew's leadership I've seen an unprecedented level of federal activity in relation to EMS. With its long-standing history of providing support to EMS, the NHTSA EMS Division was elevated to the Office of Emergency Medical Services (OEMS) with a mission to "reduce death and disability by providing national leadership and coordination of comprehensive, evidence-based emergency medical services and 9-1-1 systems."

Although working with other federal agencies has long been daily business for NHTSA, the importance of federal agency collaboration on EMS was further emphasized by Congress in the creation of the Federal Interagency Committee on Emergency Medical Services (FICEMS). Created by the secretaries of the departments of Transportation, Health and Human Services, and Homeland Security, FICEMS comprises high-level representatives from a variety of federal departments and is charged with identifying the nation's EMS needs, coordinating EMS support among federal agencies, and reporting to Congress. The National Highway Traffic Safety Administration is responsible for providing staff and administrative support to FICEMS. With the advent of FICEMS comes the opportunity to further enhance and institutionalize the already excellent cooperation among those federal agencies with an EMS mission.

To provide a formal mechanism for nonfederal input to NHTSA's EMS activities, the Department of Transportation created a National EMS Advisory Council (NEMSAC). This 26-member advisory council membership reflects the national diversity of EMS including volunteers, fire-based EMS providers, trauma surgeons, emergency physicians, nurses, and private EMS services. The combination of FICEMS and NEMSAC will help to formalize and improve the long-term federal support of EMS.

Other promising developments in federal EMS support are also occurring. For example, the creation of the Office of Health Affairs at the Department of Homeland Security (DHS) provides a DHS-specific focal point for all things medical—including EMS. The Pandemic and All-Hazards Preparedness Act (2006) assigns additional responsibilities for EMS preparedness to the Assistant Secretary for Preparedness and Response at HHS. In addition, Congress recently established a National 9-1-1 Office. Jointly operated by NHTSA and the National Telecommunications and Information Administration at the Department of Commerce, the office is physically located at the NHTSA Office of Emergency Medical Services. Its mission is to provide leadership and coordination of comprehensive and technologically enhanced 9-1-1 services. Another important example of federal collaboration efforts to assist states includes the collaboration among NHTSA, EMS-C, the Department of Homeland Security, and the Division of Injury Response in the National Center for Injury Prevention and Control at the Centers for Disease Control and Prevention (CDC) to develop information related to world-wide bombings, surge capacity issues for hospitals, and revision of the American College of Surgeons Committee on Trauma Field Triage Decision Scheme.

The synergism of several federal agencies working collaboratively to enhance EMS clearly exceeds that generated by any single agency. Collaboration and cooperation, not silo building, continue to be the mantra of federal agencies involved in EMS. Federal EMS programs have had an enormous impact on the development of state EMS systems throughout the country including North Carolina. **NCMJ**

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COMMENTARY

Recalling the Birth of Emergency Medical Services in North Carolina

George Johnson Jr., MD, April 6, 1926–May 15, 2007

In 1972 a legislative committee was formed to study emergency medical services in North Carolina with Senator O'Neil Jones as chairman. The committee included doctors, legislators, and everyday citizens who were concerned with emergency medical services (EMS) in the state.

At that time, most of the people needing emergency care were transported by hearse. There were many problems with this system of emergency transportation. We had a hearse arrive at an emergency room with no patient in the back—they'd either driven off without them or lost the person on the way. In another instance, a woman gave birth and the hearse attendants never took her underpants off. The baby died.

The members of the legislative committee wanted to improve emergency care across the state; we felt emergency services should be as good in Chinquapin as they were in Raleigh. Martin Hines from the Department of Public Health was very interested in emergency medical services and helped us in many ways. There was interest in a centralized system based in Raleigh, but we recognized that a one-man show would not work. We engaged a group in Tennessee, and they suggested dividing the state into several trauma center areas—regionalization of services was a big trend at the time. The Regional Medical Program was in full-swing, and we were on the verge of setting up the North Carolina Area Health Education Centers (AHEC) program. We didn't think a regionalized trauma system would work for emergency services because of the proximity of the medical centers at Duke University, the University of North Carolina at Chapel Hill, and Wake Forest University. We did think that we ought to upgrade the whole system, and we pushed for a new office to coordinate training and organization. We helped set up a trauma center classification system that worked well with the American College of Surgeons system. That led to the creation of a trauma system database that we still use to track cases through the system.

> *"We helped set up a trauma center classification system that worked well with the American College of Surgeons system. That led to the creation of a trauma system database that we still use to track cases through the system."*

Legislation was passed in the North Carolina General Assembly that created an Office of Emergency Medical Services (OEMS) within the Department of Human Resources. Jim Page from Los Angeles, who was a paramedic and wrote a television program about EMS, was the first chief of the OEMS. An advisory committee was formed to advise the OEMS. It was emphasized that this was an advisory committee and had no authority. The members were emergency department personnel, members of the North Carolina College of Surgeons

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George Johnson Jr., MD, widely regarded as the father of modern EMS systems in North Carolina, passed away in May of 2007 shortly after contributing his recollections of the development of EMS in North Carolina. Johnson was a distinguished, nationally prominent surgeon serving on the faculty of the University of North Carolina at Chapel Hill School of Medicine and on the staff of UNC Hospitals from 1959 until shortly before his death. In recognition of his seminal contributions to emergency care in the state, the North Carolina Office of Emergency Medical Services established the George Johnson Award for Emergency Medical Services for individuals who have made significant impact on EMS in the state.

Trauma Committee, and other personnel interested in emergency medical care. These members were included to contribute based on their expertise in emergency medicine.

Although there have been several efforts to move OEMS out of the Department of Human Resources (DHR), thankfully this could not be done. We felt emergency personnel ought to be linked closely to health, and we advised that they stay in DHR. The OEMS worked with rescue squads, EMS training programs, pediatricians, hospital personnel, physicians involved in emergency medical care, and the NC Board of Medical Examiners. Standards were set up in order to deliver emergency medical care that was uniform throughout the state.

All this worked well enough, but there were bumps along the way. Several areas wanted exemptions to the statewide rules because they thought they already had superior emergency care; this was not allowed. The firemen and rescue squads were in a different department of the state and had their own training. It was difficult to get them to abide by the standards of the OEMS, but eventually they came on board. The OEMS was able to make great use of the community colleges to train personnel; this was a great success and it continues today. **NCMJ**

Research and Evaluation in Out-of-Hospital Emergency Medical Services

Herbert G. Garrison, MD, MPH; Jane H. Brice, MD, MPH

When people dial 9-1-1 to request assistance for a medical emergency, they expect the responding paramedics and emergency medical technicians (EMTs) to provide safe, competent, and effective care. Competent practice in medicine and health care should be based on evidence that is substantiated by research. Such is far from the case for out-of-hospital emergency medical services (EMS), whose practitioners commonly utilize protocols and interventions that have limited substantiation from research. Instead, much of the EMS care delivered is based on expert opinion and consensus or has been taken directly from the hospital to the street with no investigation.

The gaps in EMS knowledge and the structural barriers to filling those gaps have been well-documented.[1-3] Investigators in North Carolina have a good track record in EMS research and are working toward filling those gaps. Research in EMS in North Carolina will be even better once investigators access a new statewide population-based data system that the state Office of EMS has implemented. There are, however, many more steps to take to allow EMS research to fill the gaps in knowledge.

Gaps in Knowledge

The gaps in EMS knowledge were made clear by a recent systematic review of the medical literature. Smith et al[4] identified 400 out-of-hospital trials with steady increases in trials through the late 1990s. Nearly two-thirds (63%) of the 400 reports of trials concerned resuscitation and cardiac care. While resuscitation research has improved outcomes from cardiac arrest and demonstrated the benefit of different specialties collaborating on one disease entity, similar progress is lacking on other fronts. As the authors point out: "The principal finding of this study is the contrast between the wide scope of the out-of-hospital field (resuscitation, airway diseases, injury, out-of-hospital medical treatments, etc) and the lack of high-quality evidence on which to guide practice. Although taking nothing away from the quality of research in this area, cardiac arrest and acute resuscitative attempts account for only 2% of all ambulance responses.… Therefore, the majority of interventions used in the out-of-hospital environment are not based on strong evidence.…"[4]

There are many other EMS interventions that require study. The National EMS Research Strategic Plan[3] assembled and prioritized an exhaustive list of core topics for which there is a

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need for investigation. Questions in need of research answers include: What are the most effective and safe EMS airway management strategies? Which EMS treatments, including destination decisions, are effective for acute cardiac ischemia? Does out-of-hospital therapeutic hypothermia mitigate brain injury? Which patients, if any, require spinal immobilization? What are the attributes of professional competency in EMS? Is air medical transport cost-effective? What is the impact of emergency department overcrowding on the delivery of EMS care?

Some questions have significant implications for North Carolina. For example, what is the right mixture of staffing an ambulance: one paramedic and one EMT, two paramedics, or two EMTs with backup from a paramedic-staffed quick response vehicle? This question is unimportant when resources are plentiful. However, resources for EMS are shrinking, volunteers are fewer, and paramedics are in short supply.[5]

Are the gaps in knowledge important? The answer is an unequivocal yes. While a call to 9-1-1 will likely produce an ambulance and a ride to the hospital, there is no guarantee the care will be consistent from one EMS system to another. A recent study comparing systems across the nation found that out-of-hospital care for trauma patients varied substantially.[6] As Delbridge and March[7] pointed out in their commentary on this study, "Rather than indicating areas of poor quality, variation in out-of-hospital care for trauma patients may indicate a collective uncertainty about the effectiveness of some interventions."

Structural Barriers

The National EMS Research Agenda[1] highlighted 5 impediments to high quality EMS research: (1) a paucity of highly skilled researchers; (2) inadequate funding; (3) failure of EMS professionals to understand the importance of conducting EMS research and translating the findings into clinical practice; (4) a lack of integrated information systems that provide for meaningful linkage with patient outcomes; and (5) logistical problems in obtaining informed consent.

Removing these barriers takes on a special urgency when one considers the impact they may be having on EMS research productivity. Since 2000 there has been a precipitous drop in the number of published EMS research trials.[4] It is unclear why this decrease in studies has occurred. But the implication is very clear: the structural barriers to EMS research are effective.

North Carolina's Role in Filling the Gaps

The good news is that researchers in North Carolina are doing their part to bridge the gaps in EMS knowledge despite the barriers. The record of EMS contributions from North Carolina is too long to list here. As examples, investigators in our state are producing new knowledge on the effectiveness of out-of-hospital electrocardiograms,[8] the role of EMS in public access defibrillation,[9] the duty of EMS in reporting domestic violence,[10] and the out-of-hospital care of stroke patients.[11] But much work remains.

Next Steps

What should we do here in North Carolina to facilitate research and evaluation of EMS interventions and to assure that the care provided on the streets and in the homes of our state is evidence-based? First, we should and do congratulate the emergency medicine programs on the work already accomplished and encourage them to keep EMS research as a priority in their departments. The academic departments of emergency medicine in this state have an obligation to lead the efforts to evaluate the evidence, conduct high quality EMS research, and make recommendations on what paramedics and EMTs should and should not be doing in the field. To this end, they should foster collaborative partnerships with other specialties that can be leveraged for external funding. In addition, they should seek EMS fellows with passion and energy and facilitate their learning and investigations. Emergency medical services research will take off when investigators with passion have the partnerships and resources in place to advance knowledge.

Second, these departments should work closely with their respective institutional review boards (IRBs) to jointly explore the problem of obtaining consent on EMS patients who are minimally to nonresponsive and who have no relatives at hand. Mutual understanding of the issues implicit in out-of-hospital informed consent will lead to stronger research protocols. The more EMS researchers interact with the IRB on the problem, the easier it will be to gain approval of out-of-hospital clinical research on unresponsive patients.

Third, while North Carolina has a good system for approving new therapies and practices, the system could benefit from a few modifications. In the current process, proposed additions are vetted by the state EMS medical director and the Office of EMS (OEMS). The medical director then makes a recommendation to the NC EMS Advisory Council. The members of that group will approve the recommendation, which then goes to the NC Medical Board. This system works well but could be improved with two modifications: (1) the state medical director should have the discretion of commissioning outside systematic reviews of proposed interventions, especially for those therapies that are controversial or are being pushed by a special interest group; and (2) the NC OEMS should develop a system for periodic examination of current approved therapies and practices to determine what should be eliminated due to a lack of support from research.

North Carolina is very fortunate to have a progressive Office of EMS. Because of its progressiveness, North Carolina now has a statewide, state-of-the-art population-based data system to which data are submitted by all EMS agencies in North Carolina.[12] Once this data is linked to outcomes, investigators will be able to study—on a broad scale—very important questions about the effectiveness of EMS interventions. This is one of the most important developments in EMS research and evaluation for our state in a long time.

Expectations

North Carolinians expect and receive a prompt response from EMS when they call 9-1-1. They have an equal expectation that EMS care will be the best possible and will be based on evidence from credible research. North Carolina provides leadership for so many other fields and we should likewise be leaders in EMS research and help break down the barriers and advance EMS knowledge. The people of our state should expect nothing less. **NCMJ**

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COMMENTARY

Emergency Medical Services Education:
Past, Present, and Future

Gregg S. Margolis, PhD, NREMT-P

As medical technology expanded and became increasingly specialized in the 1960s a need emerged for a cadre of health care workers with specific skills and knowledge. In 1966, Congress passed the Allied Health Personnel Training Act (P.L. 89-751) which paved the way for a virtual explosion in the variety and types of occupations collectively referred to as "allied health professions." Most established and newly forming allied health professions developed specialized educational program accreditation models that paralleled those of nursing and medical schools. The American Medical Association Council on Medical Education collaborated with professional associations to establish educational standards and guidelines for many health sciences education programs in this era.[1]

As a result, the educational infrastructure of most allied health programs followed a health care or medical model. Most allied health professions built educational systems by providing funding for pilot programs in established institutes of higher learning, developing faculty, and investing in national educational program accreditation and credentialing systems. Emergency medical services (EMS) education developed down a very different path which by all accounts has played a significant role in the way in which the EMS professional has been integrated into the larger health care workforce and system.

Also in 1966, the National Academies of Science National Research Council published the landmark paper *Accidental Death and Disability: The Neglected Disease of Modern Society*, which provided considerable funding for the development of EMS throughout the nation.[2] It reported that "there are no generally accepted standards for the competence or training of ambulance attendants" and recommended that "there is a need for delineation of a standard course of instruction [for ambulance personnel]." It was from this recommendation that the practice of developing nationally standardized education for EMS personnel began and continues today.

> *"An EMT in one state may not have the same (or even similar) education, training, or scope of practice as in another state. This variation causes confusion among the public and colleagues in other disciplines as well as making professional mobility and recognition challenging."*

In contrast to the model followed in most other emerging allied health professions, EMS began what would become a reliance on a centralized curriculum model. In 1969, the Highway Safety Bureau (now the National Highway Traffic Safety Administration, NHTSA) contracted with Dunlap and Associates to develop a curriculum to standardize ambulance attendant education. In 1971, the Emergency Medical Technician-Ambulance (EMT-A) National Standard Curriculum (NSC) was released and included specific learning objectives, highly detailed lesson plans, and hours of instruction.[3] This document established a precedent, and to a large extent,

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an expectation from the EMS educational community for federally developed, highly detailed course support materials.

The EMT-A NSC was a highly efficient method of stimulating the creation of EMT training programs nationwide. Especially in an area where few EMTs existed and in a time when many courses were taught by nurses or physicians, the NSC proved to be a useful way of providing consistent training to a new occupational group. In part due to the success of the EMT-A NSC, NHTSA contracted with Dr. Nancy Caroline, then with the University of Pittsburgh, to develop the first EMT-Paramedic National Standard Curriculum in 1977.

Throughout the late 1970s and 1980s, the NHTSA EMS curricula became the defacto standards for EMS education and were referenced in many state laws and administrative rules. The NSC had an impact beyond education and in many states became the basis for the scope of practice for EMS personnel. All levels of the NSC were revised in 1984 by the National Council of State EMS Training Coordinators and again in the mid-1990s under contract with the Center for Emergency Medicine in Pittsburgh, PA. The 1990s revisions became particularly contentious because the NSC revision process was the only major national forum for discussing EMS education and scope of practice issues. While the EMS community began to ask the question "Is there a better way?" another major EMS initiative was beginning to take shape.

In the mid-1990s NHTSA began a bold project to set a path for the future of EMS. The *EMS Agenda for the Future* proposed a vision for EMS beyond that of an emergency response system. Specifically, it proposed that EMS assume a larger public health role.[4] To support this goal, the agenda recommended a number of changes to the EMS educational infrastructure, including an expansion of accreditation, affiliation of higher level EMS education with academic institutions, and replacing the NSC with "core content."

NHTSA convened a work group to deliberate on ways to improve EMS education. The *EMS Education Agenda for the Future; A Systems Approach* proposed an improved system intended to prepare the next generation of EMS professionals. Drawing on the strengths of the existing system that relied heavily on federally developed curricula and those of other professions, a system was proposed that provides for efficiency, consistency, and coordination. The *EMS Education Agenda for the Future* proposed the replacement of the National Standard Curricula with 3 documents (National EMS Core Content, National EMS Scope of Practice Model, and National EMS Education Standards) and the further support of National EMS Certification and Educational Program Accreditation. The authors believe this approach blended the advantages of the experiences of both EMS and allied health education.

The EMS Education Standards, under development in 2007, are intended to replace the need for highly detailed, nationally standardized curricula. The standards are being written in such a way as to encourage instructional creativity and educational innovation while clearly conveying what must be included in EMS educational programs. The creation of the *National EMS Scope of Practice Model* (released in 2006) as a separate document facilitates the decoupling of education and scope of practice issues and should facilitate educational change initiatives.

The format of education standards, modeled after accreditation standards and guidelines, is admittedly broader and subject to more interpretation than detailed curricula or lesson plans. For this reason, the success of the EMS education standards will rely on the entire EMS educational system. When supported by national accreditation and certification, there will be considerable guidance as to what must be taught in each level of EMS education, with the flexibility of how to teach it left up to individual programs and instructors, where it should be.

In 2006, the Institute of Medicine of the National Academies (IOM) released the report *Emergency Medical Services at the Crossroads* which recommended that states strengthen the EMS workforce by adopting common EMS certification levels, accepting national certification for state licensure, and requiring national accreditation of paramedic education programs.[5] For EMS to evolve, these educational initiatives should receive support.

Four Recommendations

Adopting Nationally Consistent Levels of Practice and Nomenclature

There is considerable state to state variation in the titles and scope of practice of EMS personnel; thus, the training and education of EMS personnel varies from state to state. A recent study conducted by the National Council of State EMS Training Coordinators identified at least 39 unique levels of EMS provider (many with slightly different titles) in a survey of 29 states. An EMT in one state may not have the same (or even similar) education, training, or scope of practice as in another state. This variation causes confusion among the public and colleagues in other disciplines as well as making professional mobility and recognition challenging. The lack of consistency creates inefficiencies because educational support materials and services (eg, accreditation and certification) may not be aligned with an individual state's requirements.

Require National Certification for State Licensure

The primary purpose of licensure and certification must be to protect the public against subcompetent providers.[6] Most mature health care professions have a single national standard for the measurement and verification of entry level competence. Unfortunately, no such system exists in EMS. The National Registry of EMTs is utilized by 45 states as part of the credentialing process for each level of EMS personnel. Fourteen states and the District of Columbia use a state level credential for at least one level of EMS personnel.[7] These systems vary in credibility, validity, and content. For EMS to mature as a discipline, a single national definition of competence at each provider level must exist and be adhered to by all states.

The EMS Name Game

The credentialing and titling of emergency medical personnel is currently a confusing picture for individuals not intimately familiar with emergency medical services (EMS). First, it is essential to realize that each state has the responsibility and authority to create EMS licensure/certification levels. While many other levels exist, the National Highway Traffic Safety Administration has developed curricula for 5 levels of EMS personnel: First Responder, Emergency Medical Technician (EMT)-Basic, EMT-Intermediate (1985 edition), EMT-Intermediate (1999 edition), and EMT-Paramedic. Most states have adopted some of these levels (with minor changes in scope of practice), and many states have created additional levels to address local needs.

National level	Approximate number of training hours	Number nationally certified[1]	General role	Examples of skills and knowledge
First Responder	40-60 hours	13 510	Intended to serve as the initial responder generally arriving before other EMS resources.	Cardiopulmonary resuscitation (CPR), oral airways, bleeding control, ventilation.
EMT-Basic	110-140 hours	198 200	Intended to represent the minimum training necessary to serve as an ambulance team member.	Basic airway management, bag valve mask ventilation, automated external defibrillator (AED) use, spinal immobilization, splinting, extrication.
EMT-Intermediate 85	60-120 hours[2]	12 701	An EMT-Basic with a few selected advanced skills.	Dual lumen airways, intravenous access and fluid administration.
EMT-Intermediate 99	200-400 hours[2]	2527	Intended to provide core advanced resuscitation skills, especially in rural settings.	Endotracheal intubation, basic electrocardiogram (EKG) recognition, cardiac arrest resuscitation medications.
EMT-Paramedic	800-1200 hours[2]	61 121	Represents the highest level of EMS credential and intended to provide advanced assessment and treatment of a broad range of emergency conditions.	Needle cricothyrtomy, needle thoracentesis, advanced EKG recognition, emergency medications and pain relief.

The recently released National EMS Scope of Practice Model proposes 4 levels of credentialing for EMS personnel: Emergency Medical Responder, Emergency Medical Technician (EMT), Advanced Emergency Medical Technician (AEMT), and Paramedic. It is expected that many states will be transitioning to these levels over the next few years.

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[1] As of Jan 2007. Note, no reliable data exists on the number of state licensed/certified EMS personnel, but it may be 2 to 3 times the number of those nationally certified.

[2] In addition to EMT-Basic, which is generally a prerequisite.

Link National Certification Eligibility to Graduation from an Accredited Institution

The primary purpose of the accreditation of educational programs is to protect students and potential students from enrolling in an educational process that lacks credibility. Accreditation of educational programs plays a small role in EMS compared to most other allied health professions. The Committee on Accreditation for the EMS Professions (CoAEMSP) currently accredits 220 paramedic programs—probably representing one-half to one-third of the paramedic programs nationally. While accreditation is technically a voluntary process, most professions limit eligibility of entering the credentialing process to graduates from accredited programs. Without requiring a single national educational program accreditation process, it will be effectively impossible to implement national EMS educational change initiatives.

Increase the Role of Higher Education in EMS

One educational issue not recommended by the IOM but that deserves support is to increase the role of higher education in EMS. Formal post secondary educational institutes play a comparatively small role in EMS education. While many community college, technical schools, and universities sponsor EMS educational programs, a large percentage of EMS education remains agency or hospital based. A significant portion of EMS education still occurs in an academy setting or is sponsored by small proprietary training companies. While some of this training is excellent, it offers the student little in terms of formal recognition of EMS education toward the achievement of larger academic or degree goals.

The EMS community should recognize the associate degree as the appropriate academic preparation for paramedic level education. Emergency Medical Technician-Basic education should be sponsored by academic institutions that have the resources, student/faculty support services, and stability necessary to assure quality education. All EMS-related courses should offer college level credit.

Currently, 14 institutions offer bachelor's degrees in EMS.[8] Unfortunately, there is no consensus as to the role that these degrees play in EMS career progression and there is little consistency in the curricula. While these programs should be supported, they must be encouraged to develop a vision for the role of bachelor's (and master's) level education in EMS.

Conclusion

Occupational groups that have successfully transformed themselves have typically done so through improvement of their educational systems. Education is the catalyst for change, growth, and evolution of groups of people. The history and sociology of professions are filled with examples (many in health care) of workers who had a desire for an expanded role that offered greater service to the community. The EMS professions are at such a crossroads and will be able to realize the vision of the *EMS Agenda for the Future* only through bold leadership and support of educational change initiatives. **NCMJ**

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COMMENTARY

Responding to the Educational Needs of Our Emergency Medical Services Responders

William Lineback, BS, EMT-P

Almost 30 years ago, community colleges across North Carolina began providing instruction to members of fledgling emergency medical service (EMS) agencies—known then as "rescue squads." The role that North Carolina community colleges currently play in educating future emergency medical technicians is a direct result of the federal 1973 EMS Systems Act.

Presently, 58 North Carolina community colleges serve several roles in the delivery of medical education to current and future EMS personnel. In 2005-2006 there were 32 777 individuals enrolled in one or more EMS courses at North Carolina community colleges. In addition to preparing students with no prior medical background to become EMS personnel, community colleges provide credentialed EMS personnel with ongoing continuing education. Because community colleges throughout the state are readily accessible to the majority of North Carolina's EMS and firefighting personnel, these institutions provide much of the education necessary for these first responding professionals to remain proficient and knowledgeable of medical developments. This accessibility also serves the public well by making first aid, CPR, and safety and prevention instruction readily available at a reasonable cost. By consolidating state and county resources, community colleges also can provide access to EMS educational equipment that is beyond the budgetary reach of many smaller EMS agencies or systems. Paramedics must have access to intraosseous drills, 12-lead electrocardiogram (EKG) monitors, simulation manikins, ventilators, continual positive airway pressure devices, and other expensive equipment to become proficient. North Carolina community colleges are uniquely poised to provide access to these and other necessary pieces of equipment.

> *"In addition to preparing students with no prior medical background to become EMS personnel, community colleges provide credentialed EMS personnel with ongoing continuing education."*

Our state's community colleges also are playing a role in meeting the medical care needs of our communities across the state. With the ranks of senior citizens swelling with the influx of the baby boomers, the demand for health care workers in all fields, especially EMS, will increase for the foreseeable future. This presents several challenges to our state's community colleges that must be solved. Our colleges must be able to locate qualified and knowledgeable EMS faculty. This is difficult to do when community college faculty salaries are often lower than those found at EMS agencies, which are already shorthanded and forced to compete with colleges for the limited number of experienced EMS professionals. Also, colleges must attract more students into their EMS and health care programs. This is challenging because average starting EMS salaries in the state are low. Last, but certainly not least, community colleges must be better funded. Too many colleges are forced to squeeze by with outdated equipment, facilities in need of major repair, and inadequate staffing. Funding is a critical issue to meeting these challenges.

Emergency medical service education underwent a significant change in 2004 when modifications to the North Carolina Administrative Code were enacted. Section 10A-NCAC-13P allowed community colleges and other educational institutions

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that were providing EMS education to assume more control of their programs. These approved institutions were charged with serving as the gatekeepers for those choosing to enter the EMS workforce.

Additional changes lie ahead for education in EMS, especially in the community college setting. The National Highway Transportation Safety Administration's *EMS Education Agenda for the Future: A Systems Approach* details 5 major national education system components to be developed and implemented in the not-too-distant future: core content, scope of practice, education standards, program accreditation, and certification. While physicians will govern core content and regulatory bodies govern scope of practice, North Carolina community college EMS faculty members will have input into developing and updating education standards and community colleges will apply for EMS program accreditation.

Community colleges will also play a part in shifting EMS workforce demographics to become more representative of the communities the EMS agencies and the colleges serve. Community colleges must work to target underrepresented populations in EMS—African American, Hispanic, female—and assist their members to enter and succeed in the completion of EMS programs.

Our community colleges must look to partnering with other agencies to develop new programs and new venues for increasing the health care workforce. Those community colleges offering 2-year Associate in Applied Science EMS degree programs will need to partner with 4-year colleges and universities to offer seamless bridging to health care-related bachelor of science degree programs in EMS, nursing, premedicine, and other health care fields. Within their own programs, community colleges will need to develop bridging programs for health care workers to move from one discipline to another: registered nurse to EMT, paramedic to respiratory therapist, and so forth.

As EMS evolves and the paramedic scope of practice increases in complexity, access to EMS associate degree programs will become a necessity for potential students so that they can master the patient care procedures to be added. Currently in North Carolina, paramedics may perform intraosseous infusions, read and interpret 12- and 18-lead EKGs, perform needle cricothyrotomies, intubate (oral and nasal intubation), perform rapid sequence induction, and perform needle thoracotomies. Five to 10 years from now, especially as community needs for health care workers drive paramedics from the ambulance into the public health arena, the number and complexity of allowed procedures will likely grow.

One challenge currently being addressed by our community colleges is the increasing need for distance education offerings. Even though EMS has a strong hands-on component, much of the cognitive and affective instruction could be conducted through various nontraditional methods including Internet web-based instruction. Several community colleges in the state have developed "hybrid" courses in which the students meet in a traditional lab setting for skill instruction and evaluation while they attend the didactic portion of the course online. For courses without a psychomotor component, some colleges are offering them entirely online.

North Carolina community colleges are also adapting to meet the scheduling needs of the medical community. They are designing and providing programs with flexible scheduling to accommodate those students with rotating shift work schedules —"flip-flop" scheduling—allowing students to attend classes on changing days of the week. Several colleges are developing or offering specialized academies to EMS agencies so that newly hired personnel with limited EMS education can rapidly be taught and immediately begin to contribute to the workforce. Our North Carolina community colleges play an important part in the maintenance and growth of our state's EMS workforce and look to provide even greater contributions in the coming years. **NCMJ**

Baccalaureate Emergency Medical Services Education in North Carolina:

History, Challenges, and Opportunities

Michael Hubble, PhD

Emergency medical services (EMS) is a critical component of the public health response system, treating and transporting 25 to 30 million patients per year.[1] The number of patients treated by EMS is expected to continue to increase, and for some of these patients, their prehospital treatment will have a dramatic impact on their clinical outcomes. Consequently, a well-educated and competent prehospital workforce is an essential component of community health.

Prior to 1976 all paramedics received nondegree "certificates" as opposed to degrees to verify their training. Today these certificate programs exist alongside associate in applied science (AAS) and bachelor of science (BS) degree programs. For some, this raises questions about the necessity of simultaneously offering both degreed and nondegreed paramedic programs. Unfortunately, there is a paucity of research about the influence of educational preparation on patient outcomes.

However, some evidence suggests that education improves the delivery of EMS health care. One study noted that paramedics who held degrees, although not EMS degrees specifically, were better able to calculate drug dosages than nondegree paramedics.[2] There is also evidence that students who attend an accredited program are more likely to pass the National Registry of EMT-Paramedic exam,[3] and by extension, are better prepared for roles as field clinicians. This same study also found pass rates to be higher for those holding an AAS degree and baccalaureate degree. A separate investigation found a link between pass rates and the instructor's educational level. The first-time pass rate was 62.7% for students taught by an instructor with an associate degree, 69.4% for bachelor's degree, 72.7% for master's degree, and 78.5% for doctoral degree, which suggests the need for baccalaureate and/or graduate-prepared educators.[4] Moreover, Brown et al found that although the EMS administrators rated both degree and nondegree paramedics equally, 46% preferred hiring AAS degree paramedics over nondegree paramedics, and 40% reported promotion preference for degree paramedics.[5]

> *"Western Carolina University supports the paramedic programs within the North Carolina Community College System and recognizes the need for seamless articulation of students from the community college programs."*

In addition to the perceived clinical advantages of EMS degrees, degree programs also prepare the future generation of EMS leaders including researchers, administrators, and educators. The *EMS Education Agenda for the Future* (EMSEAF) recommends that all EMS programs attain national accreditation. At the baccalaureate level it will be particularly important to expand opportunities for degrees for EMS educational program directors because that credential is crucial for the community colleges to be able to meet the Committee on Accreditation of Educational Programs for the Emergency Medical Services Professions (CoAEMSP) accreditation requirements.

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The Role of Western Carolina University in EMS Education

College level paramedic education in North Carolina began in 1976 when Western Carolina University (WCU) established the Emergency Medical Care (EMC) program as the nation's first baccalaureate program for EMS. Concurrently, Guilford Technical Community College established North Carolina's first paramedic program leading to an AAS degree. Since then, 13 additional community college degree programs have been established in North Carolina. Accredited in 1988, WCU's EMC program remains the only baccalaureate program in North Carolina and one of only 12 similar programs in the US.

As a baccalaureate program, the EMC program has a unique dual educational role: to educate paramedic practitioners and future EMS leaders. Broadly defined, future EMS leaders include EMS administrators, educators, advanced practice clinicians, and researchers. To achieve these goals, the curriculum requires two years of general education and preprofessional coursework followed by two years of the paramedic core curriculum and area of concentration. Unique to baccalaureate degrees, the general education component develops skills in writing, thinking, and analyzing. These, along with two semesters of chemistry and two semesters of anatomy and physiology, serve as the foundation for the paramedic curriculum. The junior and senior years constitute the professional course sequence and in addition to the core paramedic curriculum, require 17 semester hours in one of two areas of concentration: science or health services management. The science concentration is essentially premedicine and includes upper level courses in biology, chemistry, and physics. The management concentration prepares graduates to assume management roles and incorporates courses in personnel administration, marketing, accounting, finance, and health policy. Both concentrations require a course in research methods and biostatistics because of the increasing role of research in EMS.

Building upon the preprofessional courses in chemistry and biology, the paramedic curriculum promotes clinical reasoning as opposed to rote memorization of signs, symptoms, and treatment algorithms. In addition to addressing state and national paramedic learning objectives, the curriculum is heavily influenced by evidence-based medicine and Bayesian clinical decision making. Furthermore, in an effort to facilitate integration into the overall health care system, students are introduced to epidemiology, injury and illness prevention, and occupational health. The curriculum is also buttressed by an extensive clinical program that includes rotations through coronary intensive care unit (ICU), neurotrauma ICU, neonatal ICU, pediatrics and pediatric ICU, labor and delivery, operating room, cardiac catheterization lab, psychiatry, and dialysis rotations, in addition to emergency department, helicopter, and ambulance rotations. Because paramedics are increasingly choosing to practice in nontraditional venues such as urgent care clinics and emergency departments, broad-based clinical experiences are crucial for well-rounded clinicians.

Challenges and Opportunities

The National Standard Curriculum (NSC) describes the knowledge base for EMS in the United States.[6] The curriculum proved useful during the formative years of EMS, however, the NSC is being replaced by a new approach to EMS education as outlined in the *EMS Education Agenda for the Future.*[7] Once implemented, the EMSEAF recommendations will define the EMS general body of knowledge, delineate the technical skills within an EMS scope of practice, provide education standards for instructors and educational programs, and define procedures for national certification of paramedics and accreditation of educational programs. The EMSEAF is EMS education's guidebook for advancing the profession.

North Carolina has many opportunities to advance EMS education. Likewise, there are many challenges to delivering educational opportunities for current and future North Carolina paramedics. Due to changing demographics in the US, the demand for paramedics is expected to climb. The National Bureau of Labor Statistics estimates that between 2004 and 2014 an additional 21 000 paramedics will be needed to meet demand.[8] This will be a serious challenge because North Carolina and the nation as a whole are currently experiencing a paramedic shortage.

Like most community college programs, WCU responded to the paramedic shortage by expanding enrollment capacity for initial paramedic training. In addition, WCU has been supportive of increasing access to baccalaureate and master degree programs using distance learning venues. It has allocated faculty and technical support to expand online access at both levels over the past 7 years. However, a stronger collaborative approach to recruitment and education is needed. A successful network should include the public school system, local EMS systems, community colleges, and WCU to consistently recruit students and deliver efficient, effective, and coordinated educational services at the associate and baccalaureate levels.

Articulation

Western Carolina University supports the paramedic programs within the North Carolina Community College System and recognizes the need for seamless articulation of students from the community college programs. To facilitate this transition, WCU has established articulation agreements with all North Carolina associate degree EMS programs. These agreements are particularly important for the distance learning program which is offered only to practicing paramedics who hold AAS degrees. The distance learning technologies enable paramedics across the state to access the program without displacing them from the communities in which the serve.

Student Support

Many students come to a university setting unprepared for the rigor of university-level academic work. While our distance learners are older and bridging from an associate degree, they face some of the same challenges as our traditional college-aged students. Many must strengthen writing, math, and science skills. To address these needs, WCU has a writing and math tutoring center that is available to all resident students and has been extended to distance learning students through distributed learning technologies.

Increasing tuition costs, coupled with limited scholarships and shrinking financial aid for students in general, have negatively impacted both student recruitment and retention. From 2001 to 2005, the cost of attending a public university in North Carolina increased 33%, and a year in school now consumes 25% of the average North Carolinian's household income.[9] To put this increase in perspective, the urban consumer price index rose only 18% during the same period. A dedicated scholarship for students interested in EMS would help attract students into the profession and make the EMS educational programs more affordable. Furthermore, graduation rates would be improved if students were not obligated to work while in school to pay for tuition and other financial obligations.

Clinical Support

The cornerstone to any paramedic training program is its clinical rotations. Unfortunately, EMS programs at WCU and the community colleges must compete for clinical space with nursing and other allied health programs. While EMS agencies recognize the recruiting benefit of entering into clinical agreements with paramedic educational programs, most hospitals have a less clearly-defined benefit.

Clinical rotations are guided by the National Standard Curriculum which recommends a minimum number of patient contacts and skills for paramedic students, but these recommendations are not based upon empirical evidence. Furthermore, in a recent analysis of paramedic graduates across the US, only 6% completed all of the clinical experiences recommended by the current National Standard Curriculum and less than half of the graduates completed the required geriatric, trauma, psychiatric, obstetric, and pediatric patient assessments.[10] Complicating matters, more recent research indicates that the NSC recommendations may underestimate the true number of repetitions necessary to attain clinical competence. Wang et al reported that up to 25 intubations were necessary to attain competence, despite the recommendation of 5 by the NSC.[11] Many EMS education programs encounter difficulty gaining access to the operating room to perform intubations.[12] To ensure the clinical competence of paramedics, it is imperative that hospitals and the physician community recognize the importance of their participation in clinical rotations for paramedic programs.

Research Support

The *National EMS Research Agenda* (NEMSRA), published in 2002, noted the lack of scientific evidence in support of most prehospital interventions.[1] The NEMSRA specifically noted the lack of cost-effectiveness and outcome studies. This widely disseminated report recommended, among other things, that educational programs include an introduction to the research process as part of the paramedic curriculum. It also recommended that academic institutions develop programs to train EMS researchers and to establish organizational partnerships that promote collaboration between academia and EMS agencies to advance the EMS scientific body of knowledge.

Recognizing the research opportunities afforded by its unique location in a university setting, WCU's EMC program is committed to promoting research in EMS. A research methods and biostatistics course is a required component of the undergraduate curriculum. At the most basic level, this course promotes an appreciation for the scientific method and the use of scientific evidence in clinical medicine as well as EMS administration. The course also prepares students for designing and implementing their own studies.

In an effort to increase the number of EMS researchers as recommended by the NEMSRA, the EMC program is launching a graduate program in the fall of 2008. The graduate program will offer tracks in EMS administration and EMS education. In addition to courses specific to each track, the curriculum requires substantial course work in research methods, epidemiology, quantitative methods, and biostatistics. This degree program will be entirely online in an effort to make it widely available to practicing EMS professionals.

To facilitate the research process for faculty and graduate students, the EMC program developed the Consortium for the Advancement of Research in EMS (CARE). The CARE consortium is composed of 15 EMS systems and 15 EMS education programs, and its goal is to facilitate EMS research by forming a partnership between academic settings, community college EMS programs, and EMS agencies. Launched in 2007, the CARE consortium will focus on the research priorities described in the NEMSRA Implementation Plan including clinical outcomes assessment, cost-effectiveness analyses, professional competence, and EMS systems.[13]

Although these research efforts are designed to advance the body of knowledge specific to EMS, they cannot occur in a vacuum. The investment of faculty time must be valued by academic institutions, and EMS agencies must also be willing to commit staff time and resources. Furthermore, an adequate funding stream for EMS research must be identified, which will likely include public and private funding.[1]

Conclusion

Although many challenges lie ahead, Western Carolina University is committed to taking the necessary steps to address the paramedic shortage, meet EMS research needs, and offer undergraduate and graduate level education for the future leaders of the paramedic profession. However, these efforts will be successful only to the extent that effective partnerships can be established and maintained with the EMS community, the North Carolina Community College System, hospitals, and the medical community at large. **NCMJ**

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COMMENTARY

Management and Financing of Emergency Medical Services

Todd Hatley, MHA, MBA, EMT-P; P. Daniel Patterson, PhD, MPH, EMT-B

Like other organizations, emergency medical services (EMS) systems have revenues and expenses. The unpredictability of calls and the oftentimes inefficient nature of EMS operations make EMS management and financing difficult. Annually, EMS costs patients, insurers, and the federal government billions of dollars.[1] In fiscal year 2002, Medicare spent $3 billion on ambulance transportation.[1] The insufficiency of reimbursement for the total cost associated with 24 hour, 7 days per week coverage is the subject of constant debate and discussion among EMS managers. Recent modifications to the reimbursement formula used by the Centers for Medicare and Medicaid Services (CMS) has both benefited and disadvantaged many of the more than 18 000 EMS systems in America;[2-4] reducing the gap between costs and revenues for some while increasing that gap for other EMS systems. The purpose of this commentary is to describe the major components of EMS financing and management and to discuss the current and ongoing challenges in EMS financing.

Revenues to an EMS system include subsidies from local governments, income from special event support, and reimbursement for transportation of patients. Fifty-five percent of revenues for an average EMS system come from Medicare, 15% from Medicaid, 5% from private payment, and 25% from the commercially insured.[5] Personnel and benefits are the largest fixed expenses for the average EMS system.[6]

Revenues and expenses are not completely uniform across systems. For volunteer-staffed EMS organizations in very rural areas, processing bills for transportation is either not possible or an unattractive practice that would take away from the volunteer nature of the organization. Thus, most revenues for such organizations come from donations and support from local governments. In addition, submitting a bill to Medicare or Medicaid does not guarantee payment. In 2000, the average collection rate for bills submitted by North Carolina EMS systems was 25%.[7]

The average cost for an ambulance transport is $415, but ranges from $99 to $1218. Average costs in very rural areas are significantly higher than costs in urban areas, $538 and $409, respectively.[8] Ten years ago, the estimated average charge for transport to the emergency department approached $400.[9] It is unclear what the true average charge for an EMS transport actually is today. In some communities, a ride to the hospital or elsewhere can be as high as $700.[10] For a trip in a helicopter, the cost can reach thousands of dollars.[11,12] A combination of factors result in high transport costs including the need to cross subsidize transport for the indigent and uninsured and the cost of 24 hours a day readiness. Extremely high rates of turnover among personnel also contribute to inefficient budgetary practices.

> *"Fifty-five percent of revenues for an average EMS system come from Medicare, 15% from Medicaid, 5% from private payment, and 25% from the commercially insured."*

The medical necessity of EMS transportation is used by CMS to determine whether or not a patient's transportation

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will be paid. For some systems, convincing the intermediaries that an ambulance transport was medically necessary is a daily and ongoing battle. Submitting multiple claims for the same ambulance transport is not uncommon. In fiscal year 2002, the Health and Human Services Office of Inspector General (OIG) determined that 25% or $402 million dollars in ambulance transports did not meet the government's criteria for medical necessity.[1] For emergency ambulance transports, CMS defines medical necessity as a medical condition that manifests itself with acute symptoms of such severity that the absence of immediate medical attention would jeopardize the patient's health.[1] For nonemergent transportation, a ride in an ambulance is medically necessary when the patient is bed-confined and/or his/her condition is such that other methods of transportation are contraindicated.[1] The OIG report identifies transports to dialysis centers as a significant source of unnecessary transports.

Financial Obstacles

Due to the rapid increase in expenditures and difficulties in administrating benefits, the federal government in the Balanced Budget Act of 1997 called for ambulance reimbursement to be placed on a fee schedule.[2] The act proposed an implementation date of January 1, 2000. Due to the quick action and concerns of numerous EMS administrator groups throughout the United States, CMS agreed to enter into a negotiated rule making process that ultimately led to a proposed fee schedule implementation date of April 1, 2002 and a final implementation date of January 1, 2006.

While EMS administrators were able to buy some time before implementation, the final rule is now in place and the financial effects are being felt by EMS providers throughout the nation. The final rule led to the establishment of a national base rate of $171 for the transport of a patient to a medical facility. This $171 rate is supplemented by adjustment factors that modify reimbursement based patient severity, region of the country, and a special adjustment for the super rural regions. However, it still falls short of covering the actual cost of transport for most EMS providers.[4]

The national base rate of $171 dollars was chosen largely on the direct cost of providing care and transporting a patient (personnel cost, equipment cost, supply cost) and failed to incorporate the significant indirect cost associated with readiness to respond to a request for service. Factoring in the total cost of providing the temporal and geographical demand coverage necessary to respond in a timely manner to medical and surgical emergencies increases per transport estimates to as much as $300 to $400. This gap between the established national rate and the total estimated cost per transport is creating a critical financial situation for many EMS providers. Some in the EMS community have even begun litigation against the government.[13]

Compensating for this fiscal gap between the Medicare and Medicaid reimbursement is critical when one considers that this reimbursement accounts for as much as 64% of most EMS providers' patient mix. Since it is mandated that EMS providers accept this reimbursement by assignment it means that increasing rates does little to increase revenue. This leaves EMS providers with the options of either increasing their local tax subsidy or decreasing operation costs. Due to widespread fiscal pressures that are being exerted on most local municipal agencies, EMS providers are meeting enormous resistance when requesting increases to local taxes to cover the cost of providing EMS. This only leaves the second option, which is to increase operational efficiency in an attempt to decrease overall operational cost.

One of the first steps many EMS providers need to take in deciding how they will compensate for decreased revenues is to spend some time developing a clear understanding of the purpose and role of their service within a given community. Many providers find themselves involved in functions other than providing emergency care. These services include things such as technical rescue, support for hazard material incidence, and other uncompensated services. In some communities, the EMS provider may be the only provider of these services, but in other communities EMS providers duplicate services more appropriately provided by other public service agencies. The decision to provide these supplemental services should be based on the needs of the community and its willingness to financially support these added services. It is important that EMS providers remember their first priority is to provide emergency medical care and transportation of patients.

The second highest leverage area of improvement that could be undertaken by many EMS providers is in the area of resource deployment. In the mid-1980s, the EMS industry was introduced to the concept of System Status Management (SSM).[14] System Status Management is a methodology used to determine the number of ambulances needed for each hour of the day, each day of the week and where these ambulances should be placed in order to respond in a timely manner to a request for emergency assistance. While the knowledge of deploying EMS resources has expanded from the use of SSM to the existence of sophisticated computer simulation models that can predict geographical grid level coverage capability, only the most sophisticated EMS systems in the nation have even adopted the use of SSM. The use of these methods could not only decrease operation costs for most EMS providers, they could also improve their ability to respond in a timely manner to the aid of sick and injured patients.

While the two issues mentioned above are important for EMS providers to address, there are many other areas in which current EMS operations could be improved and the financial viability of EMS sustained. These include things such as the implementation of more efficient and less costly education and training methods, the improved management of supply and equipment inventories, and improvements to EMS billing processes. Addressing these issues can improve EMS care of the sick and injured. However, even after implementing these ideas, the sustainability of EMS financing and management will likely continue to be a challenge for many years to come. **NCMJ**

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Service Integration and Workforce Trends in Emergency Medical Services

P. Daniel Patterson, PhD, MPH, EMT-B; Michael Yonas, DrPH, MPH

To commemorate the report credited with the development of modern emergency medical services (EMS), the Institute of Medicine of the National Academies (IOM) examined the current status and future of emergency care in America. *Emergency Medical Services at the Crossroads* reports the IOM's findings and provides an informative view of our nation's EMS or prehospital emergency care system.[1] The report is part of a trend in exploring and dissecting the American system of emergency care, identifying problem areas, and making recommendations for improvement. The IOM highlights many system-wide deficiencies that inhibit EMS from accomplishing its primary mission of responding to emergencies whenever and wherever. Based on these findings, the IOM labeled the US "ill-prepared" and referred to the current EMS situation as nothing less than a "crisis."[1]

For some time, efforts have been underway to resolve many of the EMS challenges identified in the IOM's analysis. These include promoting integration of EMS with other health care services and addressing challenges associated with maintaining a skilled and experienced workforce. More recently, health care pioneers have invested time and energy into expanding the health care role and responsibilities of EMS personnel to include more preventive and primary care tasks.[2-6] As potential momentum for the formation of future policy and research in North Carolina, these trends deserve some attention.

Integration of the EMS System

The provision of basic EMS care involves overcoming many organizational obstacles on a day-to-day basis. One such obstacle is the organizational clash between police, fire, and EMS—the 3 components of the public safety triad. While these 3 are often seen working together at the scene of an accident or emergency situation, substantial differences in roles and responsibilities have created conflict and inhibited integration.[7-9] Specifically, there appears to be a lack of mutual professional respect for the vital roles filled by EMS, hospital staff, and public safety staff. Integration among these professionals and organizations is stalled or significantly hindered by institutional and/or cultural barriers.

> *"Improved integration of EMS services with those provided by public safety, public health, and all other health care services has been touted as a solution to access and EMS infrastructure problems."*

Integration refers to the formation of a seamless communications network among all parties and agencies involved in the care of an individual's emergent or chronic health needs. Improved integration of EMS services with those provided by public safety, public health, and all other health care services has been touted as a solution to access and EMS infrastructure problems.[10,11] The Medicare Rural Hospital Flexibility Program (Flex) is perhaps the most visible integration improvement effort for EMS. This program was created as part of the Balanced Budget Act of 1997 to strengthen and improve rural health care

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infrastructure primarily by converting small rural hospitals to critical access hospitals (CAHs). A CAH is a hospital that qualifies for special reimbursement and federal funding that reduces the likelihood of the hospital closing. The Flex program endeavors to integrate EMS into Flex-related rural health care networks. Since its inception, the program has supported numerous service integration activities led by local and state authorities. Some examples include partnerships between EMS systems in different areas of a state, support for the development of state prehospital databases and information systems, and creation of EMS partnerships with many of the 1286 designated critical access hospitals.

However, the investment in integrated EMS service structures has not been universally adopted. One evaluation finds that many states have chosen to focus on bolstering education systems, addressing human resource challenges, or providing local services small grants for purchasing equipment.[12] Integration initiatives are inhibited by uncertainty among all parties over EMS's role in health care networks, EMS fears over losing autonomy, preoccupation with day-to-day challenges, and a general misunderstanding of what integration is and what it means.[13] Despite these obstacles, interest and support for the integration of EMS is high, meaning that federal and state initiatives will likely continue to promote integration as a national EMS priority.

Addressing Workforce Challenges

Improved integration may curb poor recruitment and retention of EMS professionals which are, by all accounts the most widely reported problems for EMS systems.[14-23] National EMS organizations rank recruitment and retention first in a long list of challenges for rural EMS systems.[24,25] Exploration of new EMS staffing models was recently posited by the IOM as a possible remedy to workforce problems.[1] The National Highway Traffic and Safety Administration (NHTSA) Office of EMS, the federal Office of Rural Health Policy, and the National Rural Health Association are also actively examining these issues in order to improve knowledge around the EMS workforce.

There is very little certainty over the true size of the nation's EMS workforce. Estimates range from a few hundred thousand based on documentation from the US Department of Labor[26] to as many as 1 million (including all possible first responders) which is based on a survey of states conducted by an EMS consulting firm.[27] NHTSA is leading national efforts to improve and expand what we know by funding the Longitudinal Emergency Medical Technician Attributes and Demographics Study[1] and the Emergency Medical Services Workforce for the 21st Century project.

The current body of EMS workforce research does not adequately document the critical elements associated with turnover of EMS personnel, whether paid or volunteer, leaving many questions about the nature of the workforce problem unanswered. Factors like burnout, stress, and dissatisfaction with certain aspects of the occupation have been identified in several studies as influential or potentially influential in turnover.[28-30] Few studies have explored why individuals enter the profession. Among those studies exploring entry, excitement and altruism have been identified as two important attractants.[29,31] The influence of these factors may differ across rural and urban areas. Rural community EMS systems are staffed primarily by volunteers[32] who may enter and leave the profession for reasons that differ from paid professionals. Research is needed to identify what differences may exist between volunteer and paid personnel. With funding from the federal Office of Rural Health Policy, investigators at the Cecil G. Sheps Center for Health Services Research at the University of North Carolina are exploring some of these issues.

In North Carolina, recruitment and retention are visible challenges for EMS and they receive substantial attention from the media and state EMS officials. In Wake, Cabarrus, Duplin, and other North Carolina counties EMS officials are facing critical human resource challenges including poor recruitment and high turnover.[18,21,33] In some North Carolina communities, fewer ambulances are put on the road due to inadequate staffing.[18] Reports suggest that EMS professionals in these areas leave for better pay in other systems or in other professions like nursing. In rural areas, low pay is a major factor detracting paid personnel,[33] whereas availability of time appears to be the primary detractor for volunteers.[15] The NC Association of EMS Administrators, in partnership with the NC Office of EMS, is surveying EMS officials, credentialed professionals, and students in an effort to increase the state's understanding of workforce challenges and help in the design of materials for increasing recruitment and retention.

Expanded Role for EMS Professionals

Career advancement is potentially an important factor in recruitment and retention of EMS professionals.[29,34,35] Other than assuming greater clinical responsibility through additional EMS-specific certifications, the EMS professional career is quite limited.[36] By placing EMS professionals inside the hospital and in primary health care clinic settings, as has been accomplished in many communities,[4,37,38] officials have expanded career possibilities while at the same time improving linkages between EMS and health care, which promotes integration. Nationally and internationally there is growing support for expanding the role and scope of EMS professionals.[2,37] The International Roundtable on Community Paramedicine (IRCP), for example, promotes expanded roles for EMS professionals and defines this new health care provider and model—the community paramedicine model—as "a model of care whereby paramedics apply their training and skills in 'nontraditional' community-based environments outside the usual emergency response/transport model."[3]

For many reasons, growth of community paramedicine programs in the US is possible and is potentially beneficial to EMS and communities. Community leaders are increasingly looking to midlevel and other health care professionals to fill voids in primary, dental, and mental health care services in rural and frontier areas where access is limited.[39] Emergency medical services professionals are traditionally paid less than nurses and other professionals also serving expanded roles, and thus community paramedicine models are potentially cheaper to administer and have the potential to reach more citizens with fewer resources. Emergency medical services systems and professionals have historically been community-based, are visible and recognizable, and are respected and trusted by the public. Existing federal programs like the National Institutes of Health (NIH) Roadmap Initiative can be used to test and evaluate the clinical and cost effectiveness of community paramedicine.[4] Growth of community paramedicine lies, in large part, with the recognition from researchers, community leaders, and policy makers that EMS systems and professionals are highly skilled medical professionals with an established rapport with the community.

Next Steps for Addressing Integration and Workforce Issues

Monitoring national EMS trends is important for continued growth and improvement of EMS in North Carolina. Integration of EMS is a national priority receiving support from federal initiatives and national associations sensitive to EMS issues. Many obstacles to integration exist. Improved integration, however, can be achieved through expanding the role and responsibilities of EMS professionals, which may also have a positive impact on reducing personnel turnover. Where possible, the state and local EMS leadership in North Carolina should partner with state health care leaders and academic researchers to promote testing and evaluation of diverse models of integration. Local and state officials and industry leaders must take the initiative.

Historically, EMS in the state of North Carolina has been led by innovators and out-of-the-box thinkers. Recent efforts by state EMS leaders to explore workforce problems represent forward thinking and a step in the right direction towards improving workforce conditions. Next steps should include a planned approach involving local EMS systems, community leaders, state and federal EMS leadership, and academic researchers. The NC Center for Nursing (NCCN) is a good example for North Carolina EMS. The NCCN is a state-supported agency that provides ongoing analyses of the state's nursing workforce. A perfect storm of factors including the nursing shortage of the late 1980s led to the creation of the NCCN. While workforce challenges have plagued EMS for more than 20 years, that perfect storm has never effectively materialized for EMS. Twenty years of waiting has proven ineffective. Local and state officials must act and be proactive to address ongoing challenges before the true negative effects of inadequate staffing are revealed.

North Carolina is fortunate to have an exceptional pool of academic researchers and research institutions. Unfortunately, few researchers have been successful or have recognized the NIH Roadmap Initiative as an opportunity for improving EMS clinical procedures and service structure knowledge. Few have recognized community paramedicine as an emerging model of EMS care offering a variety of research opportunities. As a research approach, community-based participatory research offers a unique model for EMS researchers to explore integration, workforce, and other EMS systems and clinical care issues. North Carolina EMS researchers and practitioners should explore community-based participatory research as a vehicle for expanding EMS research. It is increasingly being recognized as a particularly well-suited approach to research involving partnerships with community members and community based health care organizations like EMS.[40]

It is important to have some sense of national EMS priorities and trends by which we can compare North Carolina's EMS development in relation to the rest of the country. Like many states, North Carolina is in the middle of an EMS workforce "challenge," but it is responding by first assessing the size and nature of the problem. Supporting integration and research into expanded roles for EMS professionals could help North Carolina leverage limited federal funding that could be key to improving the state's EMS system. **NCMJ**

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COMMENTARY

Emergency Medical Services Information Systems

Greg Mears, MD

Emergency medical services (EMS) are often defined as the intersection between public safety, public health, and health care. From a public safety and public health perspective, EMS is the safety net for those who become suddenly ill or incapacitated. This community-level responsibility requires EMS to anticipate events, provide services, and care for patients individually or through the management and coordination of multiple patients. Due to this anticipatory role, EMS must function from a preparedness model.

A preparedness model requires that the EMS component of health care be delivered to the patient as opposed to the patient presenting on their own. Because many EMS events such as cardiac arrest and major traumatic injuries are time dependent, EMS must provide this service and care through an organized mesh of ambulances, personnel, and resources configured to assure a timely response to every event within the EMS service area. No other component of the health care industry is required to function in their day-to-day operations from this preparedness-based, "go to the patient" model. From an operational and clinical perspective, EMS is the most complex and data dependent component of the US health care system. Unfortunately, EMS is also the most underdeveloped component of the health care industry from a personnel, data, financial, educational, or resource perspective. Information systems are critical for effective EMS system implementation because each EMS event requires knowledgeable personnel, appropriate equipment, and other required resources within an optimal EMS response time to the correct location.

> *"From an operational and clinical perspective, EMS is the most complex and data dependent component of the US health care system."*

The Importance of EMS Data

In the United States, there are over 25 million EMS events each year requiring patient care or transport. North Carolina's 8.6 million people call 9-1-1 and receive EMS services over 1 million times each year. These services range from life-threatening emergencies to medical transports between hospitals and other health care facilities.

At the local EMS system level, EMS data are critical to determining where and how to allocate EMS resources to assure that the correct equipment and personnel are provided for each event in a timely fashion. Data that describe patterns of use can direct the allocation of resources, vehicles, personnel, and supplies. Information systems provide the EMS medical record, documenting the clinical care provided as well as supporting the administrative demands of the system. This documentation also gives guidance to the content of EMS personnel's initial and continuing education. Information systems provide the framework for ongoing quality management and performance improvement initiatives and data systems feed into the billing and reimbursement systems required to operationally sustain local EMS systems.

At the state level, EMS data are required to determine how to coordinate regional and statewide systems of care such as trauma, acute cardiac, and stroke. Data drive the development of operational and clinical protocols, initial education, continuing education, and medical direction needs. Technical assistance, funding, and advocacy can and should be driven by issues and needs identified and justified through a state EMS data system.

At the national level, a national EMS database is critical to define EMS needs and to support EMS as an industry and a key component of the health care system. Emergency medical service data systems can help shape national educational standards by

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identifying the needs of patients. A data system can help prioritize federal EMS funding and support decisions by the Centers for Medicare & Medicaid Services (CMS) for reimbursement levels for Medicare and Medicaid patients. A comprehensive data system can also be used for basic and policy focused research.

Linkage of EMS data to other databases at the local, state, or national level is also needed. Through the linkage of data systems, insight can be obtained beyond what each individual data source can provide. EMS data systems should be linked with vehicular crash and other injury surveillance data to provide insight into improving the safety of roadways, vehicles, and trauma systems. Linkage of EMS data to hospital data can provide insight into the service delivery, personnel performance, and clinical care provided to each EMS patient. Linkage of EMS data to trauma, stroke, injury, and medical examiner data systems can provide information on how to target, design, and implement injury prevention and public education programs.

What is NEMSIS?

In 1999 the US Department of Health and Human Services (US DHHS) through the Health Resources Services Administration (HRSA) Emergency Medical Services for Children Program (EMSC) funded a feasibility study to determine if an organized EMS data initiative could be developed to support the EMS industry as the International Classification of Diseases (ICD-9) and Health Level 7 (HL7) standards have informed the rest of the health care industry. This feasibility study led to the formal funding of the National EMS Information System Project (NEMSIS) through the US Department of Transportation (US DOT) National Highway Traffic Safety Administration (NHTSA) Office of Emergency Medical Services. The NEMSIS Project has 4 primary goals and objectives:

(1) Establish a standardized national EMS dataset which would be used to document the EMS service delivery, personnel performance, and care for every EMS event in the nation.
(2) Establish an electronic EMS documentation system in every local EMS system to support service delivery and clinical care operations.
(3) Establish a state EMS database in every state where a portion of the data collected by each local EMS system could be aggregated to support state EMS regulatory and disaster management functions.
(4) Establish a national EMS database where a portion of the data maintained by each state's EMS database could be aggregated to support federal EMS program, educational, fiscal, and advocacy needs.

Currently, the NHTSA Uniform PreHospital Dataset (Version 2.2.1) is used. This national standard has been adopted by 49 of the 50 US states. At the time of this publication New York had not adopted this EMS data standard. A total of 37 states have operational state data systems in place today. Every state has a goal, pending resources and funding, to establish a state EMS data system. In 2007, 4 states (North Carolina, Minnesota, Mississippi, and New Hampshire) are providing data to the national EMS database. Current NEMSIS Project funding and deliverables provide for a staggered implementation of the national EMS database with the addition of 10 new states per year until all states are participating.

North Carolina's EMS Data System

The North Carolina PreHospital Medical Information System (PreMIS) was developed in 2002 and currently maintains data on all EMS events in North Carolina. The data collected from the one million plus EMS events per year are used as a resource to guide local EMS systems across the state in their daily operations. Data from PreMIS are protected by North Carolina statute and are only accessible by the North Carolina Office of EMS and each local EMS System. Funding for PreMIS was initially provided through the Governor's Highway Safety Initiative. Currently, PreMIS is funded through a combination of state and federal funds associated with domestic preparedness.

Data from PreMIS are used daily in North Carolina's Bioterrorism Surveillance Program as well as in local EMS quality management and performance improvement initiatives. The Duke Endowment currently supports EMS through the EMS Performance Improvement Toolkit Project. The EMS Toolkits are detailed reports that cover a specific EMS topic. Each EMS toolkit evaluates the 100 North Carolina EMS Systems and provides custom recommendations to improve EMS service delivery, personnel performance, or clinical care. The web-based EMS toolkits have been developed to assist EMS systems with optimizing EMS system response times, thus improving EMS cardiac arrest, trauma, pediatric, and stroke care. The EMS Toolkit Project is a partnership with the NC OEMS and The Duke Endowment. Future EMS Toolkit funding will be used to assist individual EMS systems in addressing the specific problems identified by each local toolkit.

Summary

The future of EMS and the US health care system is dependent on interactive, real-time data systems that can be used to design, develop, implement, evaluate, and maintain quality evidence-based systems of care. North Carolina is a national and international leader in EMS given its support of the PreMIS System, the EMS Toolkit Project, EMS Bioterrorism Surveillance, and participation in the National EMS Database. **NCMJ**

COMMENTARY

Medical Oversight for Emergency Medical Services:
Defining Success

Brent Myers, MD, MPH, FACEP

The provision of emergency medical services (EMS) is a practice of medicine. Although it has been present in various forms since the days of Napoleon, the currently utilized EMS system in the United States began in 1966 with the publication of the EMS "White Paper" from the Institute of Medicine of the National Academies (IOM) and the passage of the Highway Safety Act.[1,2] Over the past 4 decades, the public and members of the medical community have come to rely upon the prompt, professional response of the EMS system, summoning ambulances over one million times per year in North Carolina alone.[3] Indeed, the EMS practice of medicine is one of the largest in every community because all citizens are potential patients. On an annual basis, between 7% and 9% of the population become actual patients and summon EMS via 9-1-1.

Unfortunately, these have not been 4 decades of clinical progress in EMS. There are shining examples of clinical success, but we often fail to dedicate sufficient resources to the prehospital medical effort. As the recent IOM report confirms, the federal government has not provided sufficient funding in the areas of research or disaster preparedness, with EMS receiving less than 5% of the preparedness funding since the attacks of September 11, 2001.[4] The medical community remains uncertain of exactly how to incorporate EMS physicians, for while the number of EMS fellowships continues to grow, the American Board of Medical Specialties has yet to incorporate the subspecialty of EMS into the formal board structure. Finally, the IOM report calls for a new federal agency to oversee EMS, indicating that EMS neither belongs exclusively in the National Highway and Traffic and Safety Administration (the current federal oversight agency for EMS) nor exclusively in the areas of public health or homeland security.[4] From the local to the federal level, EMS is truly at the crossroads, and leadership from physicians and the broader medical community is now urgently needed to guide us through this transition.

> *"From system design to treatment protocols to hospital destination directives, modern EMS systems require active involvement of EMS physicians to ensure clinical excellence in prehospital emergency care."*

What is an EMS Physician?

The EMS physician divides clinical activities into two spheres: the traditional, direct care activities in the emergency department and the less traditional, indirect patient care that is delegated to EMS providers in the community. In the latter role, the EMS physician is responsible for all medical components of the prehospital encounter, including dispatch algorithms for the 9-1-1 center, development and revision of patient care protocols, education for all providers, and remediation of providers when necessary. Gone are the days when the EMS physician could create protocols once every few years and meet with paramedics only when they violated these protocols. The practice of EMS medicine is truly a partnership between receiving hospitals, public health, emergency medical dispatchers, basic life support first responders, and, in most communities, advanced life support providers. This partnership requires intensive and frequent interaction with the EMS physician in order for it to function in the patient's best interest. For maximum patient benefit,

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these interactions should occur both in the formal settings of the classroom, boardroom, and conference room as well as in the informal settings of the 9-1-1 center and the houses and highways where EMS providers operate. The appropriate balance of administrative activity and in-the-street observation directly influences patient outcomes, particularly in the area of cardiac arrest.[5]

Rather than simply performing the "sign and go" tasks related to infrequent protocol revision and remediation, the modern EMS physician will be actively involved in the initial and continuing education of all participants in the medical practice. This includes reviewing protocols for the dispatch center, ensuring first responders have access to the latest medical information, and interacting with advanced life support providers on a regular basis.

The need for physician leadership is most urgent as we begin to address this simple question: Are we providing quality clinical care for our EMS patients? The overall clinical care provided by EMS involves two components: the treatments provided by EMS providers and the decisions reached about patient disposition. In regards to the former, a surprising majority of the treatments and interventions provided by EMS are supported only by anecdotal evidence and deference to historical precedent. Medical antishock trousers (MAST) and high dose epinephrine for cardiac arrest are familiar examples of established treatments that did not survive the test of scientific scrutiny. More recently, the "established treatments" of endotracheal intubation (with or without rapid sequence induction) and ventilations during cardiopulmonary resuscitation (CPR) have been called into question. Finally, with the advent of automated external defibrillators (AEDs) and thus defibrillation by basic life support first responders, the relative importance of paramedic response time is being reexamined in a scientific manner.

Decisions regarding patient disposition also directly impact the quality of care rendered by EMS, not only in the urban environments but in the suburban and rural settings as well. In the urban setting, there is compelling evidence suggesting patients with ST-segment elevation myocardial infarction be diverted to a hospital capable of percutaneous coronary intervention (PCI).[17,18] In the rural setting, investigators with the Reperfusion of Acute Myocardial Infarction in Carolina Emergency Departments (RACE) initiative and others are working to ensure prompt treatment for this patient population either by primary lytic therapy or early activation of the air ambulance for transfer to PCI.[19]

Finally, the EMS physician has the responsibility for caring for patients who suffer cardiac arrest in the out-of-hospital setting, both from sudden cardiac death and from a variety of other medical and traumatic etiologies. Mandating hospital transport for all of these patients not only consumes limited emergency department resources for futile cases, it may also impede resuscitation for those cases which are not futile. We now know that interruptions in cardiac compressions as brief as 20 seconds may decrease the probability of successful resuscitation in a meaningful way, and the movement of a patient from the location of the arrest to the ambulance will inevitably create many such pauses. In the optimal setting, the EMS system is responsible for the resuscitation of cardiac arrest, and the emergency departments and hospitals are responsible for postresuscitation care. Obviously, the EMS physician must be actively involved in all components of the EMS system for such a system to function appropriately.

The EMS system, led by the EMS physician, has the opportunity to improve the outcomes for individual patients as well as to enhance the health of the community as a whole. From system design to treatment protocols to hospital destination directives, modern EMS systems require active involvement of EMS physicians to ensure clinical excellence in prehospital emergency care.

The Challenges Ahead

The EMS physicians of 2007 face many challenges. First, we must provide leadership in the area of workforce stability and career development for our prehospital providers. No matter how involved in our medical practice we become, it is for naught in the absence of a qualified and willing workforce. As the demand for all allied health workers exceeds supply, paramedics become attractive candidates to educational institutions training nurses and respiratory therapists as well as to hospitals and medical clinics seeking highly qualified technicians to operate in the cardiac catherization lab, emergency department, or other settings. In nearly all of these situations, scheduled work in a climate-controlled environment is offered for a higher salary than EMS currently offers. Paramedics may most accurately be viewed as members of the allied health community and, as such, reimbursement must be reexamined. EMS physicians must be allies for our prehospital providers and seek to improve reimbursement for the important work they do.

The EMS physician must actively participate in defining quality in EMS. In just one example of unintended consequences, it may appear logical to support improved response times for EMS. It will surprise some to know, however, that there is no evidence in the medical literature indicating an association between advanced life support response times and survival.[14-16] Moreover, there is a clear association between response time of a BLS defibrillator and survival from cardiac arrest, but this is often not measured or reported.[21] Finally, it appears that the annual experience of a paramedic may be at least as important as the response time. In each community, cardiac arrests occur with a predictable annual incidence of about 1 per 10 000 population. As one adds more paramedics to a system with a stable population, the individual paramedic encounters fewer patients in cardiac arrest each year. Preliminary studies indicate improved survivability from cardiac arrest in areas with fewer paramedics, raising the hypothesis that rapid response of a basic provider with an AED followed by a delayed response of a well-experienced paramedic may be superior to rapid response of a relatively less experienced paramedic.[22,23] This is not surprising, as the same has been demonstrated for invasive cardiologists and other medical specialists: there is a minimum number of high acuity encounters required on a regular basis in order to maintain clinical excellence.[24-26] This, combined with the known short supply of paramedics mentioned above, may eventually place the EMS physician in the seemingly unusual position of calling for fewer paramedics while ensuring the paramedics that are in the field receive the best training, equipment, and reimbursement possible.

This is not to say the historical duties of the EMS physician may be neglected. Protocol revision and assurance of protocol compliance remain the cornerstones of excellent EMS practice. For today's EMS physician, however, these revisions must occur frequently because evidence regarding treatment and transport decisions is emerging more rapidly than at any time in the 4-decade history of EMS. Just in the past 12 months, evidence from North Carolina researchers indicates noninvasive positive pressure ventilation (NIPPV) may become the standard of care for prehospital treatment of pulmonary edema and potentially other forms of respiratory distress.[27] National and international manuscripts have challenged our current methods of CPR and defibrillation with indications that continuous compressions can markedly increase the proportion of patients with neurologically intact survival from cardiac arrest.[9,20,28] The timely revision of EMS protocols is now required to ensure optimal patient outcomes.

Assurance of protocol compliance may be adequately performed with chart review but is only optimally performed after observation in the field. Response with EMS personnel to assess both the quality of the care provided as well as the quality of the medical protocols is necessary for excellence in medical oversight.

Finally, the EMS physician is called upon to perform duties not directly related to routine, individual patient encounters. The events of September 11, 2001 and Hurricane Katrina reminded us that disaster preparedness is not an optional activity. Fortunately, in North Carolina we have several resources including Med-1 at Carolinas Medical Center in Charlotte, the Special Operations Response Team in Winston-Salem, and the State Medical Assistance Teams to assist local resources in any such response. Issues surrounding public health response to infectious disease as well as injury prevention and public safety are also issues for the EMS physician.

Where Do We Go From Here?

Although the challenges are great, the dedication of resources to address them is perhaps the most significant it has been in our 4-decade history. The clarity of the recent IOM report, the multi-center NIH supported Resuscitation Outcomes Consortium (ROC), and the outstanding initiatives emerging from the EMS Performance Center in North Carolina are just a few examples of this dedication. Funding remains a challenge, but as our treatments become more evidence-based, a more cogent argument for dollars becomes available to us. In Hubble's paper for example, we learn that the need for an intubation in the emergency department is avoided for every 6 pulmonary edema patients treated with prehospital NIPPV. The health care dollars saved by the avoidance of a single intensive care unit admission could pay for many NIPPV units in the prehospital setting. As our evidence becomes more robust, the appropriateness of increased funding will hopefully become self-evident.

In conclusion, despite all of the challenges we face, the career of the EMS physician is satisfying and rewarding. When I began my fellowship in EMS, someone with years of experience in the field stated that the duties were 80% political and 20% clinical. They actually were wrong—they are 90% political and 10% clinical on the best days. Yet, despite all of this, the opportunity to care for those cannot otherwise care for themselves is afforded every day. We impact those who have been down on their luck for years as well as those from all walks of life who experience an unexpected illness or injury—and we can help them each in unique ways. At the end of the day, via this dedicated practice, I am able to recall why I entered the medical field in the first place: to help my fellow man. **NCMJ**

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COMMENTARY

Paramedic Endotracheal Intubation

Henry E. Wang, MD, MS

Prehospital practitioners perform a range of critical life saving interventions such as delivery of cardiopulmonary resuscitation chest compressions, rescue defibrillation shocks, administration of intravenous fluids and drugs, and establishment of a patient airway. The equipment used in these interventions require special modifications to enable their portability and delivery in the field setting. For example, while inhospital cardiac arrest equipment is often stored in large mobile "crash carts," such devices would be impractical for prehospital use. Instead, paramedics use portable "jump bags" filled with medications as well as a lighter portable defibrillator/cardiac monitor.

One of the most important recent scientific findings is that medical procedures executed in the field setting may not perform equivalently to the same interventions carried out in the hospital. Thus, simply imitating inhospital practices may not necessarily improve outcomes. In some cases these prehospital interventions may lead to worsened outcomes.

Paramedic Endotracheal Intubation

An excellent example of the challenges surrounding prehospital medical interventions is endotracheal intubation (ETI). Airway management is the process of establishing an open passage between the mouth and the lungs in order to deliver life-saving oxygen. Critically ill individuals such as those suffering from cardiac arrest or major trauma are often unconscious and cannot maintain an open airway on their own. Therefore, airway management is a fundamental priority in the care of the critically ill. Without an adequate supply of oxygen, vital organs (in particular, the brain) begin to die. Airway management may encompass a spectrum of basic methods (eg, mouth-to-mouth or bag-valve-mask ventilation) or more advanced techniques (eg, endotracheal intubation).[1,2]

Endotracheal intubation (ETI) is the most prominent and invasive form of airway management. A plastic breathing tube is inserted through the mouth, between the vocal cords, and into the trachea (windpipe). Endotracheal intubation provides a direct, patent conduit to the lungs to facilitate optimal and controlled delivery of oxygen.[2] The endotracheal tube also has an inflatable cuff designed to prevent the aspiration of stomach contents into the lungs. Endotracheal intubation is the standard method for airway management in the hospital setting including the operating room, emergency department, and intensive care unit.

> *"One of the most important recent scientific findings is that medical procedures executed in the field setting may not perform equivalently to the same interventions carried out in the hospital."*

The History of Paramedic Endotracheal Intubation

Paramedics in the United States first performed field ETI over 20 years ago during an era of intense efforts to improve the out-of-hospital care of patients suffering from sudden cardiac arrest.[3] Experts viewed delivery of oxygen as a fundamental component of cardiac arrest care, and most viewed ETI as the best way to deliver oxygen to the lungs in comatose individuals. Endotracheal intubation was widely performed on cardiac arrest patients in the hospital, and thus it seemed reasonable to train paramedics to act similarly on out-of-hospital patients. Prior to this time paramedics used older methods of airway management such as bag-valve-mask ventilation and the esophageal-obturator airway, neither of which was seen as adequate in this clinical context.[4]

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The first scientific reports of paramedic ETI originated from San Diego, Columbus (Ohio), Boston, and Pittsburgh.[5-8] These groups of paramedics received intense preparation encompassing classroom and mannequin training as well as practice in the operating room on live patients. Anesthesiologists, viewed as the masters of ETI and airway management, played active training and mentoring roles in the pilot efforts. These studies garnered significant scientific attention and spurred efforts to generalize paramedic ETI throughout the United States.

Today, ETI is a standard of paramedic care. In Pennsylvania alone, paramedics perform ETI on over 11 000 out-of-hospital patients annually.[9] Clinicians view ETI as one of the interventions that distinguishes paramedic care.[10]

Controversies Surrounding Paramedic Endotracheal Intubation

Is Paramedic ETI Life-Saving?

The intention of a resuscitation intervention is to improve patient survival or other health outcomes. Since its inception, most have assumed that paramedic ETI is beneficial: ETI provides a direct protected conduit to the lungs—how could it possibly be harmful? However, many recent studies suggest that paramedic ETI may in fact not improve survival or other outcomes. In some cases, the intervention may even worsen outcomes.

Multiple studies have examined the connection between paramedic ETI and patient outcomes.[11-18] The recurrent finding among these studies is that paramedic ETI does not improve survival and, in some cases, may actually increase mortality. These studies also have not identified any neurological benefit from the procedure. For example, Gausche et al performed a prospective pseudo-randomized controlled trial alternating ETI with bag-valve-mask ventilation of critically ill children; the authors found no difference in survival or neurological outcome.[14] Davis et al evaluated out-of-hospital head injured patients intubated with the assistance of succinylcholine, a neuromuscular blocking agent.[12] The use of these drugs causes temporary paralysis of the patient to facilitate ETI and is normally reserved for physician use in the hospital.[2] Compared with historical matched controls that did not receive ETI, the experimental ETI group exhibited a higher adjusted odds of death.

We analyzed over 4000 head injured patients treated by paramedics in Pennsylvania over a 4-year period.[16] We found that those intubated by paramedics had a 4 times higher adjusted odds of death than those intubated in the receiving hospital emergency department.

ETI Adverse Events and Errors

Some have attributed worsened outcomes to adverse events and errors occurring during out-of-hospital ETI. Clinically, this is plausible since ETI is an inherently difficult process requiring the coordination of numerous cognitive and manual steps. In addition, paramedics face other latent challenges when performing ETI such as the uncontrolled chaotic nature of the field environment. For example, it is not unusual for a paramedic to provide airway management on a patient entrapped in the wreckage of a motor vehicle collision. Given these many factors, the occurrence of adverse events is not only possible but probable.

The most serious adverse event associated with ETI is inadvertent placement of the breathing tube in the esophagus. If not recognized and corrected, this error results in oxygen delivery to the stomach instead of the lungs. Katz and Falk presented the most prominent report of ETI adverse events, finding the endotracheal tube misplaced in 25 of 108 patients intubated by paramedics; in two-thirds of these cases, the tube was in the esophagus.[19] Other studies using similar methods found lower—but not negligible—rates of tube misplacement.[20,21]

Recent efforts have highlighted previously undefined ETI errors. Endotracheal intubation ideally should occur rapidly so that there is minimal disturbance to the patient's oxygen level or heart rate. Dunford et al examined a subset of 54 patients receiving succinylcholine-assisted paramedic ETI.[22] The authors found that patient oxygen saturation and/or heart rate decreased significantly during ETI in over half of the patients. Of greater concern, the paramedics considered 84% of these ETI cases to be "easy." Thus, even when equipped with state-of-the-art monitoring equipment, paramedics were not aware of these adverse events.

When individual events are aggregated, the resulting ETI error rates may be higher than expected. We collected data on over 1900 ETI performed by paramedics across Pennsylvania, focusing on reports of three error events: (1) ETI tube misplacement or dislodgement; (2) multiple ETI attempts; and (3) failed ETI efforts.[23] We found that one or more of these errors occurred in 1 in 4.5 patients receiving ETI efforts.

ETI Training and Practice

Given the complexity of ETI, one would expect that paramedics receive substantial training and practice in the procedure. However, current ETI training standards and practices may not afford adequate baseline or maintenance experience.

For example, whereas resident physicians in emergency medicine and anesthesiology must perform 35-50 ETI prior to graduation, paramedic students are required to perform only 5 ETI.[24,25] Examining a series of 7500 ETI performed by 800 paramedic students, we found that paramedic students perform a median of only 7 ETI (IQR: 4-12) during their training.[26] We also found that paramedics students required at least 15 to 20 ETI encounters to achieve adequate baseline proficiency. Emergency medicine residents typically spend 160 hours in the operating room learning ETI under the tutelage of anesthesiologists. However, in a survey of paramedic training program directors, we found that most paramedic students spend only 16 to 32 hours in the operating room learning ETI.[27]

Paramedic clinical ETI experience also falls below expected levels. Using Pennsylvania statewide data for 2003, we found that paramedics perform a median of only one ETI annually.[9] While the minimum annual number of procedures is not defined, the best air medical programs require that paramedics perform at least 12 ETI annually.[28]

While some agencies provide additional training and experience using mannequins or human simulators, the effectiveness of these training modalities remains unproven. Mannequins and human simulators do not accurately recreate the feel of live human flesh nor the heterogeneity in airway anatomy between different persons.[29] Studies linking mannequin and simulator training to paramedic ETI performance have significant limitations.[30,31]

Is Change Possible?

We now recognize that efficacy demonstrated in small controlled settings may not necessarily translate to widespread success when replicated on a large scale. In the case of ETI, the original demonstrations of the technique involved relatively small teams of paramedics receiving intense training and monitoring.[5,6,8,30] Few considered that many EMS agencies nationally would not have the resources necessary to ensure the same degrees of success. Today, our current systems of EMS care and education lack the resources to ensure success on a national scale.

There are, in fact, potential system level solutions. For example, one approach might involve substituting ETI with simpler alternate airway devices such as the Combitube or King LT airway.[1,32,33] These newer devices are relatively easy to insert, work well in a variety of different clinical scenarios, are easier to master than ETI, and may not depend on live human practice for adequate training. In order to adhere to the most recent Advanced Cardiac Life Support guidelines, several individual paramedic agencies nationally have switched from ETI to alternate airway devices.[34]

Facilitating change in ETI, however, comes accompanied by other challenges. One such challenge would be the workplace culture of EMS. Endotracheal intubation is a defining procedure of paramedic care.[10] Taking ETI away from paramedics would be like taking scalpels away from surgeons—this proposition would likely face significant resistance. The optimal method for facilitating change in the face of these many challenges remains unknown. **NCMJ**

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Emergency Preparedness in North Carolina:
Leading the Way

Jane H. Brice, MD, MPH; Roy L. Alson, MD, PhD

North Carolina is situated in an ideal climatic location to be at risk for natural disaster. Hurricanes, ice and snow storms, and tornadoes all strike the state with fair regularity. As such, the emergency responders in North Carolina have had to develop and hone their preparedness skills and maintain a state of readiness. They do not have the luxury to let down their guard. Man-made disasters such as recently experienced in the chemical fire in Apex or the pharmaceutical plant explosion in Kinston also test the preparedness of our responders on the front lines.

Changes in the environment in which we live require constant surveillance and assessment of threats in the community. Recent experiences with SARS in Canada and the isolated case in Chapel Hill dramatically illustrate the effect of new pathogens on communities. As we watch the progression of avian flu in the world, EMS must be ever vigilant as both they and the emergency department are likely to be the first to report the spread of disease in their environments.

In addition, the practice of medicine has evolved in the last few years. Hospitals have fewer available beds due to downsizing, nursing shortages, and minimizing the financial margin. Medicine has begun to emphasis home care. Patients are discharged from the hospital sooner and sicker. There is a smaller margin of error for these patients. More patients are maintained at home on ventilators, home oxygen, and in bed-bound states. When disaster strikes, these patients are most at risk. Finally, our emergency departments are overcrowded with admitted patients awaiting an available and clean bed, making surge capacity slim.

The last 10 years have taught several major lessons to EMS, hospitals, and the medical community at large. First and foremost, we have recognized that hospitals do not provide medical care in a vacuum. Hospital disaster plans used to focus solely on the hospital and were primarily mass casualty plans. We now see hospitals, the medical community, EMS, fire departments, and law enforcement working together with public health and emergency management to develop comprehensive community-wide plans. Lines of communication and coordination are being established before events. As mandated by the Joint Commission on the Accreditation of Healthcare Organizations, hospitals have embraced this community approach to disaster preparedness and are partners with EMS in emergency preparedness.

> *"Responding to a major statewide disaster such as experienced on the Gulf Coast in 2005 is not a matter of if but when. 'Will North Carolina be ready?'"*

Responding to a major statewide disaster such as experienced on the Gulf Coast in 2005 is not a matter of if but when. "Will North Carolina be ready?" is the question many emergency planners are asking. In the past 6 years, funding for preparedness equipment and activities has increased substantially thanks to the attention of the federal government in the wake of the 9/11 events. Planners have also embraced the notion that disaster preparedness must be scalable, flexible, and sustainable. Cross-institutional planning between emergency responders, hospitals, community officials, and industry has resulted in more robust,

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comprehensive, and integrated plans that allow a community or region to react in concert to mitigate the effects of disasters.

As required by Homeland Security Presidential Directive-5, adoption of the National Incident Management System by all emergency responders (eg, hospitals, EMS, public health) has allowed for a common language and better communication among providers. Incident command uses the concept of management by objective and is task-oriented rather than person-oriented.

Mass-casualty incidents affect particular segments of communities, but disasters have consequences that are felt across entire communities and regions. An “all-hazard” approach to emergency preparedness has demonstrated the greatest potential for success. In an “all-hazards” model a standardized framework for disaster response is developed and followed with the ability to supplement response with specific entities such as decontamination as the incident dictates. While the federal government offers substantial assistance in the event of a disaster, this help may be days to weeks away and communities have to plan to be self-supporting for 72 to 96 hours.

Where Does North Carolina Stand?

North Carolina’s emergency responders stand at the forefront of emergency preparedness compared to the rest of the nation. The North Carolina State Medical Response System (SMRS) is a joint partnership of the North Carolina Office of Emergency Management, the North Carolina Office of Emergency Medical Services, and the North Carolina Department of Public Health. Role modeling at the state level the partnerships that are most effective in emergency preparedness, the SMRS has set the standard for both regional and local level preparedness. Utilizing a comprehensive approach based around the administrative organization of the Trauma Program’s Regional Advisory Councils, the SMRS has set up several layers of emergency preparedness.

The central concept of SMRS is that it is scalable and flexible. Incorporating assets at the local, regional, and state levels, the SMRS is able to mount an integrated response with common equipment, protocols, and training. At the core of this response is the State Medical Assistance Team program (SMAT) with tiered levels of team response. The SMAT layers are based out of county (SMAT 3), regional (SMAT 2), and state (SMAT 1) bases. This concept has been proven effective in responses to tornados and the recent Apex chemical plant fire as well as responses to Hurricane Katrina.

Through Health Resources and Services Administration (HRSA) grants, North Carolina has provided funding and other resources for individual counties to develop SMAT 3 teams. While not required, counties are encouraged to develop and maintain the training for SMAT 3 teams. At present, 25 counties have taken advantage of this opportunity. Primarily prehospital in orientation, these teams have the ability to rapidly set up technical decontamination systems to deal with weapons of mass destruction (WMD) or hazmat events. SMAT 3 teams also have the ability to assist with onsite medical care and triage in a mass casualty incident and are currently undergoing training to deal with blast injuries and structural collapse events.

Each of the 8 trauma regional advisory councils (RACs) in the state serves as the sponsor for a SMAT 2 team. These teams have the ability to support hospital based decontamination as well as provide care in a portable 50-bed medical facility that can be set up in either temporary shelters or fixed structures. Each facility is contained in a 55-foot tractor trailer (See Figure 1.) and can be used as a stand-alone acute care or alternate care facility. The units can be utilized in combination forming a larger medical facility with maximum surge capacity of 400 beds for our state. To form the SMAT 2 response, each hospital within a RAC commits a few staff members to support the SMAT operation based upon the size of the member hospital. SMAT 2 operations are thus enabled without compromising the staffing of any one medical facility. Members of the SMAT 2 team train with the system on an annual basis and, in addition to disasters, the units have been deployed to support events such as the Tall Ships sail in Beaufort last summer. Current purchases to augment the SMAT 2 operations include 2 portable digital field x-ray systems for the state, 3 pharmacy trailers, and a stock of portable ventilators.

The SMAT 1 is based at the Special Operations Response Team (SORT) headquarters in Winston-Salem. Containing a

Figure 1.
NC SMAT 2 Trailer

more robust decontamination capability to deal with large-scale WMD events, the SMAT 1 inventory includes a tractor trailer-based field hospital and an 80-bed special medical needs trailer, which allow set up of a special needs shelter in a fixed facility. The Special Operations Response Team also maintains a tractor trailer with basic medical supplies for deployment during disasters as well as a rapid deployment field medical unit.

Carolinas Medical Center in Charlotte has developed and deployed under government funding a tractor trailer mounted intensive care unit and operating room facility called MED 1. Serving as the critical care area during the NC SMAT deployment to Waveland, Mississippi during the aftermath of Hurricane Katrina, the team has received extensive media coverage and accolades.

Public health has not been neglected in the process. Funding has been provided to increase training of public health agencies across the state and to upgrade laboratory facilities for the Division of Public Health to allow for timely diagnosis. Seven public health regional surveillance teams (PHRST) have been established and are operational, providing both technical support and epidemiological tracking for unusual diseases in our state. Lastly, the North Carolina Health Alert Network (NCHAN) uses a multimodel system for 24/7 distribution of health related information to health departments, medical facilities, and response agencies.

In a related function, the NC State Medical Asset Resource Tracking Tool (SMARTT) has been successfully deployed. It allows hospitals to enter bed status and availability in real time so that planners can use this information to allocate patients and assets during real events. The SMARTT system will eventually include EMS responders, special teams such as hazardous materials teams, and local clinics and physicians' offices.

Much has been done, but there is still much to do. Dealing with the special needs populations remains problematic and unsolved. Development of SMAT 4s to specifically address the special needs communities with input from home health agencies and nursing facilities is now underway along with a system to track medical records and medications for this population. Special needs equipment is being purchase and stockpiled. Dual use capability of special needs equipment is being pursued with home health agencies and community colleges across the state. Equipment can be used to train nursing and allied health professions students on a daily basis and, in an emergency, equipment would be used by the students and other health care providers to provide a special needs shelter on the campus in a coordinated manner, with all the necessary assets centrally located for the region.

North Carolina is extremely fortunate. Due to our cooperative approach, North Carolina is a leader in disaster response and states across the southeast are emulating our system of tiered response. We cannot rest on our laurels. We must continue to examine the risks and adapt our preparations. Finally, as practitioners we must realize that the victims we discuss are our patients. Therefore, we must take an active part in the preparation for and the provision of disaster medical care by volunteering to serve on a team, being certain that our practices can and do remain open in the event of a disaster or other incident in our communities, or being personally prepared with our families for disaster. Above all, we must remember that disaster response is really the ultimate team sport and that we are fortunate to be part of a top team. **NCMJ**

COMMENTARY

Emergency Medical Communication in North Carolina:

Past, Present, and Future Challenges

Carl C. Van Cott

If the best equipped ambulance arrives unannounced at the emergency room door and the hospital is unprepared for the arrival, the system has broken down and patients can be lost because of it. There must be good reliable communications between the person reporting the accident, the dispatcher of the appropriate vehicle and personnel, the police and fire departments (when called for), the hospital emergency department, the medical specialists available to the hospital, and those bigger hospitals (trauma centers) to which the patient might in some cases be sent directly.

This excerpt from the 1973 Report of the Legislative Research Commission to the General Assembly of North Carolina recognized the importance of emergency medical services (EMS) communications to the safety and quality of emergent care. Since its inception, EMS communications has made measured progress. This article explores some history, examines the current status of EMS communications, and highlights some of the future challenges faced in North Carolina.

An EMS communication system must be examined under two operational conditions: routine or day-to-day operations and disaster or larger scale emergency situations. For the local systems to be effective, wide area standards for operations and equipment, radio frequencies, and technical requirements must be provided. These standards must be sufficient to ensure compatibility and interoperability throughout all systems statewide. Communication functions must also adapt if an emergency situation escalates. Communications must be capable of extending to adjacent counties, states, and national disaster management agencies. The establishment of interoperable systems requires time to develop and needs consistent financing and direction. System creation is an evolutionary process requiring understanding and acceptance. Common goals and language must exist to facilitate this development.

> *"National long-term plans may convert all public safety communications to a common frequency band, but this will not be possible in the short term and requires interim systems to remain functional as the new systems and equipment become defined and available."*

Public Access Communication

In the 1970s public access to emergency services was uncoordinated. Numerous telephone numbers were listed on the inside cover of local telephone directories for the various sources of EMS and rescue services. Callers seeking assistance were fortunate if they could identify the telephone number necessary for their needed emergency service; they may have had to call multiple phone numbers and choose between the various services and providers, thus being delayed in obtaining assistance.

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Currently, public access to EMS is achieved through universally available 9-1-1 emergency telephone systems. Public Safety Answering Points (PSAPs) have been established in all 100 North Carolina counties and the state has progressed to being served fully by "Enhanced 9-1-1," also known as E9-1-1. Enhanced 9-1-1 enables a PSAP to determine the caller's location from data linked to the telephone number. Considerable effort has been expended in implementing these E9-1-1 systems. The introduction of new communications technologies has, however, created new challenges. For example, an estimated 70% of calls to PSAPs in North Carolina are now made from cellular telephones, but many PSAPs cannot accurately identify the location of the cellular telephone. Similarly, Voice over Internet (VoIP) telephones, also a popular new technology, do not automatically tie to the system that provides user location information. This requires the user to register the VoIP telephone to a location. These differences may cause delays and inaccuracies in dispatching emergency help, which can result in loss of life and property.

Cellular telephones also offer new advantages for EMS communication. They have features such as geographic positioning systems (GPS), digital picture and video transmission and reception capabilities, text messaging, and mapping capabilities. These new capabilities, however, are not utilized by most 9-1-1 centers. They could have considerable usefulness in the emergency dispatching system. Methods to utilize these new system capabilities for EMS systems should be explored. For example, a cellular caller could send pictures of a crash location or other emergency situation, in essence extending the eyes of the dispatcher to the emergency scene. Consider the range of possibilities when the cell phone device in the field can also receive messages or video from the 9-1-1 dispatcher. This could provide information on how to perform cardiopulmonary resuscitation (CPR) or other emergency procedures or even direct evacuations in preparation for an impending weather event or other large scale emergency.

Dispatch and Coordination Communication

In times past, virtually no training was provided to emergency dispatchers. Dispatching services were not recognized as having a high degree of importance and were not always provided 24 hours a day. Sometimes emergency telephone numbers changed from day to night depending on which person took the ambulance home that evening. Times have changed. Telecommunicators that function in a coordinated PSAP are generally required to have a minimum level of telecommunications training. There is increasing recognition of the important role telecommunicators play as the first of the first responders and the sole point of contact for all emergency services. The dispatcher is responsible for making the decision of what services are to be dispatched and for the coordination of all of the emergency functions and field responses. If this function is poorly performed, nothing else will go well in the response. Telecommunicators are rightfully assuming recognition in a new profession.

Emergency medical dispatch (EMD) training is available throughout North Carolina. Emergency medical dispatch certification is an advanced life support service that requires a medical director. Currently, 73 communications agencies or 63% of the approximately 115 emergency dispatch centers within the state have approved EMD programs.[1] These centers are trained to recognize life-threatening conditions and provide telephonic direction in medical emergencies such as childbirth and CPR.

Emergency medical services communications understanding must extend further to the educational requirements for all users of the system. This education must include training for the public on how and when to call for assistance and what to expect when they call. The dispatcher's training must include providing prearrival medical instructions. Field responders and hospital personnel need instruction on how to use their communications equipment. Methods must be developed to accurately and quickly exchange information about a patient's condition and treatment, and a standardized radio reporting template to present a patient to the emergency department must be developed. Finally, education must extend to licensing radio systems, maintaining the equipment, and testing the operational readiness of the entire emergency communications system.

Public Safety Answering Point operations should be encouraged to recognize the importance of certification and training programs. These certifications also extend to fire and law enforcement operations. Caller algorithms (flip cards and computer programs) for directions to provide assistance to callers must continue to be reviewed and expanded to a broadened array of programs and to additional medical conditions where early intervention can be critical. All emergency communications centers should have the ability to provide CPR instructions over the telephone. All emergency answering points should be able to provide information on the location of nearby automatic electronic defibrillators in high population areas such as malls, airports, fairs, and other public gathering places and to be able to provide instruction on the use of these devices to the caller.

Devices that provide mapping, location, and direction information to emergency events must be made commonly available to PSAPs, emergency response vehicles, and field responders. Vehicle GPS systems should be widely available to report to the PSAP the location of ambulances and to provide the dispatcher with information on the location of the closest units available to respond to any given situation. Coordination of emergency communications services between geographic areas such as cities and counties must become the rule and not the exception. There should be a common statewide approach to providing public safety services.

Medical Communication

In the early 1970s physician medical direction communication to field EMS units did not exist. Notification of an impending patient arrival via ambulance at a hospital was sporadic and information concerning a patient's condition was provided only as a local service option. In most instances it did not exist. Hospital radio systems operated on various radio frequencies with different channel designations. A statewide common hospital radio frequency was not available. Ambulance personnel making patient transports to out-of-county hospitals generally were not able to communicate after leaving their local service area.

A statewide common hospital very high frequency (VHF) was implemented in the later half of the 1970s and a standardized channel name was designated. During the 1980s and 1990s every ambulance and every hospital with an emergency department had a radio that operated on 155.340 MHz, now commonly called “340.” A state publication entitled Dial Codes provided information about each hospital’s radio frequencies and telephone and radio access numbers or codes. Ultra high frequency (UHF) “MED” radio systems were widely implemented and paramedic advanced life support communications systems were installed. These radio systems had the ability to transmit a patient’s electrocardiogram to aid in patient care and treatment.

In the late 1990s wide area compatible hospital radio systems in parts of the state began to decline, both in numbers and in operational reliability. In part this was due to the lack of consistent funding to encourage hospitals and EMS agencies to install systems that met statewide standards and to the failure of hospitals to keep their radio equipment in prime operating condition. At times there was disagreement on who was responsible for providing the radio or maintaining the ambulance-hospital equipment serviced, especially when the services were under different administrative structures.

All hospitals in North Carolina with emergency departments currently have radios licensed on the state hospital 340 VHF frequency. Some of these radios have not been replaced or upgraded since the original installation 25 or more years ago. Even when functional, the single frequency hospital radio system is overloaded in metropolitan areas and during disaster situations.

Some counties and EMS agencies that previously had equipment operating on the state standard UHF MED channels have now removed these radios, electing not to repair or replace older radio equipment in favor of purchasing new 800 MHz systems. The expanded capabilities of the 800 MHz trunked systems, however, extend only to users that function within the same communications network. Compatibility between adjacent counties or to other communications systems may not exist or is difficult to achieve due to differences in the equipment when it is supplied by different manufacturers. Unless common direction and standards are consistently available, system designs may fail to maintain common statewide frequencies. This can result in situations where an ambulance transporting outside the county is not able to communicate with the receiving hospital or is unable to maintain contact en route. Cellular telephones appear to fill this communications gap, but they do not function when the telephone network becomes overloaded. This situation is common during disasters and can occur even during moderate traffic congestion situations.

The North Carolina Medical Communications Network (NCMCN) has been developed to provide common geographic wide area UHF radio coverage. The state network of radio repeater installations operates on two channels to increase connectivity between hospitals. The system functions both for routine radio communication and during disasters. The system serves as a redundant system to local EMS radio systems and as an interim system for disaster medical communication. By October 2007 NCMCN radios will be installed in all hospitals within North Carolina. Even with this advancement in statewide capabilities, channel capacity of the system is not sufficient to ensure communications during large scale emergencies or disasters. Additionally, there are currently insufficient numbers of ambulances equipped with UHF radios to ensure operational capability with the system.

Efforts are underway to create a new public safety statewide radio network in the 800 MHz spectrum. This system is the Voice Interoperability Plan for Emergency Responders or “VIPER” network. The system is intended for use by all emergency responders including law enforcement, fire, and EMS services.

A medical communications component has been added to the VIPER network to provide an additional layer of compatible medical radio operation to hospitals and EMS services. This component is designated the Viper Medical Network (VMN), and it provides another radio option for hospitals and EMS services. Funding to encourage wide participation in this system has not yet been identified. The first level of deployment of the VMN is underway through funding provided by the US Health Resources and Services Administration (HRSA). Eventually, it is envisioned that every hospital in the state will have access to its own “talk group” on the network, which will enable any hospital or ambulance to establish voice contact from anywhere within the state.

Complicating the advancement of the new VIPER system is the necessity to provide additional radios to ambulances. In the short term this could result in an ambulance being required to have up to three separate radios installed—one functioning on the hospital VHF 340 for communications on the statewide VHF hospital frequency and with its local dispatch operations, a second for the UHF NCMCN, and a third to participate in the VIPER VMN 800 MHz state trunked network. This amount of radio equipment is costly to acquire and maintain. Unfortunately, there does not appear to be any easy alternative. Some efforts are underway by the state and some counties to install gateway systems that will patch between various radio systems. For these systems to function, however, the radio coverage between the patched systems must be geographically coincidental. Until all systems statewide can be upgraded to a common band or to the VIPER system or until equipment becomes available to enable radio operation compatibility on the many systems and radio bands, multiple radios in hospitals and ambulances will continue to be required. Furthermore, alternative sources for equipment compatible with the VIPER network must be identified. Equipment is currently available from only a very limited selection of suppliers. Technical assistance and guidance regarding radio communications as well as the VIPER network must be made available to hospitals and EMS providers.

National long-term plans may convert all public safety communications to a common frequency band, but this will not be possible in the short term and requires interim systems to remain functional as the new systems and equipment become defined and available. There are already known technical situations and pending FCC actions that impact the development of these high capability systems. Developments of new capability systems and technology will keep EMS systems in a state of flux for years to come.

Implementation of an EMS communications system is an evolutionary process. Implementation requires a series of compromises and trade-offs made within the confines of time and funding. Directives, rules, laws, technology, motivation, and expectation all influence the outcome. Every aspect of the communications system must continually be revisited, evaluated, refined, refurbished, and improved to maintain North Carolina's readiness and ability to provide the services to respond and be prepared for the eventualities. **NCMJ**

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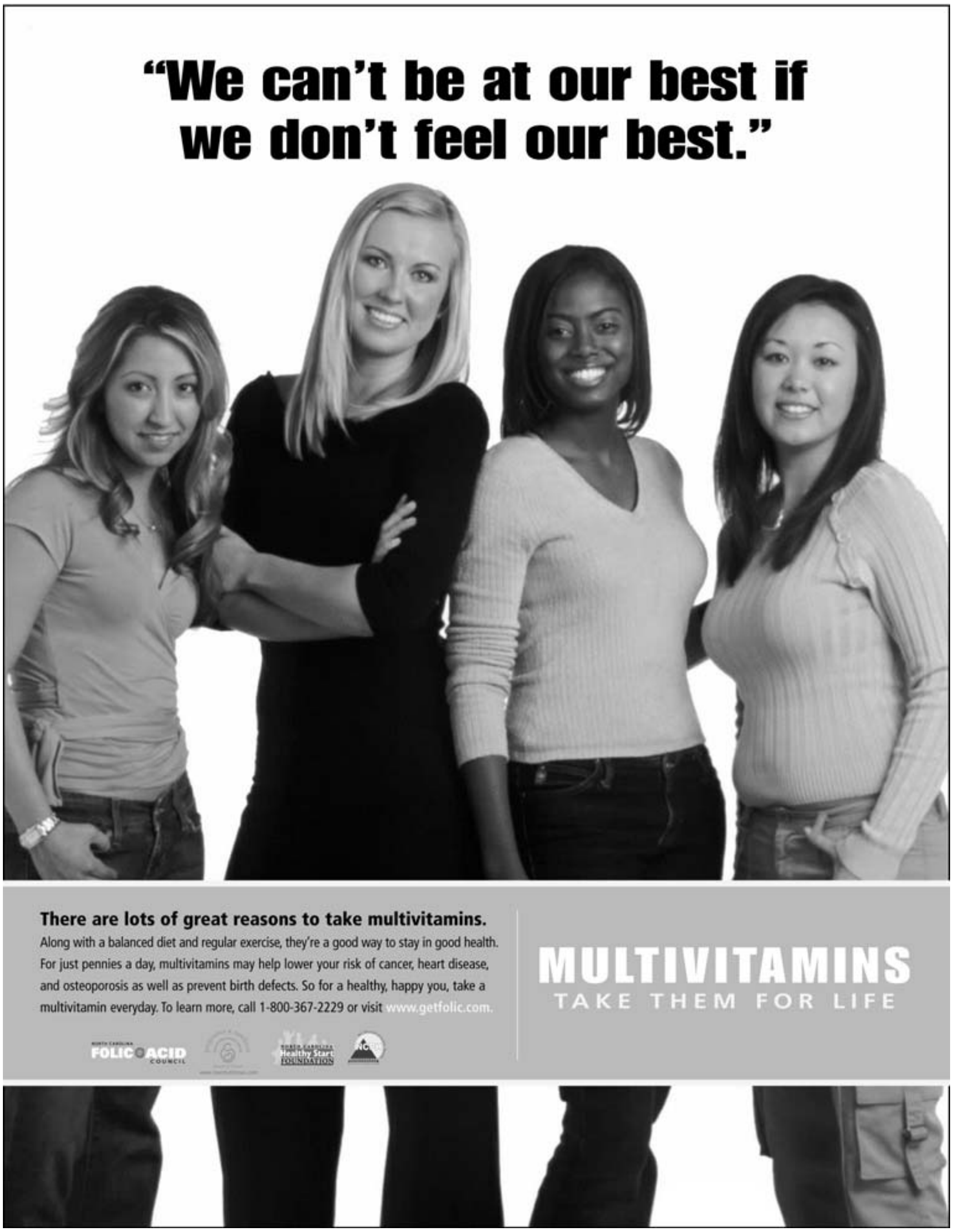

The Future of Emergency Medical Services Communications Systems:

Time for a Change

Kevin K. McGinnis, MPS, EMT-P

Modern emergency medical services (EMS) are approximately 35 years old. The transformation of ambulances from "horizontal taxicabs" capable of little more than patient transportation to a system capable of sophisticated, life-saving, prehospital and hospital intervention has been dramatic. Emergency medical services communications systems have, by and large, not experienced similar transformation. Current and developing advances in communications technology could address this.

Immediate opportunities for EMS communications systems to integrate such advances exist, and more are evolving in the federal and national arenas. Incorporating broadband as a means of improving communications among EMS providers, between EMS, fire, and police, and between EMS and hospitals is one example. In affecting these advances, EMS has the potential to become the greatest user of public safety bandwidth and a very large user of federal communications funding.

There is no assurance that EMS will have access to such capabilities or funds. Additionally, EMS is not prepared to lobby for new resources and capabilities. First, we need to determine what information prehospital and hospital emergency care providers need, in what form, and at what stage in the course of an EMS patient care episode. It is the EMS community itself, including state and local government agencies responsible for EMS, that must organize to take advantage of these opportunities and capabilities.

Where We Are

The commentary by Carl Van Cott highlights the evolution of the existing EMS radio systems including the very high frequency (VHF) radio channels and ultra high frequency (UHF, in the 460MHz range; often called the "10 med channels") channels for ambulance to hospital (for reporting patient condition and seeking medical direction) and other communications. With the exception of electrocardiogram (EKG) biotelemetry sent over the UHF EMS channels, these communications were solely for voice use. Even today, the EMS communications system probably consists of 98% voice and 2% biotelemetry and other data transmissions.

Some local EMS systems have been solicited to participate in new or existing regionwide or statewide 700MHz and 800 MHz radio systems that are usually operated by law enforcement and/or government transportation agencies. These systems offer more voice channels for specializing communications but have significantly less transmission range, which makes them less practical in rural areas. Governmental owners of such systems solicit new users like EMS when the cost of maintaining an existing system becomes challenging. For rural EMS operations, this can be an expensive proposition. Erecting new antennae, for example, would be necessary. In addition, when urban EMS systems become integrated into 700/800 MHz systems, the

> *"Each segment in the EMS response presents potential delays. Each also presents opportunities to accelerate appropriate medical intervention through improved communications that enable some events, decision making, and actions to occur more simultaneously."*

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specialty centers involved must often maintain VHF/UHF capabilities for communicating with ambulances coming in from outside of that area.

Broadband capacity at 2.4 MHz is a technology being provided by some municipalities for public internet access in urban environments. Municipalities are also encouraging public safety agencies to employ this technology. Broadband will become increasingly important to EMS as data communications are utilized more. Careful consideration, however, should be given when considering its use for mission-critical communications and for any communications involving confidential patient information. The unlicensed and public access characteristics of this system render its reliability and security suspect. Another broadband service at 4.9 MHz is reserved for licensing by public safety organizations. Use of this service is believed to alleviate reliability and security issues to a greater extent. Both 2.4 MHz and 4.9 MHz services are extremely short range and, thus, of use in primarily urban environments.

Where We Could Be

During an EMS emergency call today, events, decision making, and resulting actions largely occur on a sequential basis as new information is presented. In a rural car crash, for instance, the crash occurs, the crash is detected, EMS is called, EMS responds, EMS arrives and evaluates, additional resources are called (eg, extrication services, helicopter), additional resources respond, medical direction is sought and provided, treatment is administered, and the patient is transported. Each segment in the EMS response presents potential delays. Each also presents opportunities to accelerate appropriate medical intervention through improved communications that enable some events, decision making, and actions to occur more simultaneously. Delays during EMS calls can cost tens of minutes, if not hours, during the patient's "golden hour," the time from the crash event to when the patient arrives under a surgeon's scalpel.

In the future, through advanced automatic crash notification (AACN) systems in cars, standard equipment on many car models now produced, the crash event and location will be available to local EMS and other responders almost immediately. Current and future AACN features can also transmit change in velocity at crash, direction of impact, air bag deployment, seatbelt status, number of occupants, and rollover status. Future systems may include an "urgency algorithm" which notifies responders of the likelihood that an occupant was severely injured in the crash. Not only does this virtually eliminate the delay in detecting and locating crashes, but it allows prehospital and hospital providers to be immediately notified of all or severe crashes in their response/catchment areas. With appropriate protocols in place, simultaneous dispatch of ground and air ambulances and extrication services could then occur in severe crashes. Similarly, hospitals and trauma centers could notify their staffs to be ready and notify prehospital responders of their availability to take patients. One can imagine similar capabilities in "help, I've fallen and can't get up" devices for populations at risk.

When EMS responders arrive at the scene in the future, they will be able to do more simultaneously. The initial provider at a car crash will make a quick, triaging assessment of each patient, placing and leaving a small electrocardiogram (EKG) and vital signs monitor on each, inserting each patient's emergency health record "smart card" into his personal digital assistant (PDA) or communications device, describing brief findings about each into a lip microphone which is translated to a text file, and shooting brief video of each through a shoulder or head camera. Each of these data streams goes into patient-specific data bases in the responder's PDA and is transmitted to a mobile data unit in the ambulance.

Once additional responders are assigned to patients, their devices are used to enter their identifications, monitor patient vital signs, and add new voice/text and video data into the respective patient-specific data files. The EMS scene coordinator, as well as yet to arrive EMS, extrication, and helicopter crews and the local and trauma center hospital staffs can access databases for updates on any or all of the patients' conditions. Field providers utilize PDAs or mobile data units like laptop or tablet computers. Hospital staff may use the same or desktop units. All are combination voice and data communications units. Looking at a screen with a patient's real-time vital signs, video image, and provider's notes, medical direction physicians can begin to anticipate more information they may want and orders they will give crews at the scene or en route to the hospital. As patients become assigned to specific EMS crews for transport to specific hospitals, access to their databases becomes limited to their prehospital and hospital providers. Best routing to a scene and then from scene to hospital by ground ambulance can be determined through local transportation agency real-time traffic monitoring databases.

The Technology Required

This vision for where we could be comes at a price and with risks. In April 2007 the Blackberry network crashed. Technology such as mobile data units, PDAs, and computers with integrated voice communications exist today, but these can be costly. Personal digital assistant-based emergency health record entry and reliable speech-recognition technology has been developed in military systems such as the Battlefield Medical Information System Tactical,[1] which is available for commercial licensure. Video and vital signs monitoring for one or multiple patients through miniaturized devices has been demonstrated by a research and development group coordinated through Johns Hopkins.[2] A number of EMS systems have piloted video use in ambulances

If hospital and prehospital emergency care and other public safety players involved in any EMS call maintain databases detailing the status and availability of their resources, it becomes theoretically possible to network them in a system that is accessible by the field PDAs and other devices described. Then we add to the network those databases created by public safety, advanced automatic crash notification, traffic and other control/dispatch centers that describe evolving car crashes, EMS call, traffic flow, and other system events. Finally added is the ad hoc patient databases created at the scenes of EMS calls, and these 3 components become a "network of networks" in which voice and data communications can exist. To complete the system picture, the screen of any of the data/voice communications devices could present a simple, map-like picture of the provider's response or catchment area. The screen would depict icons for all the relevant events occurring in real time (eg, car crashes, ambulance calls) and resources (eg, local hospital emergency department, EMS, fire rescue). By selecting an icon, an authorized user could then drill down on an event or resource to find out more about it. At the lowest level of a car crash event icon, one might find the patient video, vital signs, and provider notes data described earlier.

Federal and National Activities and Opportunities for State and Local Action

If EMS is going to participate in the type of data communications network described above, it must acquire communications frequencies with greater bandwidth than it has now. The VHF/UHF and 700/800MHz capabilities it now utilizes have bandwidth sufficient for voice communications and simple EKG biotelemetry. Sending text data (like provider's notes), real-time vital signs data, basic streaming video, higher definition video, and medical quality video require increasingly wider frequency bands to provide the speed of data transmission needed to send these files for real-time use. Transmitting a huge video file on one of today's EMS VHF frequencies would be slower than sending it by dial-up internet access. For vital signs transmission, at least wide-band capability would be needed, and for high to medical quality video, broadband is required. With multiple EMS crews sending data to various hospitals in any one area at the same time, the bandwidth required could well outstrip that available.

Congress and the Federal Communications Commission (FCC) have ordered analog television stations off a frequency band in the 700 MHz range (channels 60-69; 746 MHz-806 MHz). They have allocated some of this for public safety use and the FCC is now considering proposals for how it will be divided up when it is released in 2009. The remainder was to be auctioned in 2009 for commercial use with a billion dollars of the proceeds to go to public safety in states and locales for improving radio interoperability. Congress is likely to approve the expenditure of that $1 billion to be spent this year. The National Public Safety Telecommunications Council, FCC, and US Department of Homeland Security (SafeCom Interoperability Program) websites can be monitored for progress.[3,4,5] Despite the early availability of these funds, there are proposals before the FCC to give the remaining analog TV channel range to public safety for a national broadband network under the supervision of a public safety controlled consortium rather than auctioning them off for commercial use.

The SafeCom Program is constantly developing tools for state and local interoperability and system development efforts. Included in these are guidelines for the development of statewide interoperability executive committees. Such committees exist in most states by one name or another and should be targeted by EMS interests to seek inclusion for public safety broadband planning efforts and access to bandwidth.

The FCC has ordered that the VHF and UHF frequencies that include the traditional EMS frequencies be made even narrower by 2013. This means that where there once existed one narrow-band channel for use, there will be as many as four. Local EMS agencies that have been attracted to the current 700/800MHz system offerings in their states because of the availability of many open channels for EMS use may find that sticking with their VHF/UHF systems provides not only greater range and less expense but more voice channels in few years. **NCMJ**

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Spotlight on the Safety Net

A Community Collaboration
Kimberly M. Alexander-Bratcher, MPH

Mecklenburg Emergency Medical Services Agency

Mecklenburg Emergency Medical Services Agency, better known as Medic, provides emergency and nonemergency paramedic level medical services to the citizens of Mecklenburg County. Medic is part of a unique partnership between Mecklenburg County, Carolinas HealthCare System, and Presbyterian Health Care/Novant Health. Since fiscal year 1997, Medic has reduced ambulance response times, implemented higher clinical standards, and reduced the taxpayer subsidy per call by half. The agency will answer more than 85 000 calls for medical help this year. Medic also conducts frequent community education programs on health, safety, injury prevention, and emergency-related issues.

In 1996, the Mecklenburg Board of County Commissioners and the county management staff worked closely with emergency medical services (EMS) management and leaders in both the medical and business communities to address the needs of the county's EMS department. Together, they were committed to meeting future needs in the ever-growing Charlotte-Mecklenburg community. The goal was and continues to be enhancement of Mecklenburg's emergency medical services to create a high-performance EMS system. A joint plan was also received by the community's two major hospital systems—the Carolinas HealthCare System and the Presbyterian Health Care System. In the fall of 1996, the Mecklenburg Board of County Commissioners decided to form a partnership with the two hospital systems to provide prehospital emergency medical care and transportation.

Medic maintains its own communication center known as Central Medical Emergency Dispatch (CMED). Central Medical Emergency Dispatch's 3 primary responsibilities are to: (1) prioritize and dispatch 9-1-1 requests for service and coordinate all EMS resources within Charlotte-Mecklenburg; (2) dispatch all Mecklenburg County volunteer fire departments; and (3) serve as the central warning point for two nuclear power facilities or other disasters that may occur. All requests for emergency services are handled via an enhanced 9-1-1 system. All 9-1-1 calls for Medic and/or county fire are routed to CMED by the Charlotte-Mecklenburg Police Department, which serves as the primary public safety answering point (PSAP). Central Medical Emergency Dispatch serves the community as the backup PSAP should there ever be a problem with the primary PSAP communications center. Efficient use of emergency medical resources is achieved by a state-of-the-art Computer Aided Medical Priority Dispatch System, global positioning satellite tracking equipment, onboard mobile status terminals, System Status Management programs, and nationally-certified emergency medical dispatchers who prioritize incoming calls and provide prearrival medical instructions to all 9-1-1 callers. Medic's CMED received national accreditation from the National Academies of Emergency Dispatch as a Center of Excellence in 2002.

At present, there are approximately 170 full-time and approximately 32 part-time field employees working at the paramedic or emergency medical technician (EMT) levels. There are also education and quality improvement staff, logistics team members, fleet maintenance workers, and human resource and financial staff. Medic currently responds to greater than 90% of all requests for emergency services within 9 minutes and 59 seconds. During any given 24-hour period, 150 to 300 calls are dispatched. Mecklenburg Emergency Medical Services Agency is the busiest EMS provider in North and South Carolina. In 2002, Medic units responded to over 70 000 calls (all responses) and conducted over 48 000 transports.

A new and innovative division at Medic is the Education and Simulation Center. Under the direction of Kevin Staley, Medic's Medical Services director, a state-of-the-art medical simulation center has been

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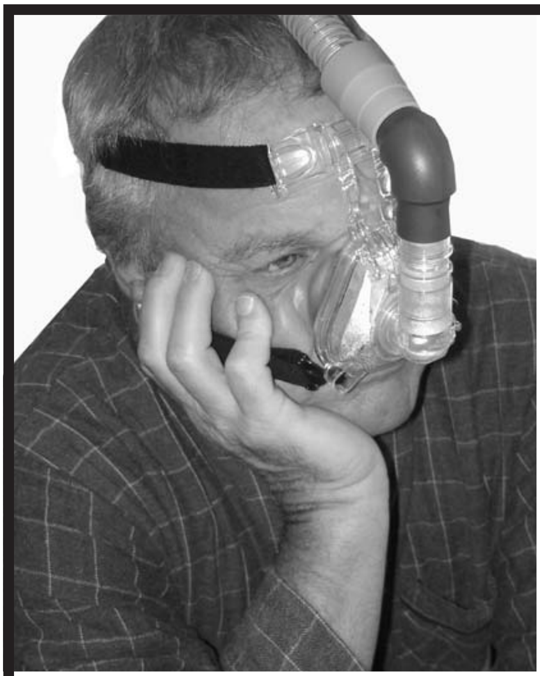
developed which includes multiple sound stages, high-fidelity mannequins, control rooms, digital reproduction capabilities, and review rooms. This resource affords EMTs and paramedics a unique and progressive methodology for their continuing education. Multiple scenarios have been developed and adopted that enhance the provider's ability to deliver evidence-based emergency medical care. Similar training is currently being adopted at medical universities and nursing schools across the country. A human gross anatomy lab has also been included in this center to enhance each provider's understanding of the anatomical relationships in the human body. Medic is in partnership with the Center for Prehospital Medicine at Carolinas Medical Center which provides full-time EMT-paramedic and EMT-basic courses of instruction throughout the year. These courses are open to the public as well.

The field of emergency medical service is rapidly evolving. The Mecklenburg Emergency Medical Services Agency is mirroring the larger changes being experienced throughout the medical marketplace as a whole. This model has been designed to ensure high quality clinical care, provide efficient and reliable EMS services at a reasonable cost to consumers, and provide the community with an operationally and financially stable system. Prehospital emergency medical care is in essence the provision of health care to those afflicted by unexpected illness or injury. While EMS is considered a public service, many will debate the notion of EMS being a component of public safety. Regardless, incorporating EMS into both health care systems and county oversight in the community strengthens the concept of health care delivery and ensures that citizens and visitors in the Charlotte-Mecklenburg community receive the highest level of quality patient care possible. As such, Medic is modeling a new design for the future of EMS.

Contributions from Tom Blackwell, MD, FACEP,
medical director of Mecklenburg Emergency Medical Services Agency



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Running the Numbers

A Periodic Feature to Inform North Carolina Health Care Professionals About Current Topics in Health Statistics

From the State Center for Health Statistics, NC Department of Health and Human Services
http://www.schs.state.nc.us/SCHS

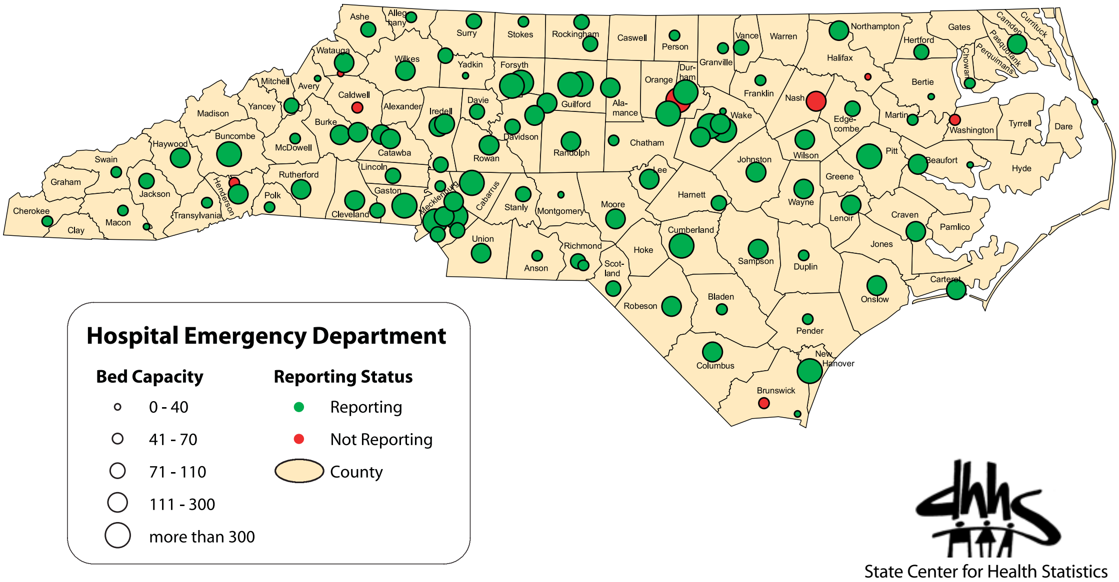
North Carolina Emergency Department Visit Data Available for Public Health Surveillance

The National Center for Health Statistics estimates there were 110.2 million emergency department (ED) visits throughout the United States in 2004 and has documented a steady increase in the number of ED visits over the past decade.[1] Secondary data from ED visit records are timely, comprehensive, population-based, and electronically available through hospital information systems. These data are increasingly in demand for use in biosurveillance and other public health surveillance efforts.

In North Carolina, 111 hospital-based EDs provide unscheduled acute patient care on a 24 hours a day, 7 days a week (24/7) basis. The North Carolina Emergency Department Database (NCEDD) project began in 1999 as a voluntary pilot project to demonstrate the ability to collect and standardize ED visit data from disparate hospital electronic information systems. In 2004 the North Carolina Division of Public Health partnered with the North Carolina Hospital Association and the University of North Carolina at Chapel Hill School of Medicine to create the North Carolina Hospital Emergency Surveillance System (NCHESS) and the provision of ED data for public health surveillance became mandatory.

As of July 1, 2007 93% (103 of 111) of hospital-based, 24/7 acute care EDs in North Carolina are providing visit data electronically at least once a day through NCHESS to be used by the North Carolina Disease Event Tracking and Epidemiologic Collection Tool (NC DETECT). (See Map 1.) NC DETECT is the web-based early

Map 1.
Hospital Emergency Departments Reporting to NC DETECT by General Bed Capacity As of July 1, 2007 (103 hospitals reporting)



State Center for Health Statistics

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event detection and timely public health surveillance system in the North Carolina Public Health Information Network (See http://www.ncdetect.org.). The ED data in NC DETECT include all visits to North Carolina EDs: patients who were admitted to the hospital, transferred to another facility, discharged home or into law enforcement custody, or who left without being seen or against medical advice. NC DETECT uses the algorithms from the Early Aberration Reporting System (EARS) of the Centers for Disease Control and Prevention (CDC) to monitor several data sources for suspicious patterns. The reporting system also provides broader public health surveillance reports for emergency department visits related to hurricanes, injuries, asthma, vaccine-preventable diseases, occupational health, chronic diseases, and other topics.

For the purposes of biosurveillance, ED visits in North Carolina are grouped into syndromes based on analyses of the chief complaint, initial ED temperature, and history of the present illness (when available). The syndromes are based on the CDC's Syndrome Definitions for Diseases Associated with Critical Bioterrorism-associated Agents.[2]

NC DETECT serves more than 200 hospital-based and public health users at the local, regional, and state levels. All users must be approved by the North Carolina Division of Public Health before access to the system is granted. Depending on the assigned user role and data source, users have access to secure, web-based county and/or hospital views of the data and can access a variety of tabular and graphical reports. On several reports, users can specify the date ranges and can display the results by ICD-9-CM final diagnosis codes. Reports with dynamic mapping capabilities as well as an ad hoc query tool are under development.

As ED participation in NC DETECT approaches 100%, these data provide population-based analysis opportunities. The NC DETECT database will add approximately 3.5 million new ED visits each year when all hospital EDs are participating. Table 1 presents the distribution of primary diagnoses for the almost 3 million North Carolina

Table 1.
Number and Percent Distribution of Emergency Department Visits, by Major Disease Category (Primary Diagnosis Only): North Carolina, 2006

Major disease category*	ICD-9-CM code range	Number of visits	Percent distribution
All visits		2 977 543	100.0
Infectious and parasitic diseases	001-139	77 549	2.6
Neoplasms	140-239	10 563	0.4
Endocrine, nutritional and metabolic diseases, and immunity disorders	240-279	78 397	2.6
Mental disorders	290-319	112 427	3.8
Diseases of the nervous system and sense organs	320-389	122 958	4.1
Diseases of the circulatory system	390-459	124 264	4.2
Diseases of the respiratory system	460-519	249 851	8.4
Diseases of the digestive system	520-579	156 799	5.3
Diseases of the genitourinary system	580-629	124 667	4.2
Diseases of the skin and subcutaneous tissue	680-709	81 685	2.7
Diseases of the musculoskeletal system and connective tissue	710-739	201 680	6.8
Symptoms, signs and ill-defined conditions	780-799	595 237	20.0
Injury and poisoning	800-999	511 647	17.2
Supplementary classification	V01-V82	80 073	2.7
All other diagnoses	280-289 630-677 740-779	62 793	2.1
Unknown/Missing**		386 953	13.0

* Based on the *International Classification of Diseases, 9th Revision, Clinical Modification* (ICD-9-CM).
** Includes invalid codes and blank diagnoses.

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ED visits reported for 2006. One in 5 ED visits received a primary diagnosis related to nonspecific symptoms and conditions (eg, fever, syncope, headache, chest pain) and a similar proportion have a primary diagnosis related to injury or poisoning. Many ED visits (13%) are submitted with missing or unknown primary diagnoses, including visits assigned invalid diagnosis codes.

A distinctive feature of the ED data in NC DETECT is their timeliness. Because the data are submitted and updated twice a day, they are particularly useful for surveillance and situational awareness in rapidly developing outbreaks or disasters. However, not all data elements are immediately available. Thus, early analyses of the data rely on the patient's presenting information, including demographics, chief complaint or reason for visit, history of the present illness, and initial vital signs, whereas analyses that require final diagnosis codes may need to wait 3 to 6 months to ensure acceptable levels of completeness.

NC DETECT allows public health epidemiologists and infection control specialists to significantly increase the speed of detecting, monitoring, and investigating public health events statewide. State and hospital-based epidemiologists monitor the biosurveillance syndromes daily to identify suspicious signals. Epidemiologists systematically review visit-specific information for detailed signal analysis and can also view syndromes and signals stratified by age groups. If an outbreak is suspected, additional investigation measures and appropriate notification can be quickly applied. In addition, rapid initiation of surveillance for new conditions and situations (eg, chemical explosion, peanut butter contamination) can be established by NC DETECT using keyword-based analyses of ED chief complaint and triage notes. These custom reports can be developed and disseminated in less than 2 hours.

All 111 North Carolina EDs are expected to be providing data to NC DETECT by the end of 2007. Efforts are underway to present reports of counts, percents, and population-based rates through the web-based reporting system. Additional users of the data are welcomed, based on application and authorization through the website and the North Carolina Division of Public Health. For further information, contact the authors at ncdetect@listserv.med.unc.edu or visit http://www.ncdetect.org.

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Contributed by Anna E. Waller, ScD, and Amy I. Ising, MSIS, University of North Carolina, School of Medicine, Department of Emergency Medicine and Lana Deyneka, MD, MPH, NC Department of Health and Human Services, Division of Public Health, General Communicable Disease Control Branch

Scotland Memorial Hospital Emergency Center Improvements

In 2004 when Scotland Health Care System approved a project that would renovate and expand the Emergency Center at Scotland Memorial Hospital, it was decided the hospital would not borrow money for the project, but that funding would come from hospital reserves and fundraising—including grants. The health system approached The Duke Endowment with their plans and were awarded two grants of $200 000 each to support the development of Scotland Memorial Hospital's vision for its emergency facility and the services it provides.

Scotland Memorial Hospital is a 104 acute care bed, not-for-profit, community-owned hospital in Laurinburg, North Carolina. Located in the Sandhills region of the state, the hospital serves the health care needs of citizens of Scotland, Robeson, Hoke and Richmond counties in North Carolina and Marlboro County, South Carolina. Built in 1983, Scotland Memorial Hospital's Emergency Center (EC) was a state-of-the-art facility at the time of the hospital's construction. With 6400 square feet, the EC was designed to accommodate 10 000 patients annually. With the exception of a small addition in 1986, the EC underwent no major changes or expansions in the next two decades, while the annual number of patients treated rose to approximately 23 000. This significant increase in patient visits overwhelmed available space and forced patients, equipment, and care into every corner of the EC.

Many patients presenting to the EC are sicker than in years past, requiring more time-consuming assessments and testing. In fact, nearly 20% of Scotland Memorial's EC patients require hospital admission in order to treat their illnesses. Over 60% of all inpatients are admitted through the EC. These numbers indicate that the EC has become the hospital's "front door." Compounding the problems caused by lack of EC space was that inpatient hospital beds were often full. The patients who need to be admitted from the EC had nowhere to go, thus exacerbating the Center's capacity limitations for patients requiring treatment.

To address the growing need, Scotland Health Care System approved a multifaceted project that included renovating and expanding the Emergency Center. The first grant from The Duke Endowment provided capital funding for the structural expansion of the EC. The EC increased from 6400 square feet to over 24 000 square feet along with growing from 14 curtained bays to 20 private rooms. Additionally, the new EC includes:

- A "fast track center" for nonurgent patients to receive care.
- A second triage and evaluation room to permit patients to be assessed more quickly.
- Two separate trauma rooms, offering greater privacy for patients and their families.
- An expanded waiting room.
- A separate pediatrics waiting area to protect children from the potentially traumatic experience of an EC waiting area.
- A modernized and expanded nurse's station that increases the visibility to patient rooms and houses computers and modern communication equipment.
- A quiet, private space for families coping with life-threatening illness, injury, or death of a loved one.

A second grant from The Duke Endowment helped fund the cost of hardware, software, and employee and physician training required for implementation of a new Emergency Center Patient Tracking and Information System that will go online August 14, 2007. This comprehensive system will result in increased patient safety and quality of care, improved provider efficiencies, and decreased patient waiting times. Benefits of a tracking and information system include:

- Identifying a patient's physical location and the status of his or her examination and diagnosis with the touch of a computer screen.
- Eliminating breakdowns in communication and long wait-times in the multi-step process of physician examination, order writing, and order completion.
- Reducing errors from illegible handwriting through touch screen technology.
- Diminishing misdirected lab requests and misplaced lab results.
- Monitoring and advising patients from outside of the EC through off-site access to patient records.

The expansion and renovation of the EC, along with the requisite changes, and the renovation of acute care bed space was a major project for Scotland Memorial Hospital. Through this initiative the citizens of the Scotland area receive quality, compassionate emergency care 24 hours each day, 7 days a week, in a facility that offers them privacy and security while accommodating the equipment and staff needed to serve them. The multifaceted project has had a significant impact on the health and economic well-being of Scotland Memorial Hospital and the community.

Karen Gainey, marketing coordinator, and Becca Hughes, foundation director, of Scotland Health Care System contributed to this profile.

ACIPHEX® \a-sə-ˌfeks\
(rabeprazole sodium)
Delayed-Release Tablets

BRIEF SUMMARY

Before prescribing ACIPHEX®, please see full prescribing information.

INDICATIONS AND USAGE

Healing of Erosive or Ulcerative Gastroesophageal Reflux Disease (GERD)

ACIPHEX® is indicated for short-term (4 to 8 weeks) treatment in the healing and symptomatic relief of erosive or ulcerative gastroesophageal reflux disease (GERD). For those patients who have not healed after 8 weeks of treatment, an additional 8-week course of ACIPHEX® may be considered.

Maintenance of Healing of Erosive or Ulcerative Gastroesophageal Reflux Disease (GERD)

ACIPHEX® is indicated for maintaining healing and reduction in relapse rates of heartburn symptoms in patients with erosive or ulcerative gastroesophageal reflux disease (GERD Maintenance). Controlled studies do not extend beyond 12 months.

Treatment of Symptomatic Gastroesophageal Reflux Disease (GERD)

ACIPHEX® is indicated for the treatment of daytime and nighttime heartburn and other symptoms associated with GERD.

Healing of Duodenal Ulcers

ACIPHEX® is indicated for short-term (up to four weeks) treatment in the healing and symptomatic relief of duodenal ulcers. Most patients heal within four weeks.

Helicobacter pylori Eradication to Reduce the Risk of Duodenal Ulcer Recurrence

ACIPHEX® in combination with amoxicillin and clarithromycin as a three drug regimen, is indicated for the treatment of patients with *H. pylori* infection and duodenal ulcer disease (active or history within the past 5 years) to eradicate *H. pylori*. Eradication of *H. pylori* has been shown to reduce the risk of duodenal ulcer recurrence. (See **CLINICAL STUDIES** and **DOSAGE AND ADMINISTRATION** in full prescribing information.)

In patients who fail therapy, susceptibility testing should be done. If resistance to clarithromycin is demonstrated or susceptibility testing is not possible, alternative antimicrobial therapy should be instituted. (See **CLINICAL PHARMACOLOGY, Microbiology** in full prescribing information and the clarithromycin package insert, **CLINICAL PHARMACOLOGY, Microbiology**.)

Treatment of Pathological Hypersecretory Conditions, Including Zollinger-Ellison Syndrome

ACIPHEX® is indicated for the long-term treatment of pathological hypersecretory conditions, including Zollinger-Ellison syndrome.

CONTRAINDICATIONS

Rabeprazole is contraindicated in patients with known hypersensitivity to rabeprazole, substituted benzimidazoles or to any component of the formulation.

Clarithromycin is contraindicated in patients with known hypersensitivity to any macrolide antibiotic.

Concomitant administration of clarithromycin with pimozide and cisapride is contraindicated. There have been post-marketing reports of drug interactions when clarithromycin and/or erythromycin are co-administered with pimozide resulting in cardiac arrhythmias (QT prolongation, ventricular tachycardia, ventricular fibrillation, and torsade de pointes) most likely due to inhibition of hepatic metabolism of pimozide by erythromycin and clarithromycin. Fatalities have been reported. (Please refer to full prescribing information for clarithromycin.)

Amoxicillin is contraindicated in patients with a known hypersensitivity to any penicillin. (Please refer to full prescribing information for amoxicillin.)

WARNINGS

CLARITHROMYCIN SHOULD NOT BE USED IN PREGNANT WOMEN EXCEPT IN CLINICAL CIRCUMSTANCES WHERE NO ALTERNATIVE THERAPY IS APPROPRIATE. If pregnancy occurs while taking clarithromycin, the patient should be apprised of the potential hazard to the fetus. (See **WARNINGS** in prescribing information for clarithromycin.)

Amoxicillin: Serious and occasionally fatal hypersensitivity (anaphylactic) reactions have been reported in patients on penicillin therapy. These reactions are more likely to occur in individuals with a history of penicillin hypersensitivity and/or a history of sensitivity to multiple allergens.

There have been well-documented reports of individuals with a history of penicillin hypersensitivity reactions who have experienced severe hypersensitivity reactions when treated with a cephalosporin. Before initiating therapy with any penicillin, careful inquiry should be made concerning previous hypersensitivity reactions to penicillin, cephalosporin, and other allergens. If an allergic reaction occurs, amoxicillin should be discontinued and the appropriate therapy instituted. (See **WARNINGS** in prescribing information for amoxicillin.)

SERIOUS ANAPHYLACTIC REACTIONS REQUIRE IMMEDIATE EMERGENCY TREATMENT WITH EPINEPHRINE. OXYGEN, INTRAVENOUS STEROIDS, AND AIRWAY MANAGEMENT, INCLUDING INTUBATION, SHOULD ALSO BE ADMINISTERED AS INDICATED.

Pseudomembranous colitis has been reported with nearly all antibacterial agents, including clarithromycin and amoxicillin, and may range in severity from mild to life threatening. Therefore, it is important to consider this diagnosis in patients who present with diarrhea subsequent to the administration of antibacterial agents.

Treatment with antibacterial agents alters the normal flora of the colon and may permit overgrowth of clostridia. Studies indicate that a toxin produced by *Clostridium difficile* is a primary cause of "antibiotic-associated colitis".

After the diagnosis of pseudomembranous colitis has been established, therapeutic measures should be initiated. Mild cases of pseudomembranous colitis usually respond to discontinuation of the drug alone. In moderate to severe cases, consideration should be given to management with fluid and electrolytes, protein supplementation, and treatment with an antibacterial drug clinically effective against *Clostridium difficile colitis.*

PRECAUTIONS

General

Symptomatic response to therapy with rabeprazole does not preclude the presence of gastric malignancy.

Patients with healed GERD were treated for up to 40 months with rabeprazole and monitored with serial gastric biopsies. Patients without *H. pylori* infection (221 of 326 patients) had no clinically important pathologic changes in the gastric mucosa. Patients with *H. pylori* infection at baseline (105 of 326 patients) had mild or moderate inflammation in the gastric body or mild inflammation in the gastric antrum. Patients with mild grades of infection or inflammation in the gastric body tended to change to moderate, whereas those graded moderate at baseline tended to remain stable. Patients with mild grades of infection or inflammation in the gastric antrum tended to remain stable. At baseline 8% of patients had atrophy of glands in the gastric body and 15% had atrophy in the gastric antrum. At endpoint, 15% of patients had atrophy of glands in the gastric body and 11% had atrophy in the gastric antrum. Approximately 4% of patients had intestinal metaplasia at some point during follow-up, but no consistent changes were seen.

Steady state interactions of rabeprazole and warfarin have not been adequately evaluated in patients. There have been reports of increased INR and prothrombin time in patients receiving a proton pump inhibitor and warfarin concomitantly. Increases in INR and prothrombin time may lead to abnormal bleeding and even death. Patients treated with a proton pump inhibitor and warfarin concomitantly may need to be monitored for increases in INR and prothrombin time.

Information for Patients

Patients should be cautioned that ACIPHEX® delayed-release tablets should be swallowed whole. The tablets should not be chewed, crushed, or split. ACIPHEX® can be taken with or without food.

Drug Interactions

Rabeprazole is metabolized by the cytochrome P450 (CYP450) drug metabolizing enzyme system. Studies in healthy subjects have shown that rabeprazole does not have clinically significant interactions with other drugs metabolized by the CYP450 system, such as warfarin and theophylline given as single oral doses, diazepam as a single intravenous dose, and phenytoin given as a single intravenous dose (with supplemental oral dosing). Steady state interactions of rabeprazole and other drugs metabolized by this enzyme system have not been studied in patients. There have been reports of increased INR and prothrombin time in patients receiving proton pump inhibitors, including rabeprazole, and warfarin concomitantly. Increases in INR and prothrombin time may lead to abnormal bleeding and even death.

In vitro incubations employing human liver microsomes indicated that rabeprazole inhibited cyclosporine metabolism with an IC_{50} of 62 micromolar, a concentration that is over 50 times higher than the C_{max} in healthy volunteers following 14 days of dosing with 20 mg of rabeprazole. This degree of inhibition is similar to that by omeprazole at equivalent concentrations.

Rabeprazole produces sustained inhibition of gastric acid secretion. An interaction with compounds which are dependent on gastric pH for absorption may occur due to the magnitude of acid suppression observed with rabeprazole. For example, in normal subjects, co-administration of rabeprazole 20 mg QD resulted in an approximately 30% decrease in the bioavailability of ketoconazole and increases in the AUC and C_{max} for digoxin of 19% and 29%, respectively. Therefore, patients may need to be monitored when such drugs are taken concomitantly with rabeprazole. Co-administration of rabeprazole and antacids produced no clinically relevant changes in plasma rabeprazole concentrations.

In a clinical study in Japan evaluating rabeprazole in patients categorized by CYP2C19 genotype (n=6 per genotype category), gastric acid suppression was higher in poor metabolizers as compared to extensive metabolizers. This could be due to higher rabeprazole plasma levels in poor metabolizers. Whether or not interactions of rabeprazole sodium with other drugs metabolized by CYP2C19 would be different between extensive metabolizers and poor metabolizers has not been studied.

Combined Administration with Clarithromycin

Combined administration consisting of rabeprazole, amoxicillin, and clarithromycin resulted in increases in plasma concentrations of rabeprazole and 14-hydroxyclarithromycin. (See **CLINICAL PHARMACOLOGY, Combination Therapy with Antimicrobials** in full prescribing information.)

Concomitant administration of clarithromycin with pimozide and cisapride is contraindicated. (See **PRECAUTIONS** in prescribing information for clarithromycin.) (See **PRECAUTIONS** in prescribing information for amoxicillin.)

Carcinogenesis, Mutagenesis, Impairment of Fertility

In a 88/104-week carcinogenicity study in CD-1 mice, rabeprazole at oral doses up to 100 mg/kg/day did not produce any increased tumor occurrence. The highest tested dose produced a systemic exposure to rabeprazole (AUC) of 1.40 µg•hr/mL which is 1.6 times the human exposure (plasma $AUC_{0\text{-}\infty}$ = 0.88 µg•hr/mL) at the recommended dose for GERD (20 mg/day). In a 104-week carcinogenicity study in Sprague-Dawley rats, males were treated with oral doses of 5, 15, 30 and 60 mg/kg/day and females with 5, 15, 30, 60 and 120 mg/kg/day. Rabeprazole produced gastric enterochromaffin-like (ECL) cell hyperplasia in male and female rats and ECL cell carcinoid tumors in female rats at all doses including the lowest tested dose. The lowest dose (5 mg/kg/day) produced a systemic exposure to rabeprazole (AUC) of about 0.1 µg•hr/mL which is about 0.1 times the human exposure at the recommended dose for GERD. In male rats, no treatment related tumors were observed at doses up to 60 mg/kg/day producing a rabeprazole plasma exposure (AUC) of about 0.2 µg•hr/mL (0.2 times the human exposure at the recommended dose for GERD).

Rabeprazole was positive in the Ames test, the Chinese hamster ovary cell (CHO/HGPRT) forward gene mutation test and the mouse lymphoma cell (L5178Y/TK+/–) forward gene mutation test. Its demethylated-metabolite was also positive in the Ames test. Rabeprazole was negative in the *in vitro* Chinese hamster lung cell chromosome aberration test, the *in vivo* mouse micronucleus test, and the *in vivo* and *ex vivo* rat hepatocyte unscheduled DNA synthesis (UDS) tests.

Rabeprazole at intravenous doses up to 30 mg/kg/day (plasma AUC of 8.8 µg•hr/mL, about 10 times the human exposure at the recommended dose for GERD) was found to have no effect on fertility and reproductive performance of male and female rats.

Pregnancy

Teratogenic Effects. Pregnancy Category B: Teratology studies have been performed in rats at intravenous doses up to 50 mg/kg/day (plasma AUC of 11.8 µg•hr/mL, about 13 times the human exposure at the recommended dose for GERD) and rabbits at intravenous doses up to 30 mg/kg/day (plasma AUC of 7.3 µg•hr/mL, about 8 times the human exposure at the recommended dose for GERD) and have revealed no evidence of impaired fertility or harm to the fetus due to rabeprazole. There are, however, no adequate and well-controlled studies in pregnant women. Because animal reproduction studies are not always predictive of human response, this drug should be used during pregnancy only if clearly needed.

Nursing Mothers

Following intravenous administration of ^{14}C-labeled rabeprazole to lactating rats, radioactivity in milk reached levels that were 2- to 7-fold higher than levels in the blood. It is not known if unmetabolized rabeprazole is excreted in human breast milk. Administration of rabeprazole to rats in late gestation and during lactation at doses of 400 mg/kg/day (about 195-times the human dose based on mg/m^2) resulted in decreases in body weight gain of the pups. Since many drugs are excreted in milk, and because of the potential for adverse reactions to nursing infants from rabeprazole, a decision should be made to discontinue nursing or discontinue the drug, taking into account the importance of the drug to the mother.

Pediatric Use

The safety and effectiveness of rabeprazole in pediatric patients have not been established.

Use in Women

Duodenal ulcer and erosive esophagitis healing rates in women are similar to those in men. Adverse events and laboratory test abnormalities in women occurred at rates similar to those in men.

Geriatric Use

Of the total number of subjects in clinical studies of ACIPHEX®, 19% were 65 years and over, while 4% were 75 years and over. No overall differences in safety or effectiveness were observed between these subjects and younger subjects, and other reported clinical experience has not identified differences in responses between the elderly and younger patients, but greater sensitivity of some older individuals cannot be ruled out.

ADVERSE REACTIONS

Worldwide, over 2900 patients have been treated with rabeprazole in Phase II-III clinical trials involving various dosages and durations of treatment. In general, rabeprazole treatment has been well-tolerated in both short-term and long-term trials. The adverse events rates were generally similar between the 10 and 20 mg doses.

Incidence in Controlled North American and European Clinical Trials

In an analysis of adverse events assessed as possibly or probably related to treatment appearing in greater than 1% of ACIPHEX® patients and appearing with greater frequency than placebo in controlled North American and European trials, the incidence of headache was 2.4% (n=1552) for ACIPHEX® versus 1.6% (n=258) for placebo.

In short and long-term studies, the following adverse events, regardless of causality, were reported in ACIPHEX®-treated patients. Rare events are those reported in ≤1/1000 patients.

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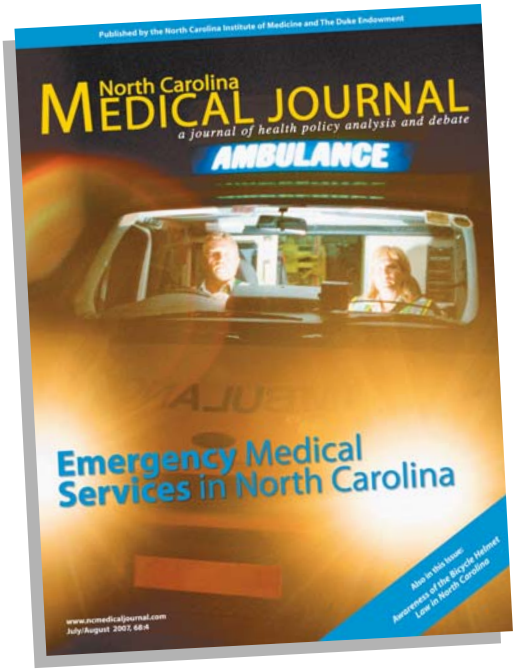

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Dr. David Kong (far left) and Dr. Sydney G. Short (far right) with Cath Lab staff
Dr. Michael G. Kidd (third from left) and Dr. Eric W. Miller (fourth from left) with Anesthesiology staff

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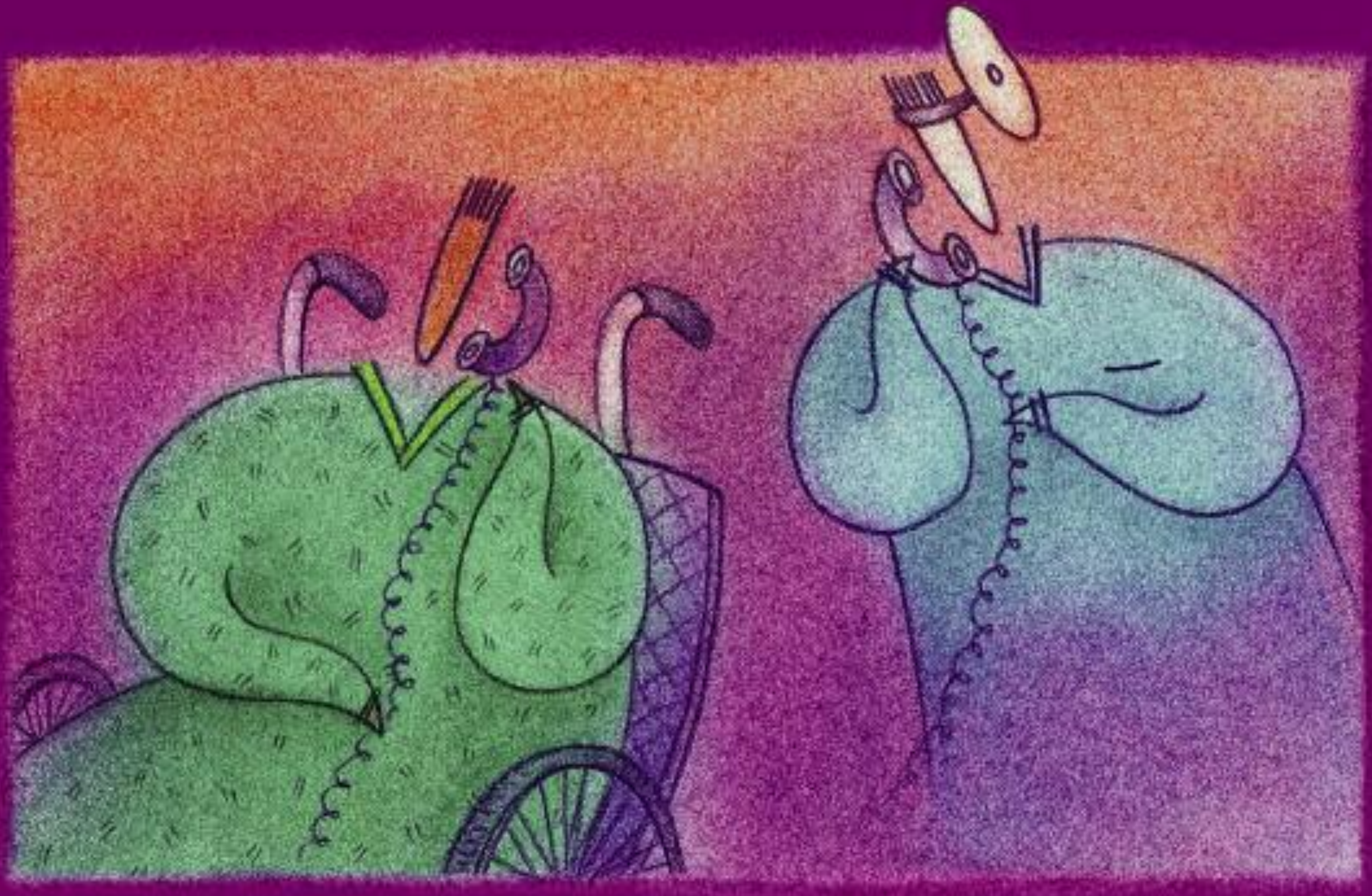

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Publishers of the *North Carolina Medical Journal*

The North Carolina Institute of Medicine

In 1983 the North Carolina General Assembly chartered the North Carolina Institute of Medicine as an independent, nonprofit organization to serve as a nonpolitical source of analysis and advice on issues of relevance to the health of North Carolina's population. The Institute is a convenor of persons and organizations with health-relevant expertise, a provider of carefully conducted studies of complex and often controversial health and health care issues, and a source of advice regarding available options for problem solution. The principal mode of addressing such issues is through the convening of task forces consisting of some of the state's leading professionals, policy makers, and interest group representatives to undertake detailed analyses of the various dimensions of such issues and to identify a range of possible options for addressing them.

health policy
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The Duke Endowment

The Duke Endowment, headquartered in Charlotte, NC, is one of the nation's largest private foundations. Established in 1924 by industrialist James B. Duke, its mission is to serve the people of North Carolina and South Carolina by supporting programs of higher education, health care, children's welfare and spiritual life. The Endowment's health care grants provide assistance to not-for-profit hospitals and other related health care organizations in the Carolinas. Major focus areas include improving access to health care for all individuals, improving the quality and safety of the delivery of health care, and expanding preventative and early intervention programs. Since its inception, the Endowment has awarded $2.2 billion to organizations in North Carolina and South Carolina, including more than $750 million in the area of health care.

The Duke Endowment

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Effective Patient-Practitioner Communication

COMMENTARIES

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Tarheel Footprints in Health Care

Recognizing unusual and often unsung contributions of individual citizens who have made health care for North Carolinians more accessible and of higher quality

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Paula Nobles, RN, BSN
Pediatric Case Manager, Washington Pediatrics – AccessCare

AccessCare is a network of primary care physicians committed to providing the highest quality medical care for North Carolina's Medicaid population. AccessCare is the largest of 14 local networks of primary care providers that contract with the North Carolina Department of Health and Human Services to develop disease management and case management initiatives and coordinate prevention, treatment, and other services. This system of networks, coordinated by Community Care of North Carolina, enhances the Carolina ACCESS Medicaid program by developing physician-led community partnerships to improve care and reduce costs by connecting Medicaid enrollees with a medical home.

Within AccessCare, patient educators and case managers play a special role in helping patients understand their conditions and options along with managing their often complicated diseases. Paula Nobles, RN, BSN, is definitely an invisible hero in the world of case management for the enrollees of Beaufort County. A 1997 Magna Cum Laude graduate of the East Carolina University School of Nursing, Ms Nobles formerly worked as a staff nurse in obstetrics, pediatrics, and the newborn nurseries at Beaufort County Hospital and Pitt County Memorial Hospital. She joined AccessCare in June 2004 as a pediatric case manager with Washington Pediatrics. Her supervisors say that Ms Nobles has used her solid nursing education to cohesively mesh the worlds of hospital nursing and community case management.

Ms Nobles' current areas of specialty include asthma and pediatric obesity. She coordinates the monthly asthma and weight reduction clinics and has received further training in childhood hearing, chronic obstructive pulmonary disease, and smoking cessation. She is a referral resource for the provider staff of Washington Pediatrics, Beaufort County Health Department, Beaufort County Department of Social Services, and Children's Developmental Services Agencies. In addition she assists school nurses and other community health care providers and always graciously accepts assignments to orient new staff at AccessCare as well as staff from other North Carolina Medicaid networks. Ms Nobles also has volunteered to assist staff in other counties assess high-risk patients that may be in need of case management services.

Ms Nobles, who once described herself as being quiet and meticulously organized, has quietly yet dramatically evolved into one of the best community case manager leaders in her county. A typical work week for Ms Nobles may consist of conducting patient-practitioner education, coordinating and directing the Asthma and Weight Reduction Clinics, planning and implementing patient care plans for various disease processes, electronically documenting all case management duties in the NC Medicaid Case Management Information System, attending local and statewide meetings, and effectively serving the providers and case managing the enrollees of Washington Pediatrics. Her work helps to improve quality of care while implementing cost savings. At the 2005 North Carolina Pediatric Society meeting, one eastern North Carolina pediatrician was quoted saying, "I heard about the case manager at Washington Pediatrics, and I want a case manager in our office that mirrors exactly what Dr Ainsworth's case manager does for their office. I hear she is excellent!"

In addition to serving as an advocate for the Carolina ACCESS enrollees of Beaufort County, Ms Nobles is involved in other health-related community activities. She serves as a preceptor for ECU School of Nursing bachelor of science in nursing students, provides asthma education to students at Beaufort Community College, and has written articles on pediatric obesity for the *Washington Daily News*. She serves on the Beaufort County Task Force on sudden infant death syndrome and codirects the Weight Reduction Summer Camp in Beaufort County with pediatrician Dr Debbie Ainsworth.

For her efforts and accomplishments in case management and support services for the pediatric Access patients in Beaufort County, the editors of the *North Carolina Medical Journal* are pleased to recognize Paula Nobles, RN, BSN, and all case managers and patient educators across the state for their contribution to the health and well-being of all North Carolinians.

ARTICLE

Knowledge and Practice of Foodborne Disease Clinical Specimen Testing and Reporting in North Carolina, 2004

Pia D. M. MacDonald, PhD, MPH; Michelle R. Torok, PhD, MPH; Jean-Marie Maillard, MD, MSc; Martha Salyers, MD, MPH; Leslie A. Wolf, PhD; Amy L. Nelson, PhD, MPH

Abstract

Background: *Detection of foodborne disease outbreaks relies on health care practitioners (HCPs), infection control practitioners (ICPs), and clinical laboratorians to report notifiable diseases to state or local health departments.*

Methods: *To examine knowledge and practices about notifiable foodborne disease reporting among HCPs and ICPs in western North Carolina and among clinical laboratorians statewide, participants responded to a self-administered questionnaire about foodborne pathogen testing and reporting, referencing* Campylobacter, *shiga-toxin producing* Escherichia coli, *and other organisms.*

Results: *Three hundred seventy-two of 1442 health care providers participated in this survey. Of 372 study participants, fewer than 20% knew that both the clinician and the laboratorian were legally responsible for reporting the study pathogens. Most laboratorians identified the ICP (57%) as responsible for reporting. There was a lack of understanding about which infections and test results were reportable.*

Limitations: *The response rate was very low, particularly among HCPs; participants may have been biased towards those with a particular interest in foodborne disease or surveillance. This descriptive study cannot be used to determine rates of reporting among the medical community.*

Conclusions: *Although not legally obliged to report, ICPs were found to play a significant role in disease reporting. Dissemination of surveillance information and training through the established network of North Carolina ICPs may be ideal for improving foodborne disease surveillance in this state.*

Key words: *Foodborne disease, surveillance, reporting*

Foodborne pathogens are responsible for an estimated 76 million illnesses, 325 000 hospitalizations, and 5200 deaths annually in the United States.[1] Reporting of foodborne disease by physicians and laboratories (passive surveillance) is the backbone of outbreak detection; local health departments also identify outbreaks by those affected in the community. Passive surveillance in the US has been shown to be inadequate for many foodborne diseases when compared to other sources of data.[2-8]

Additionally, the US food supply has been targeted in at least two successful deliberate releases of biological agents.[9,10] Enhancement of disease surveillance, laboratory identification, and outbreak detection and control are needed to prepare for bioterrorist acts involving the food supply.[11] Therefore, the foodborne disease reporting system in North Carolina should be described and evaluated in order to identify areas to improve foodborne disease reporting and better protect North Carolina citizens.

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In North Carolina all clinical laboratory facilities and physicians are required by state law to report certain diseases/organisms to the state or the local health department. While not legally mandated to report communicable diseases, infection control practitioners (ICPs) also may play an important role in the passive surveillance system. Clinical surveillance for foodborne illness in North Carolina is conducted through clinician reports to the local health department via a mail-in card reporting system, which should be preceded by a phone report for diseases reportable within 24 hours. Most laboratory-based diagnoses are reported at the state level to the General Communicable Disease Control Branch of the Epidemiology Section via mail, phone, fax, or Internet. Foodborne diseases that are currently notifiable in North Carolina include *Campylobacter*, *Escherichia coli (E. coli)* O157:H7 (Shiga-toxin producing *E coli*, STEC), foodborne *Clostridium perfringens*, *Listeria monocytogenes*, *Staphylococcus aureus*, *Salmonella*, *Shigella*, *Vibrio vulnificus*, *Vibrio* other, and the category "foodborne other or unknown."[12]

The NC State Laboratory of Public Health accepts clinical specimens for the isolation of enteric microorganisms from public health care providers. Fecal specimens are examined for the presence of enteric pathogens including *Salmonella* serotypes, *Shigella*, *Campylobacter*, *Yersinia*, and *E. coli* 0157:H7. Reference isolates are accepted from public and private health care providers for identification and/or serotyping. The State Laboratory of Public Health also participates in the Centers for Disease Control and Prevention PulseNet System,[13] which permits detection of foodborne outbreaks within a state or widespread and diffuse outbreaks across states or countries.[14]

Although passive surveillance systems are relatively incomplete,[2] consistent disease reporting is thought to provide enough information to discern important occurrences of excess disease. However, it is important to ensure that these passive components of the notifiable disease reporting system are operating efficiently to detect outbreaks, bioterrorist incidents, and emerging infectious diseases. In this study, we describe the knowledge and practices of foodborne disease reporting and screening as well as diagnostic testing among North Carolina health care practitioners (HCPs), ICPs, and laboratorians.

METHODS

Survey of Health Care and Infection Control Practitioners in Western North Carolina

Health care practitioners and ICPs were surveyed in 2004. Contact information for HCPs in western North Carolina came from a database compiled by the Cecil G. Sheps Center for Health Services Research at the University of North Carolina at Chapel Hill (UNC-Chapel Hill) and maintained by the NC Medical Board. All medical and osteopathic doctors (excluding residents), physician assistants, and nurse practitioners whose professional status was "active" were included. Health care practitioners with at least 8 hours per week of direct patient care and a business address in 1 of the 19 counties in western North Carolina were included in the study. A list of ICPs in hospitals located in western North Carolina was obtained from the Statewide Program for Infection Control and Epidemiology at UNC-Chapel Hill. Surveys, an introductory letter, and an Institutional Review Board fact sheet were mailed to HCPs and ICPs in western North Carolina. Nonresponding individuals were mailed another survey package 4 weeks after the original mailing. Nonresponders to the second mailing were sent an identical mailing 8 weeks after the original, for a total of 3 mailings. Health care practitioners included in the analysis practiced in internal medicine, pediatrics, family practice, general practice, obstetrics/gynecology, and emergency department specialties.

Survey of Laboratories in North Carolina

Laboratories statewide were contacted in 2004 through NC Micronet, a database designed for rapid dissemination of emergency information to clinical microbiologists in North Carolina. Laboratories were included in the study if they had fecal specimens submitted for bacterial screening in 2003. The survey was posted on a secure server/Web site at the State Laboratory of Public Health, and the contact person on the NC Micronet list at each laboratory was e-mailed survey information, an introductory letter, and an Institutional Review Board fact sheet and was asked to participate. Contacts who did not complete the survey within 2 weeks received a reminder e-mail, and contacts who did not complete the survey within 4 weeks of the initial e-mail were contacted by telephone. Because laboratory surveys were sent electronically, the resources existed to survey laboratories statewide.

Survey Content and Data Analysis

This survey was modeled closely after the Centers for Disease Control and Prevention's FoodNet surveys.[15] All study participants were asked questions about the diagnostic testing and reporting requirements of *Campylobacter*, Shiga-toxin producing *E coli*, *Salmonella*, *Shigella*, and infection with *Vibrio* species. Some questions also included *L monocytogenes* and *Yersinia* infection.

The major domains of the survey included practice information (specialty, setting, location); foodborne disease experience (number of patients seen with acute diarrheal illness in past 30 days, clinical history of last patient seen with acute diarrheal illness, factors relating to requesting/not requesting a stool specimen, location of bacterial stool culture testing); and reporting practices (who in the facility reports positive test results to the local and state health departments). Questions about foodborne illness and prevention patient education, confidence in diagnosing, and treating foodborne illness as well as confidence in the local health department's ability to investigate disease outbreaks also were asked. The survey contained both closed and open-ended questions as well as a 5-point Likert scale.

Data from HCP and ICP surveys were manually entered into a Centers for Disease Control and Prevention EpiInfo database and reviewed for accuracy and completeness. Laboratorian surveys were downloaded into a Microsoft Access database. Data frequencies and proportions were examined.

All participants provided informed consent for the survey.

This study was approved by the University of North Carolina at Chapel Hill's Biomedical Institutional Review Board.

RESULTS

Survey of Health Care and Infection Control Practitioners in Western North Carolina

Surveys were sent to 1442 HCPs in western North Carolina. There were 319 respondents who fit the inclusion criteria; 53 respondents worked less than 8 hours per week and were excluded from the analyses (response rate: 319 of 1389, 23%). Respondents included physicians (228 of 319, 72%), nurse practitioners (55 of 319, 17%), and physician assistants (36 of 319, 11%). Among physicians, 38% were in family practice (87 of 228), 16% were in internal medicine (36 of 228) or a subspecialty (7%, 16 of 228), 13% each were in the emergency department and pediatrics (30 and 29 of 228, respectively), and the remainder were in obstetrics/gynecology (10%) or pediatric subspecialties (3%). Medical specialties for 18 participants were unknown.

Surveys were sent to ICPs at 21 facilities in western North Carolina and 11 responded. Seven of the responding ICPs worked in a hospital while the remaining 3 worked in more than one setting (eg, a hospital and long term care facility).

Diagnostic Testing Knowledge and Practice

The majority of HCPs noted that stool samples were tested at their hospital laboratory (74%, 227 of 306); 21% reported that screens were performed at independent laboratories (65 of 306); and 5% (14 of 306) did not know. Thirteen participants

Table 1.
North Carolina Laboratories and Health Care and Infection Control Practitioners in Western North Carolina Who Report That the Laboratory Screens for These Pathogens

Enteric Bacterial Pathogen	Laboratories No. (%) (N=42)	Health Care Practitioners No. (%) (N=319)	Infection Control Practitioners No. (%) (N=11)
Salmonella			
Yes	39 (100)	270 (90)	11 (100)
No	0	1 (<1)	0
Don't know	…	26 (9)	0
Shigella			
Yes	40 (100)	266 (89)	11 (100)
No	0	1 (<1)	0
Don't know	…	31 (10)	0
Campylobacter			
Yes	34 (87)	239 (81)	7 (78)
No	5 (13)	7 (2)	2 (22)
Don't know	…	48 (16)	0
E coli O157/STEC			
Yes	22 (60)	143 (53)	5 (50)
No	15 (40)	51 (19)	4 (40)
Don't know	…	76 (28)	1 (10)
Vibrio			
Yes	11 (35)	60 (23)	4 (44)
No	20 (65)	66 (25)	4 (44)
Don't know	…	137 (52)	1 (11)
Yersinia			
Yes	16 (43)	4†	…
No	21 (57)		
Don't know	…		
L monocytogenes			
Yes	3 (10)	…	…
No	26 (90)		
Don't know	…		

† Noted as part of an "other" response, percentage not calculable

failed to respond to this question.

In general, HCP respondents identified the same pathogens as part of a routine screen. (See Table 1.) About half thought *E coli* O157:H7 was tested for routinely. Fewer thought *Vibrio* species were included in the routine screen, and many respondents were unsure about *Vibrio* and *E coli* O157:H7. Two individuals noted that *E coli* O157:H7 was screened for in cases with bloody stool. In an open-ended response, 4 individuals said *Yersinia* and 4 said *Giardia* testing were part of the screen.

Most ICPs (10 of 13) noted that stool samples were tested routinely at their hospital laboratory while several (3 of 13) indicated that the samples were tested by independent laboratories. According to most (8 of 9) of the ICPs, hospital laboratories conducted all stool screens, and 1 ICP reported 90% of cultures being conducted there. An additional ICP reported that all routine cultures were performed at a commercial laboratory.

Knowledge of Reporting Requirements

Among HCPs, 45% to 57% incorrectly thought that only clinicians were responsible for reporting, depending on the pathogen (Figure 1), while 13% incorrectly thought that only the laboratorian was responsible for reporting these diseases (range, 12% to 14%). On average, 5% to 7% of HCPs correctly noted that both clinicians and laboratorians were legally responsible for notifying the health department of these pathogens. An additional 21% to 31% did not know who should report the study pathogens. Eight percent of HCPs (24 of 296) incorrectly identified *Campylobacter* as nonreportable, 8% (22 of 289) correctly identified *Yersinia* as nonreportable, and 1% to 3% of HCPs incorrectly identified the remaining diseases as nonreportable.

Among ICPs, almost half (4 of 11) incorrectly thought that only the clinician was responsible for reporting infections with the study pathogens; a few (2 of 11) incorrectly thought that only the laboratorian was responsible for reporting these pathogens; the same proportion (2 of 11) correctly thought that both the clinician and the laboratorian were responsible for reporting; and some (4 of 11) thought some other person was responsible for reporting. *Yersinia* infection was correctly identified as nonreportable by 1 ICP. No ICP identified *Campylobacter*, STEC, *L monocytogenes*, Salmonellosis, Shigellosis, or *Vibrio* as "not reportable."

Reporting Practices

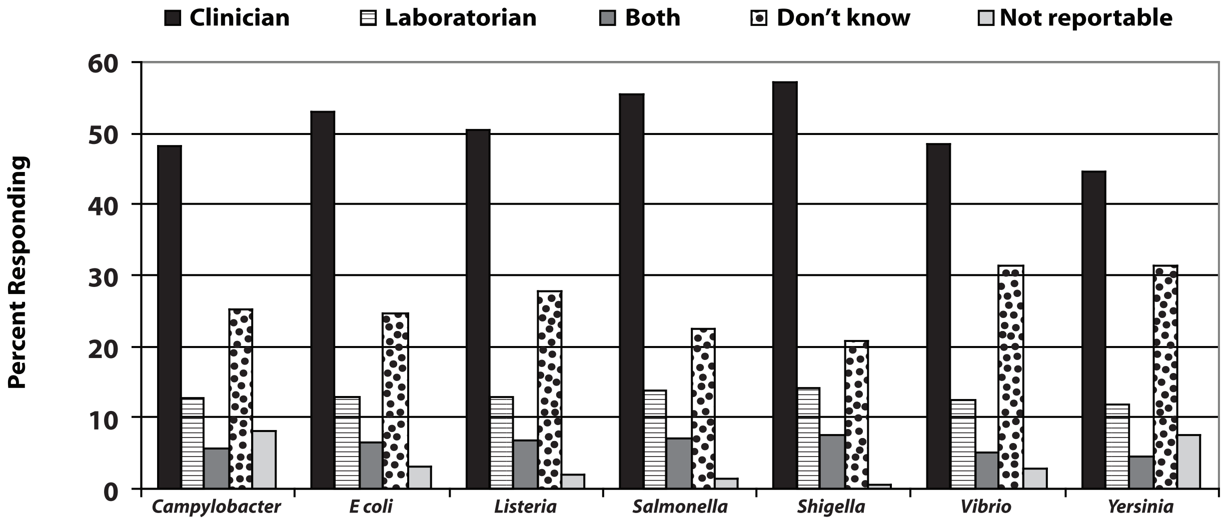
When asked who in the facility completes the state's communicable disease report card, HCPs reported that the physician (38%, 121 of 315), nurse (14%, 45 of 315), nurse practitioner (6%, 19 of 315), physician assistant (3%, 9 of 315), or another provider who saw the patient (3%, 10 of 315) completed the disease report card. However, 15% of respondents (48 of 315) did not know who completed the card in their office. Another 29 HCPs (9%) said that ICPs, the laboratory (8%, 24), or the office manager or other administrative personnel (<2%, 6) completed the card.

Infection control practitioners may report notifiable diseases to the health department, but they are not legally required to do so. Nevertheless, most of the Infection control practitioners (8 of 11) noted they completed the disease report card; 2 reported that the physician and 1 reported that the laboratorian completed the card.

Survey of Laboratories in North Carolina

E-mails giving the Web site for the survey were sent to 108 clinical diagnostic laboratories in North Carolina. Forty-eight laboratories responded and 42 fit laboratory inclusion criteria,

Figure 1.
Percent of Western North Carolina Health Care Practitioners Who Think Clinicians and/or Laboratorians Are Legally Responsible for Reporting *Campylobacter*, *E coli* O157/STEC, *L monocytogenes*, *Salmonella*, *Shigella*, and *Vibrio* Species, and *Yersinia* to the Health Department.



for a response rate of 41% (42 of 102). The participating laboratories were primarily hospital or medical-center based laboratories (39 of 42), but 2 were independent commercial laboratories, and 1 was a military base laboratory.

Diagnostic Testing Knowledge and Practice

We asked laboratorians about pathogens included in their routine enteric screen and most reported including *Salmonella*, *Shigella*, and *Campylobacter*. Fewer included *E coli* O157:H7, *Yersinia*, and *Vibrio*. Routine screening for *L monocytogenes* was rare. (See Table 1.)

When a positive result was determined for a foodborne pathogen, more than half of laboratorians (25 of 40) forwarded isolates to the State Laboratory of Public Health within 24 hours. Several (3 of 40) forwarded isolates weekly while others (4 of 40) never sent isolates, and the remaining respondents forwarded isolates monthly, yearly, within some other time frame, or whenever needed. Some sent isolates to the county health department (n=8), presumably to forward to the State Laboratory of Public Health.

Knowledge of Reporting Requirements

For *Campylobacter*, *L monocytogenes*, Shiga-toxin producing *E coli*, *Shigella*, and *Salmonella*, 36% to 41% of 39 respondents from clinical diagnostic laboratories incorrectly thought that only the laboratorian was responsible for reporting (Figure 2); 26% to 32% incorrectly thought only the clinician was responsible for reporting; and 5% incorrectly thought *L monocytogenes* was nonreportable. For *Vibrio*, 33% of laboratorians thought only laboratories were responsible for reporting, 33% thought only clinicians were responsible, and 3% thought *Vibrio* was nonreportable. For *Yersinia*, 28% said only the laboratorian was responsible for reporting, and 31% said only the clinician was responsible; 10% correctly thought *Yersinia* was nonreportable. For all study pathogens, an average of 27% (range, 23% to 28%) of respondents (n = 9-11) identified both clinician and laboratorian as responsible for reporting.

Reporting Practices

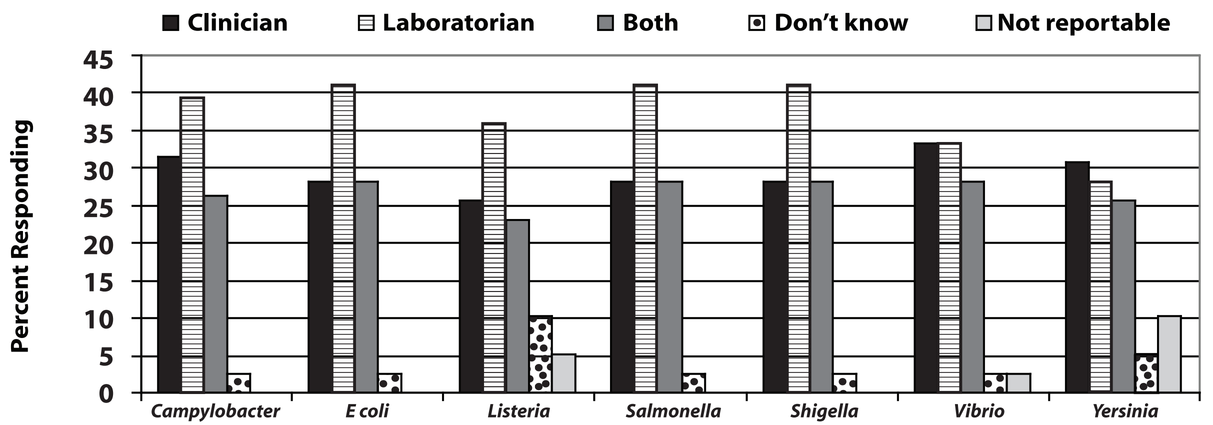
The majority of laboratorians (21 of 38) reported notifiable test results to the health department by mail. Some (10 of 38) used a fax, 1 individual each reported using the telephone and the Internet, and some (5 of 38) did not know how data was reported. When asked who in their laboratory actually reported notifiable results, most laboratorians (23 of 41) said the ICP was responsible while others (15 of 41) said the microbiologist was responsible. One each said the laboratory manager was responsible, automated computer reporting was used, or he/she notified an epidemiology clinic.

DISCUSSION

This survey of participants in the North Carolina communicable disease reporting system identified gaps in knowledge of foodborne disease testing and deficiencies in foodborne disease reporting practices. All of the pathogens included in this survey are part of the routine bacterial stool culture screen at the State Laboratory of Public Health, but hospital and independent laboratories may include different pathogens. Survey results indicate HCPs and ICPs were uncertain about the pathogens included in a routine screen at the laboratories used by their office or facility. Lack of knowledge about the routine panel at their reference laboratory could result in significant underdiagnosis and underreporting of foodborne pathogens if clinicians assume diagnostic tests will be performed on stool samples because they are considered "routine," when they are not actually part of the routine screen at their particular reference laboratory.

The routine screening practices of laboratories to identify the pathogens in the survey are comparable to those of the

Figure 2.
Percent of North Carolina Laboratorians Who Think Clinicians and/or Laboratorians Are Legally Responsible for Reporting *Campylobacter*, *E coli* O157/STEC, *L monocytogenes*, *Salmonella*, *Shigella*, and *Vibrio* Species, and *Yersinia* to the Health Department.



national foodborne surveillance sites of FoodNet, where most laboratories routinely culture for *Salmonella*, *Shigella*, and *Campylobacter* species, but fewer routinely culture for *E coli* O157:H7 (57%) and *Y. entercolitica* (50%). Fifty percent of FoodNet sites routinely test for *Vibrio* species,[16] which is more than among the North Carolina laboratories surveyed. In a study of laboratories in Gulf Coast states, only 22% of stool specimens submitted to laboratories with *Vibrio* culturing capability were screened for *Vibrio* species, and only 24% of the laboratory directors in these facilities knew that the organism was reportable in their state.[17] There may be a potential for underdiagnosis of this infection in North Carolina and other US states due to lack of testing. The costs in materials and labor of testing stool samples may continue to be one barrier to reporting.[17]

A limitation of the present study was the low response rate among HCPs (22%) and laboratorians (39%) and the small number of ICPs (n=11). Since respondents may have more interest and knowledge in foodborne illness testing and reporting compared to other clinicians and laboratorians, the data presented here may overestimate the knowledge and practices around foodborne disease testing and reporting. Data on the workplace setting of nonresponders was not available.

Participants seemed aware of the most frequently tested foodborne pathogens but they were deficient in knowledge of reporting requirements. All pathogens included in the survey are reportable in North Carolina except *Yersinia*. Eight percent of HCPs, 1 ICP, and 10% of laboratorians correctly thought *Yersinia* was not a reportable diagnosis. Three percent to 5% of laboratorians incorrectly thought *L monocytogenes* and *Vibrio* species were not reportable, and 8% of HCPs incorrectly thought *Campylobacter* was not reportable. *L monocytogenes* was added to the North Carolina notifiable disease list in 2001.

An average of 57% of HCPs knew the clinician was responsible for reporting notifiable diseases to the health department whereas an average of 64% of laboratorians knew that reporting the study pathogens was their responsibility. Health care practitioners may be expected to report confirmed cases less often than laboratories because there is a delay in obtaining diagnostic confirmation from the laboratory and patients may no longer be under the clinician's treatment. Only 6% of HCPs and 25% of laboratorians recognized that both clinicians and laboratorians were required to report notifiable diseases. Schramm,[18] who assessed the origins of confirmed case reports in Vermont in the late 1980s, found that 71% of case reports were from laboratories, 10% from nurses including ICPs, 10% from physicians' offices, and 9% from elsewhere. Thus, recognition by laboratorians of their responsibility to report may be key in the passive surveillance system. In North Carolina physicians are required to report "after the disease or condition is reasonably suspected to exist."[12] In many circumstances, reasonable suspicion of a foodborne acute diarrheal illness may be difficult to define without laboratory confirmation.

Most laboratories forward foodborne pathogen isolates to the State Laboratory of Public Health within 24 hours, but some forward them less frequently or never. As part of the Centers for Disease Control and Prevention PulseNet system, the State Laboratory of Public Health serotypes some foodborne pathogens. Thus, especially in the context of a foodborne disease outbreak, timely forwarding of isolates by laboratories should be encouraged.

Limited knowledge among laboratories about the legal responsibility for reporting notifiable results may reflect the fact that many hospital laboratories depend on ICPs to report laboratory results under surveillance. Nevertheless, since reporting is the legal responsibility of the clinical laboratory, our findings indicate a need to educate laboratorians on the communicable disease reporting process and requirements.

The study also points to a need to increase awareness and knowledge among HCPs. The vital role played by clinicians in state surveillance systems is undisputed.[19-21] The HCP's interaction with the patient is the front line of disease surveillance. Studies in the US and elsewhere have found that knowledge of the reporting system is deficient among physicians with low rates of reporting notifiable disease,[3,22] suggesting that increased communication with physicians could enhance passive reporting.[22]

This survey is the first study to examine notifiable disease testing and reporting awareness in North Carolina. To our knowledge it is also the first assessment of awareness of reporting requirements among participants in the disease reporting system through which foodborne illness due to a biological attack may be likely to first appear: ICPs, clinical diagnostic laboratorians, and primary care physicians and health care professionals.

The study results indicate that ICPs play a significant role in reporting diseases though they are not currently legally obligated to report in North Carolina. Infection control practitioners were identified by 9% of HCPs, 73% of ICPs, and 57% of laboratorians as being the persons who actually submitted reports of disease to the health department. Many ICPs actively monitor their institution's laboratory and clinical data to identify reportable cases. Dissemination of surveillance information and training opportunities through the well-established network of ICPs may offer opportunities to improve foodborne disease surveillance in North Carolina. Formally incorporating ICPs into the disease reporting structure also may enhance the passive surveillance system. Reaching HCPs who do not have contact with an ICP is an issue that needs further exploration. Efforts to facilitate disease reporting for HCPs also should be considered. For example, a printed statement on laboratory test results could serve to remind laboratorians and HCPs which pathogens are included in a routine stool culture screen and increase indirect communication between the laboratory and HCPs. Laboratory results for reportable positive pathogens also could include a reporting reminder to the HCP or, for computerized laboratory results, could provide an Internet link for web-based reporting. **NCMJ**

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Urgent Medical Decision Making Regarding a Jehovah's Witness Minor:

A Case Report and Discussion

Paul R. Brezina, MD, MBA; John C. Moskop, PhD

Abstract

Background: *Physicians strive to respect the autonomy of patients. The emergent care of Jehovah's Witnesses, however, leaves health care providers struggling with ethical and legal questions. These are further compounded when the patient in question is a minor.*

Case: *A girl aged 15 years presented with anemia, a large ovarian mass, massive hemoperitoneum, and parents who were devout Jehovah's Witnesses who refused administration of blood products. Following discussion of the patient's condition and treatment options with the patient, her family, members of the treatment team, and consultants, the patient was transferred to a hospital that offered a blood conservation program for surgical patients. The patient received surgical management without the need for blood transfusion. Her surgeons, however, reserved the legal right to give blood if an emergent need arose despite the lack of parental consent.*

Conclusion: *Society grants considerable legal latitude in dealing with Jehovah's Witness minors, and physicians must be aware of the legal and ethical parameters surrounding the care of such patients.*

The right of competent adults to make decisions regarding their medical care is well established in US law and ethics and widely recognized throughout the medical community.[1] Jehovah's Witnesses' refusal of blood products is a commonly referenced example of this right.[2] Whether minors also have a right to make such decisions regarding care, however, is much less clear.[3] Legal and ethical standards regarding the autonomy and rights of minors have evolved over time. Due to this evolution, confusion exists within the medical community regarding the appropriate response to a minor whose parents refuse medically necessary treatment.

We present a patient who is a female minor with anemia, an urgent surgical need, and parents who are devout Jehovah's Witnesses who refuse administration of blood products. The following article describes this case, reviews the beliefs of Jehovah's Witnesses regarding blood products, discusses legal standards for medical treatment of minors, and offers practical guidelines for physicians in these situations.

Case Description

A girl aged 15 years presented to the emergency department of a tertiary care hospital with the chief complaint of 2 weeks of increased abdominal girth and constipation. These symptoms had previously been evaluated by primary care doctors who instructed the patient to come to the emergency department after failed outpatient treatments for constipation. On exam, the abdomen was tensely distended with no guarding or rebound, and the remainder of the physical exam was normal. There was mild tachycardia of approximately 105 beats per minute but otherwise normal vital signs. The rest of the review of systems was negative.

The patient stated she had no prior medical, obstetric, or surgical history, had never used any alcohol, tobacco, or drugs, had no significant family history, no history of sexual activity, and no known drug allergies. She noted normal monthly menses since age 11. Her last menstrual period began 1 week prior to presentation. The patient's family was present at all times in her care and stated they were devout Jehovah's Witnesses. The parents, upon meeting the medical team, expressed their intention to remain at the patient's bedside at all

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times during her hospitalization. This was not challenged by the medical staff. The parents stated that under no circumstance would they accept a transfusion as a part of their daughter's treatment even if it meant the death of their daughter. When questioned directly, the patient also refused blood products even if this could save her life. The hospital ethics team was consulted and risk management was notified.

Laboratory results showed a negative urine pregnancy test and hematocrit of 32.5%. A computed tomography scan showed a right adnexal mass, likely ovarian in origin, with mixed solid and cystic components, measuring 10 x 10.6 cm and with massive ascites. There was no evidence of peritoneal seeding. The liver, spleen, adrenals, appendix, pancreas, and kidneys were normal. No adenopathy or osseous lesions were seen. Ultrasound-guided paracentesis was performed, removing 3 liters of fluid. Analysis showed a large amount of blood and an albumin level consistent with an exudative process.

The patient was given intravenous hydration, and a repeat complete blood count showed a drastic drop in her hematocrit to 20.9% with worsening tachycardia. Intravenous iron and *Procrit*® were begun, and interval monitoring of the patient's blood levels was changed to every 6 hours. An urgent consultation meeting with the patient and her family, the medical team, and the ethics team was conducted. Also present were several elders from her church. The parents stated their refusal to permit the use of blood products. In response to an option suggested by the ethics consultants, they requested transfer to a facility "more comfortable with bloodless surgery."

Following this meeting with the ethics consultants and family, the treatment team began aggressive efforts to accommodate the request for transfer. Hospital attorneys made preliminary contact with a local judge in case a court hearing was deemed necessary. Six hours later the hematocrit remained stable at 22%. Another tertiary care center in the state that offered a "blood conservation program" accepted the patient, and within 24 hours the patient was transferred in stable condition.

The patient was taken to surgery at that institution 2 days later with a hematocrit of 25%. The parents were told that blood would be given if needed, and the parents signed an "acknowledgement statement" detailing their understanding that emergency transfusion would not be withheld from a minor regardless of parental refusal. In surgery, a right salpingo-oophorectomy was performed as was removal of a 10 cm right ovarian mass and 5 liters of bloody ascites. Blood loss during the procedure was reported to be 25 cc. Pathology of the mass revealed a granulosa cell tumor, juvenile type. No blood was given and the patient was discharged in stable condition.

The Religious Context: Jehovah's Witnesses

Jehovah's Witnesses are members of an international religious community who adopt a literal interpretation of the Bible and assert that their faith is a restoration of early Christianity.[4] Jehovah's Witnesses comprise a small proportion of the population in both North Carolina and the nation. In 2001 approximately 0.6% of the US population and less than 0.5% of North Carolina residents identified themselves as Jehovah's Witnesses.[5] Jehovah's Witnesses cite the following biblical passages from the King James Bible to support their belief that accepting blood products is a serious sin:[6,7]

- Genesis 9:4 "Blood ye shall not eat."
- Leviticus 17:12-14 "No soul of you shall eat blood… whosoever eateth it shall be cut off."
- Acts 15:29 "That ye abstain…from blood."
- Acts 21:25 "Gentiles…[should] keep themselves from things offered to idols and from blood."

This sin is considered so grave by the faith that any direct partaking of blood results in the "loss of eternal life."[3] Therefore, it is common for Jehovah's Witnesses in critical need of blood transfusions to choose death over acceptance of blood products. The right of adults to make this decision is well accepted in the medical and bioethics literature and widely respected in medical practice.[3] The ability of minors, however, to comprehend the gravity of such a decision or to make an autonomous decision independent of the wishes of their parents is much less clear.

The Legal Context: Treatment of Minors

The legal limits of Jehovah's Witness parents to dictate the activity of their children were first addressed in the 1944 US Supreme Court case *Prince v. Commonwealth of Massachusetts*.[8] This case involved a girl aged 9 years named Sarah Prince who was instructed by her Jehovah's Witness guardian to sell religious literature on public streets in Brockton, Massachusetts. This prompted discontent in the community, and the child and her guardian were convicted of violating a child labor law that read, "No boy under twelve and no girl under eighteen shall sell, expose, or offer for sale any newspapers, magazines, periodicals or any other articles of merchandise of any description."

The case was appealed to the US Supreme Court which upheld the conviction. The Court concluded that there exists an "interest of society to protect the welfare of children" and supported the "State's assertion of authority to that end." Furthermore, the Court established that "Parents may be free to become martyrs themselves. But it does not follow they are free, in identical circumstances, to make martyrs of their children before they have reached the age of full and legal discretion when they can make that choice for themselves."[8]

This decision established the right of the state to supersede parental authority, and it has shaped current legal opinion regarding the administration of emergency blood transfusions and other medical care to minors. Indeed, legal protection of minors from abuse and neglect is now well established in both federal and state law. The federal Child Abuse Prevention and Treatment Act defines child abuse or neglect as any act or failure to act by a parent or caretaker of a child, usually under the age of 18 years, "resulting in imminent risk of serious harm, death, serious physical or emotional harm, sexual abuse, or exploitation."[9]

Although federal law provides a general framework for and funding support of child protection activities, each state establishes its own specific child abuse and neglect policies and enforcement programs. The case described above took place in North Carolina which has a clearly defined policy regarding the state's authority to supersede the wishes of parents or guardians. The North Carolina "Treatment of Minors Act" of 2005 includes the following passage:

> It shall be lawful for any physician licensed to practice medicine in North Carolina to render treatment to any minor without first obtaining the consent and approval of either the father or mother of said child . . . where the parents refuse to consent to a procedure, and the necessity for immediate treatment is so apparent that the delay required to obtain a court order would endanger the life or seriously worsen the physical condition of the child. No treatment shall be administered to a child over the parent's objection as herein authorized unless the physician shall first obtain the opinion of another physician licensed to practice medicine in the state of North Carolina that such a procedure is necessary to prevent immediate harm to a child.[10]

This statute gives physicians the authority to provide emergency medical care to minors including blood transfusions without parental consent or a court order, provided that they obtain a second physician's opinion that there is an immediate need for treatment. The statute also provides an account of when treatment constitutes an emergency, namely, "when the delay required to obtain a court order would endanger the life or seriously worsen the physical condition of the child."

Hospitals have an ethical obligation to delineate expressly to the guardians of minors the parameters of the law and how medical care will be administered. The institution operating the "blood conservation program" in the above case routinely utilizes acknowledgement statements in circumstances involving the medical care of minors whose parents seek to refuse blood transfusions.[11] These statements serve as a tool ensuring and documenting that clear and complete disclosure of the hospital's intentions are conveyed to the patient's guardians. Similar statements may be viewed at http://www.noblood.com. Failure of the parents to sign such a document would not alter the care administered to the minor under North Carolina law in the event a life saving transfusion is required. From a legal and ethical standpoint, the statement serves to document formally that a clear dialogue was conducted between the hospital and the parents regarding the emergent administration of blood products.

It is important to note that North Carolina's minor treatment statute also provides legal protection to physicians who choose not to override parental refusal of treatment for a minor child. The minor treatment statute cited above goes on to state:

> "Provided, however, that the refusal of a physician to use, perform or render treatment to a minor without the consent of the minor's parent, guardian, or person standing in the position of loco parentis, in accordance with this Article, shall not constitute grounds for a civil action or criminal proceedings against such physician."[10]

North Carolina law thus gives legal protection and discretion to physicians to make a considered decision, based on the moral arguments and the specific circumstances of the case at hand, either to honor or to override parents' refusal of treatment for their minor child. To make this decision, physicians must identify and weigh a constellation of values including family integrity, religious freedom, the wishes of the parents and of the minor patient, and the life and health of the minor patient.

It is also worth noting that North Carolina is one of a small minority of states that does not grant to parents an exemption from charges of child neglect if they withhold medical treatment from their child as a result of their religious beliefs.[12] At least 41 states provide such a religious exemption from child abuse and neglect laws, although many of these states permit courts to order necessary treatment for children even when parents are protected by religious exemption laws from conviction for criminal abuse or neglect.[13]

In addition to the emergency treatment exception noted above, North Carolina law allows treatment of minors without parental or guardian consent in several other particular circumstances. By statute, minors can consent to treatment for the following specific medical conditions: sexually transmitted and other reportable diseases; pregnancy (but not abortion); abuse of controlled substances or alcohol; and emotional disturbance.[14] Emancipated minors can consent to their own medical treatment.[15] In North Carolina, minors aged 16 and 17 years may petition the court for a judicial decree of emancipation. Minors who are married or members of the armed forces of the United States are also emancipated under North Carolina law. In nonemergency situations, the Department of Social Services may, after investigation, assume custody for a minor when it determines that the minor needs treatment that parents are unwilling to provide.[16] Finally, although some states permit older or "mature" minors to make at least some of their own medical treatment decisions, North Carolina law does not recognize this "mature minor rule."[16]

The Case Revisited: Practical Guidelines

In the United States, adult patients with decision-making capacity have wide-ranging authority to accept or refuse medical treatment recommendations. Parents also have significant responsibility and authority to choose the medical care of their children, but that authority is circumscribed by certain legal and moral limits. Conflicts between the medical treatment choices of parents for their minor children and the treatment recommendations of physicians often resist easy resolution because they pit deeply held principles of professional ethics, such as respect for the wishes of parents and minor patients and the duty to protect the life and health of patients, against one another. The case described above offers a widely recognized example of this type of conflict. When such conflicts occur, physicians should be able to recognize their causes and pursue options for conflict resolution. In the concluding section of this article, we offer several practical guidelines for addressing these situations.

When a patient or the patient's representative refuses a recommended treatment, it is important to elicit and acknowledge the reasons for that refusal. In the case we describe here, both the parents and the adolescent patient clearly expressed their refusal of blood products and cited their religious beliefs as Jehovah's Witnesses as the reason for that refusal. In open and respectful discussion with members of the treatment team, the patient and her parents demonstrated that they had an adequate understanding of the patient's medical condition, the potential need for blood products to treat that condition, and the potential consequences of forgoing this treatment. The team could thus establish that the refusal of blood products was not based on a misunderstanding about the nature or seriousness of the patient's condition or about the rationale for this treatment.

In most situations, we suggest that health care professionals discuss treatment options with adolescent patients both with and apart from their parents or others to ensure that the patient is able to express wishes or concerns that he or she is unable or unwilling to express to family members. In the case discussed, the family chose to remain with the patient, presumably to prevent administration of unwanted treatment without their knowledge or consent. The patient appeared to understand the situation and clearly expressed a refusal of blood products. There was no indication that she disagreed in any way with her parent's views or wished to speak privately with her physicians, so the treatment team decided not to insist on a private discussion with the patient.

By acknowledging a family's religious beliefs and values as the reason for their refusal of treatment, members of the health care team can demonstrate that they have listened to and understood that reason and that they respect the importance of those beliefs and values. We hold that it is important to do this as a sign of respect for the patient and parents as moral agents. For similar reasons, it is important for the health care professionals to articulate the reasons for their treatment recommendation. In this way, the health care professionals make clear the values that underlie that recommendation and commend those values to the patient and family. By offering reasons for their recommendation, the health care professionals also make clear that they too are moral agents responsible for their actions.

When professionals, patients, and parents express their opinions, beliefs, and guiding values, they can begin to seek common ground. Recognizing the value of respecting family wishes and religious freedom, for example, physicians might pledge to the patient and family that they will not pursue blood transfusions or will not do so unless the patient's life is in imminent danger. Recognizing the value of life, the patient and parents might express a willingness to accept blood products if absolutely necessary to save the patient's life, although they did not do so in this situation. This search for common ground can identify shared beliefs and values and can sometimes lead to a resolution of conflict.

Table 1.
Practical Guidelines for Addressing Refusal of Treatment for Minor Patients

(1) Elicit the reasons for the refusal.

(2) Clarify any misunderstandings about the patient's condition, prognosis, or treatment options.

(3) Seek a private discussion with adolescent patients.

(4) Acknowledge beliefs and values informing the refusal.

(5) Articulate the reasons for the treatment recommendation.

(6) Seek common ground.

(7) Enlist assistance in identifying and evaluating options.

(8) If conflict is intractable, make a considered moral judgment.

We recommend that health care professionals seek assistance from others when they encounter conflicts with patients and families regarding treatment choices. In the case we describe, the treatment team sought advice from both the hospital's ethics consultation and risk management services. Risk managers offered advice on the legal options available to the team. Ethics consultants suggested an option unavailable in the hospital, namely, a surgery program better prepared to accommodate the family's wishes. As described above, the family expressed interest in this option and a transfer to a hospital with such a program was accomplished with a successful outcome for the patient.

When conflict about treatment for a minor patient is rooted in incompatible and deeply held values, it may prove intractable. In this case, the parents and the patient might have refused transfer, but also persisted in their refusal of blood products. The patient's condition might have deteriorated, and the need for a blood transfusion might have become more urgent or emergent. As described above, North Carolina law permits 2 physicians to administer emergency medical treatment over the patient's and parent's objections, but it also protects physicians from liability if they choose to honor the parent's refusal of treatment. Thus, law does not dictate the physician's action, and the physician's decision is ultimately a moral one. Physicians should exercise this important moral responsibility with careful reflection on the relevant moral principles and values and on the particular circumstances of the case at hand. **NCMJ**

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North Carolina
MEDICAL JOURNAL

POLICY FORUM

Effective Patient-Practitioner Communication

COMMENTARIES

> *“Patient-centeredness requires a fundamental redesign of clinical communication from speaking the language and syntax of health care professionals to the plain language all people understand.”*

INTRODUCTION

Policy Forum:
Effective Patient-Practitioner Communication

The Institute of Medicine of the National Academies released its report, *Health Literacy: A Prescription to End Confusion*, in April 2004. The report made clear that low health literacy affects the educated and wealthy as well as the uneducated and poor, touching the lives of countless individuals. Miscommunication affects every facet of our lives. It occurs for many different reasons including someone not listening closely, people misinterpreting what they hear, or someone not understanding. Regardless of how miscommunication occurs, it can lead to inappropriate action, inaction, frustration, or anger. When miscommunication happens in a relationship, it can be hurtful or confusing. When miscommunication occurs within the patient-practitioner relationship in a health care setting, it can lead to illness, inappropriate procedures, slow or no recovery, and even death.

The potential for such serious consequences prompted the North Carolina Division of Public Health and North Carolina Institute of Medicine to form a task force on health literacy. The task force was supported with funding from the Heart Disease and Stroke Prevention Branch in the Chronic Disease and Injury Section of the Division of Public Health via a US Centers for Disease Control and Prevention grant and with additional support from the NC Division of Medical Assistance. The task force found that low health literacy is a major, perhaps the most important, contributor to poor patient-practitioner communication. The health care system is very complex, medical terminology takes years of training to master, and the stress of illness can make the simplest things difficult. Communication between practitioner and patient can be impaired by these and other things including differences in language and cultural perceptions of disease and health care.

This issue of the *North Carolina Medical Journal* explores many facets of the patient-provider communication process. We draw on national and state-level work on health literacy and communication to highlight problems that occur and to suggest improvements to make our health care system safer and more effective. North Carolina is fortunate to have some of the nation's foremost researchers in the area of health literacy, and we are pleased that Darren DeWalt, MD, has shared some of his research on the epidemiology of low health literacy as well as naming possible interventions. Strategies are explored for improving practitioner-patient communication in physician and dentist offices, pharmacies, long-term care facilities, and hospitals. We also focus on the role of lay health educators and advisors whose use and effectiveness in North Carolina has been demonstrated. We present the perspectives of individuals with low literacy and English as a second langue and offer ideas for implementing communications strategies for practitioners and low literacy adults through education and public marketing.

One-third of the nation's population may have difficulty understanding basic health information. It is imperative that we take a closer look at health communication, improving individuals' understanding of their health and how to appropriately manage illness when it occurs.

Thomas C. Ricketts, III, PhD, MPH
Editor-in-Chief

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Managing Editor

ISSUE BRIEF

Addressing Health Literacy Through Improved Patient-Practitioner Communication

Mark Holmes, PhD; Thomas J. Bacon, DrPH; L. Allen Dobson, MD, FAAFP; E. Kiernan McGorty, JD, PhD; Pam Silberman, JD, DrPH

Our health care system relies increasingly on the patient to exercise clinical decisions, perform self-management, and navigate the complex health care system. In 2003, the Institute of Medicine of the National Academies of Science released a report on the quality of the United States health care delivery system and included patient-centeredness among the 6 dimensions of quality.[1] Recent developments in the US health care system embrace this fundamental shift in health care delivery including increased use of self-management for chronic diseases, consumerism (eg, higher deductible health plans and cost and quality transparency initiatives), and patient activation (eg, Web sites and patient-oriented electronic medical records). All these developments help transform our system to one that holds the patient, rather than the provider, at the center of the system.

> *"If patients have difficulty compiling, processing, understanding, and acting on the information necessary to make informed decisions consistent with their desires, then the central assumptions underpinning the movement toward patient-centeredness are unfulfilled."*

However, all these policy and market developments rely on the ability of patients to act effectively as stewards of their own health. In actuality, people vary widely in their capability to understand and analyze health information and to make informed decisions. A patient's ability to make informed decisions is dependent on his ability to process and synthesize information. Patients may have difficulty understanding clinical information, treatment regimens, or how the health system works. If patients have difficulty compiling, processing, understanding, and acting on the information necessary to make informed decisions consistent with their desires, then the central assumptions underpinning the movement toward patient-centeredness are unfulfilled.

Researchers have long understood high quality patient-provider communication is a key determinant of a patient's health.[2,3] Effective communication has multiple dimensions, but attention has recently turned to the concept of health literacy. *Health literacy* can be defined as the degree to which individuals have the capacity to obtain, process, and understand the basic health information and services needed to make appropriate health decisions. Note that the concept of *health literacy* differs from that of *literacy*. Health literacy entails a broader set of skills and abilities than basic reading and writing. Health literacy requires

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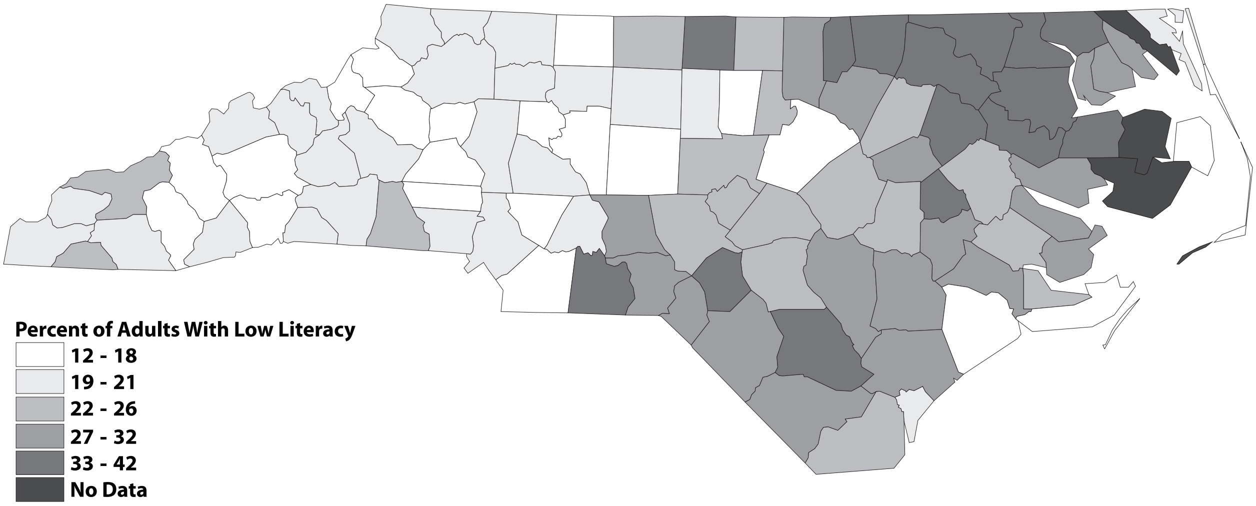
some reading skills but also the abilities to understand oral communication, use numbers and math skills, and understand the health system on a basic level. Health literacy also encompasses the ability to communicate with health care providers and their staffs.

In the summer of 2006, the Chronic Disease and Injury Section of the NC Division of Public Health (NC DPH) asked the NC Institute of Medicine (NC IOM) to convene a Task Force on Health Literacy. The task force was a collaborative effort between the NC IOM, the NC Department of Health and Human Services (NC DHHS), and the NC Area Health Education Centers (NC AHEC). The task force was funded by the Chronic Disease and Injury Section in the Heart Disease and Stroke Prevention Branch of NC DPH through a Centers for Disease Control and Prevention grant and the NC Division of Medical Assistance. Cochairs of the task force were Thomas J. Bacon, DrPH, executive associate dean of The University of North Carolina at Chapel Hill (UNC) School of Medicine and director of NC AHEC, and L. Allen Dobson, MD, FAAFP, assistant secretary for health policy and medical assistance of the NC Department of Health and Human Services. The task force consisted of 49 other members representing providers and state medical associations, patient and consumer advocates, state government, adult literacy organizations, and other interested parties. The task force met 7 times over 9 months and made 14 recommendations which are discussed below.[a]

Health literacy plays a central role in the patient-practitioner exchange and improving this type of communication can help address the adverse impacts of low health literacy. Patients with low health literacy may have difficulty reading a bus schedule or interpreting a simple bar graph. The prevalence of low health literacy is remarkably high; nearly one-half of US adults function at marginal or limited health literacy.[b] Although everyone is at risk for low health literacy, especially during times of considerable stress (eg, immediately following an unexpected diagnosis), low health literacy is more common in some populations. Older, less educated, lower income, and uninsured and publicly insured adults, along with racial and ethnic minorities, are more likely to have low health literacy. Using the known prevalence rates of low health literacy by demographic group, along with population data for each North Carolina county, prevalence estimates of low literacy can be computed for most North Carolina counties. (See Figure 1.) As with many health conditions, poverty-stricken areas tend to have higher prevalence of low health literacy.

Those who primarily speak a language other than English tend to have lower health literacy, even when literacy is assessed in their native language. Cultural issues, in addition to language issues per se, may inhibit effective patient-practitioner communication. For example, practitioners treating patients from Mexico may interpret *mal de ojo* (the evil eye) literally as conjunctivitis without appreciating the patient's cultural perspective. These cultural misunderstandings greatly inhibit effective patient-practitioner communication and hence are important to consider. In this issue, H. Nolo Martinez, MS, PhD,

Figure 1
Percent of Adults with Low Literacy



Source: Reder, Stephen. The State of Literacy in America. http://www.nifl.gov/reders/reder.htm.
Map Produced by North Carolina Institute of Medicine.

Estimates not available for counties with population below 5000.

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[a] For brevity, the recommendations are simplified and shortened here. The full recommendations are contained in the report available on the NC Institute of Medicine Web site at http://www.nciom.org.

[b] Most assessments of health literacy are of literacy per se. Although some instruments specifically designed to assess health literacy have been developed, they are relatively recent and have not been used widely.

expands on communication issues particular to nonnative English speakers in his commentary "Communicating Health Information to English as a Second Language Patients."

Low health literacy affects many measures of health in a negative way. In fact, there is no one factor more important in predicting an individual's overall health status than literacy ability. Low health literacy is associated with poorer outcomes in general health status, depression, asthma, diabetes control, and HIV control. Low literacy leads to higher rates of hospitalization and late stage prostate cancer on detection and lower rates of mammography, Pap smear, pneumococcal immunization, influenza immunization, and sexually transmitted disease screening. Furthermore, low literacy patients have higher average medical costs.[4] Low health literacy affects the health of children as well. Asthmatic children of low health literacy parents are more than twice as likely to miss school and more than 3 times as likely to be hospitalized as asthmatic children of adults with higher health literacy.[5] Darren DeWalt, MD, MPH, a national expert in health literacy, discusses the epidemiology of health literacy in greater detail in his article "Low Health Literacy: Epidemiology and Interventions" later in this issue of the journal.

Although research demonstrating the negative health effects of low health literacy is well developed, few interventions designed to improve understanding, knowledge, and other key factors leading to improved health outcomes have been shown to be specifically effective for low health literacy populations. Dr DeWalt and other researchers in North Carolina are developing national expertise in this area. However, translating research into practice remains a challenge; despite efforts across the nation to speed the translation of research from "bench to bedside," there remains a considerable time gap between when research is published and the point at which that knowledge is incorporated into widespread practice. **The task force recognized this fact and recommended that state foundations should leverage the research expertise existing in the state and fund a Center for Health Literacy Excellence** charged with increasing provider awareness of low health literacy, enhancing the capacity of adult literacy professionals to address problems of low health literacy, developing a library of health information and best practices, and increasing the skills of providers in treating patients with low health literacy.

Some of the most promising research on improving patient understanding and ability to self-manage is associated with chronic disease. For example, UNC researchers have identified effective strategies to improve outcomes for diabetes patients with low health literacy, and a pilot study on heart failure patients demonstrated strong evidence of improved outcomes (eg, a 30% reduction in hospitalization and death).[6] Because chronic diseases account for such a large portion of medical spending[7] and for diminished quality of life,[8] strategies to improve outcomes for patients with low health literacy can yield tremendous results.

In addition to the evidence-based models shown to be effective, there are some models currently existing in North Carolina that appear to be promising. Two such models are outlined in "Lay Health Educators' Roles in Improving Patient Education" by Susan Auger, MSW, and Sarah Verbiest, MSW, MPH. These models appear to improve the ability of patients with low health literacy to understand and act on health information. For example, Ms. Auger helped develop *Teach with Stories*. This method uses narratives and *photonovellas*, which are illustrated brief stories popular in Spanish-speaking societies, to frame and personalize a particular health issue, allowing the patient/client to more effectively identify with and internalize the conveyed information.

Communication also can be hindered when practitioners are unaware of the low health literacy levels of their patients and, thus, use medical terminology that is too technical. Unfortunately, national studies have found practitioner awareness of limited health literacy to be low. One study presented medical residents with case studies and histories suggesting limited health literacy as a cause of an adverse outcome, yet less than 25% of the residents identified it as a cause.[9] Another study that assessed the health literacy knowledge of graduating nursing students found less than half correctly identified the age group with the highest risk of low health literacy, and only 15% correctly identified health literacy—not socioeconomic status—as the more important predictor of health status.[10] Furthermore, practitioners underestimate the prevalence of low health literacy in their patient panel.[11] One of the reasons practitioners underestimate the prevalence of low health literacy may be that many patients have learned how to mask their literacy problems. Clues are often subtle. Patients may dismiss conveyed written information by stating they left their glasses at home and will read it later, or they may seem to be unengaged in a discussion about their health or therapy. Medical histories and other forms filled out by patients may be missing key information. In short, it is incumbent on practitioners to be aware of the subtleties that suggest a patient has low health literacy. When practitioners miss these cues, the results may be dramatic. Toni Cordell powerfully outlines her experience with these problems in "Chasing the Monster."[c] Although every patient has a different experience, one of Ms Cordell's central points is that patients need to feel sufficiently empowered to let their providers know when they do not understand the plan developed for them.

Because low literacy may be difficult to perceive, some experts advocate for universal precautions and treatment of all patients as if they have low literacy. Other experts have developed screening tools that are useful in identifying patients who may have low literacy. One example is a 6-question screen that presents the patient with a nutrition label from an ice cream box and takes 3 minutes to administer.[12] Timothy W. Lane, MD, and J. Carson Rounds, MD, discuss the practitioner's view of health

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[c] Ms Cordell, along with many others who have experienced the adverse effects of poor health communication, chronicles her experience in a video available on-line from the AMA Foundation at http://www.ama-assn.org/ama/pub/category/8115.html.

literacy in "A Failure to Communicate." Medical practitioners aren't the only health care professionals who are faced with the problem of low literacy and poor communication, M. Alec Parker, DMD, outlines the issues existing in dental settings in his commentary, "A Perspective on Doctor-Patient Communication in the Dentist's Office."

There are best practices designed to maximize communication effectiveness with patients with low health literacy. For example, the teach-back method—querying patients with phrases such as "OK, I just gave you a lot of information. Let me make sure you got it all. How often are you going to take this medicine?"—allows practitioners to assess patient understanding. This method has been shown to increase patient recall from 61% to 84%.[13] As an additional example, the Partnership for Clear Health Communication has identified the *Principles for Clear Health Communication*[14] that should be used when developing written health information:

(1) Use easy to follow layouts and simple pictures.
(2) Write information at an appropriate level.
(3) Replace complicated medical words with plain language.
(4) Use pictures and diagrams.
(5) Focus on desired behavior instead of medical facts.
(6) Make information culturally sensitive and personally relevant.

Although these principles are somewhat obvious, they may be violated in daily practice. For example, medical histories may ask patients whether they have ever had hypertension, but many patients may only know they have "high blood pressure." Patient-centeredness requires a fundamental redesign of clinical communication from speaking the language and syntax of health care professionals to the plain language all people understand.

Health professions certification and licensing boards recognize the value of effective communication and require evidence of effective communication for maintenance of certification. Nonetheless, most practitioners receive little to no training on communication techniques during their formal training. Although recent trainees may be more aware of literacy issues, other strategies will be necessary to increase awareness among current practitioners. Karen D. Stallings, RN, MEd, and Thomas J. Bacon, DrPH, outline strategies the NC Area Health Education Centers program can utilize in their commentary "Health Professions Education to Promote Health Literacy: Leverage Points and New Opportunities." The task force recognized the barrier of low awareness among practitioners and endorsed a systemwide effort to combat this knowledge gap. **The task force recommended that institutions and organizations that train health professionals incorporate health literacy training into their curricula.** Medical and health professional schools, community colleges, the NC Area Health Education Centers program, professional associations, and organizations offering practice support should ensure their curricula are designed to increase the understanding of health literacy among all practitioners. Gail S. Marion, PA-C, PhD, Sonia J. Crandall, PhD, Frank Celestino, MD, William McCann, PsyD, and Julienne K. Kirk, PharmD, describe how Wake Forest University School of Medicine is integrating effective communication pedagogy into curricula for its health professional training programs in "Cultivating Patient-Centered Communication Skills Training Across the Medical Education Continuum: A Model for Practice."

Of course, the list of changes practitioners are being asked to incorporate into their daily practice pattern is ever increasing. One study found that primary care physicians would spend, on average, 7.4 hours a day delivering evidence-based preventive care guidelines to a typical patient panel—allowing no time for the acute needs for which many patients seek care.[15] Effective communication strategies are but one of many practice changes demanded of practitioners. Changes will be more effective and permanent if the practitioner internalizes the issue and understands the importance of the improvement and the value of the change. Although health care practitioners are committed to delivering high quality health care to their patients, changes in reimbursement policy could encourage providers to practice effective communication—such as the teach-back method. The task force recommended that reimbursement policy can encourage more effective communication. Furthermore, some promising practices—such as group visits—are not reimbursed by all payers. Therefore, the task force adopted some recommendations related to reimbursement policy. For example, **NC Medicaid should pilot reimbursement models that teach patient self-management, and other payers should consider reimbursing for existing billing codes for individual and group self-management visits.**

Disease and case management, which focus on chronic conditions, are excellent candidates for achieving quality improvement in patients with low health literacy. Disease and case management often include components that attempt to increase a patient's knowledge and ability to manage her own health. **The task force recommended that the NC Department of Health and Human Services, Community Care of North Carolina, NC Division of Public Health, and payers incorporate best practices into disease and case management initiatives and explore the use of nonprint information to enhance the understanding of patients with low health literacy.**

Although there are many promising practices for enhancing the effectiveness of communication with patients with low health literacy, some of these practices may not be sustainable in the current reimbursement environment. Cost savings and improvement in quality of life for the patient (which often drive reimbursement design) might be evident only within a deliberate demonstration project aimed at developing a sustainable new model of care. Traditionally, funding other than reimbursement revenue is necessary to develop and refine such a model; providing funds for such projects has often been the domain of foundations. **Therefore, the task force recommended that foundations fund demonstration projects that use promising new models of care that increase communication to patients, and payers should modify reimbursement policy to support successful models.**

Enhancing patient-practitioner communication could not only lead to better compliance, but it may also reduce the risk of malpractice claims. Research has shown a better patient-practitioner relationship reduces the risk of malpractice claims.[16] Some malpractice carriers conduct risk management workshops for covered practitioners. **As a result, the task force recommended that malpractice carriers incorporate information on health literacy into risk management seminars.** Gerald B. Hickson, MD, and A. Dale Jenkins discuss the relationship between communication and malpractice in greater detail in their commentary "Identifying and Addressing Communication Failures as a Means of Reducing Unnecessary Malpractice Claims."

Naturally, health care is often delivered in settings other than a medical office. Promising practices exist in these settings as well. For example, the Iowa Hospital System has prioritized addressing low health literacy throughout its system of 24 hospitals and 430 clinics. Individual hospitals choose specific initiatives aimed at improving practitioner-patient communication. Mary Ann Abrams, MD, MPH, and Barbara Earles, RN, MHA, CPHRM, from the Iowa Health System explain how they redesigned the informed consent process, typically one of the more complicated forms patients are required to sign and digest, in "Developing an Informed Consent Process With Patient Understanding in Mind." The consent form signing process offers an important time for patient learning.

The task force recommended that all health care organizations and institutions develop criteria and policies to ensure best practices are followed for written information, Web sites, and other audio and visual media designed for client and family use. Additionally, philanthropic foundations should give priority to those organizations and institutions that enact these changes. The task force recognized that insurers and payers may be limited by existing laws and regulations regarding consumer insurance information, so the North Carolina Department of Insurance should seek changes in existing insurance laws that may inhibit understandability. The types of organizations charged in this recommendation include hospitals, health care systems, dental offices, and long-term care facilities.

Long-term care facilities face a multitude of challenges that might make the effects of low literacy more problematic in those settings. These include lower patient cognition, more acute health care needs, higher prevalence of chronic disease, and more reliance on medications. Yet, in these settings there is often increased reliance on patient empowerment because there are more opportunities for problems to arise due to a greater need for coordinating care among the facility staff and consulting clinicians. Dennis Streets, MPH, MAT, LNHA, outlines issues particular to long-term care facilities in "Effective Practitioner-Patient Communication in Long-Term Care."

Just as health care is delivered by practitioners from many disciplines and in settings other than the physician or dentist in an office, health is affected by entities other than health care providers. The state has many disparate forms of interactions with individuals which may affect their health directly or indirectly. The NC Department of Health and Human Services consists of many agencies providing direct services to North Carolinians such as public health, aging, and mental health services. Because many of the department's clients are at higher risk for having low health literacy and department actions affect so many people, creating a department-wide culture to adopt practices known to be effective with low health literacy patients can lead to considerable improvement in communication effectiveness. **The task force recommended that the NC Department of Health and Human Services develop criteria and policies to ensure best practices are followed for written information, Web sites, and other audio and visual media designed for client and family use.**

In addition, the task force recommended that agencies within the department, including but not limited to Community Care of North Carolina, the Division of Public Health, the Division of Mental Health, Developmental Disabilities and Substance Abuse, and the Division of Aging, have staff at the local level trained in best practices for low health literacy patients and charged with disseminating that information to staff.

Today, patients receive health information from many sources in addition to their health care practitioner. For example, the Internet is a common source of information, and friends, family, and coworkers often volunteer or are consulted for advice. **Therefore, the task force recommended that the NC Department of Health and Human Services, health care systems and providers, and payers explore and improve other ways of educating patients that may be more effective for patients with low health literacy.** Examples include trained lay health advisors and patient navigators, group education settings, and information dissemination in nontraditional forums (eg, religious institutions, community fairs, and barber shops).

The task force spent considerable time on the special challenges inherent in pharmaceuticals. Medication errors lead to high costs and adverse health effects (including preventable deaths) in our health care system. Research has found that patients with lower health literacy have poorer understanding of drug labels. Even patients who correctly explain the instructions may struggle to demonstrate how to correctly take the medication.[17,18] Studies have found that instructions such as "Take two pills twice a day" are more likely to be misinterpreted by patients with lower health literacy. Part of this confusion may be due to the design of the "average" medication bottle. A study of medication labels from across the country found that the types of elements most pronounced on the label—such as the pharmacy name and prescription number—are not pertinent to helping the patient take the medication correctly. Furthermore, warning stickers on labels are commonly misinterpreted, and patients with lower health literacy are more likely to misinterpret labels such as "Take with food" or "Swallow whole: do not crush or chew." **Therefore, the task force recommended that the NC Board of Pharmacy, in collaboration with other key stakeholders, develop requirements for consumer information and medication labels making them more readily interpretable to those with low health literacy.** Michael S. Wolf, PhD, MPH, and Stacey Copper Bailey, MPH, explore this issue in more detail in their commentary "Improving Prescription Drug Labeling."

Likewise, the role of pharmacists as medication counselors can be enhanced to improve patient understanding and compliance. The Asheville Project, a program that intensively used medication therapy management to increase patients' abilities to effectively manage asthma and diabetes, demonstrated the cost savings associated with such interventions during and beyond the intervention period.[19,20] One barrier to enhancing the role of pharmacists as medication counselors is the current reimbursement environment. Pharmacists have experienced a 56% increase in their workload filling prescriptions in the last decade.[21] In light of such increased demands, it is difficult to expect pharmacists to undertake more active medication counseling without a realignment of incentives. Although there is some evidence that these types of practice redesigns are effective, more studies are needed. Traditionally, foundations have been willing to fund pilot projects demonstrating the effectiveness of new models of care. **Therefore, the task force recommended that North Carolina foundations fund demonstration projects enhancing the role of pharmacists as medication counselors and that payers reimburse successful models.** Michael D. Murray, PharmD, MPH, discusses what North Carolina state law requires in terms of pharmacist counseling and highlights successful pharmacy initiatives in "Medication Instruction by Pharmacists: Making Good on an Offer."

Of course, the most direct approach to limiting the adverse health effects of low health literacy is to increase literacy skills for everyone. The task force believed initial efforts aimed at improving consumers' health literacy should be targeted at the most vulnerable populations. Adult education services and systems, such as literacy councils and adult basic education offered by community colleges, provide an existing mechanism through which to achieve that goal. Although adult education only reaches a small segment of the population (ie, between 2 and 3 million of the 94 million US adults with limited literacy skills), these individuals can bring the skills they learn back to their families and communities. Adult education teachers, state directors of adult education, and basic skills program leaders all see the benefits of using health issues to teach literacy. In a survey of adult basic educators, over 90% of teachers viewed adult education as an appropriate setting to teach and learn about health issues.[22] Teachers who used health to educate their students reported lessons based on health issues enhanced students' dialogue, discussion, vocabulary, reading, language development, and critical thinking. Teachers report students' interests, participation, and motivations were greater when health was the topic of the educational exercise when compared to other areas. A national survey of state directors of adult education found respondents believed health was an appropriate topic for adult education both as a content area and as a skills area.[23] **The task force recommended that adult literacy programs incorporate health literacy concepts into curricula.** Sandra J. Diehl, MPH, discusses her experience and possible approaches in adult education in "Incorporating Health Literacy Into Adult Basic Education: From Life Skills to Life Saving."

Naturally, patients have a responsibility to do their part to improve communication with their practitioner. The health care environment can be intimidating to the average consumer, and medical language can be confusing. The task force believed that patient activation can be enhanced through adoption of a social marketing campaign aimed at increasing awareness of the importance of asking questions when consumers do not understand health information. Again, there are some promising practices to guide these efforts. The Justus-Warren Task Force and the Chronic Disease and Injury Section of the NC Division of Public Health partnered on an award-winning campaign called "Lost In Translation,"[24] which targeted people with cardiovascular disease. The campaign conveyed the importance of having a dialogue with practitioners to ensure understanding of clinical information. Messages need not be disease-specific. The Partnership for Clear Health Communication developed a campaign called Ask Me 3 which directs consumers to ask 3 questions at each health care visit: (1) What is my main problem? (2) What do I need to do? (3) Why is it important for me to do this?

This population-based message can lead to more effective communication and hence better understanding and outcomes. **The task force recommended that the NC Division of Public Health adopt a social marketing campaign, including partnerships with key organizations and stakeholders, to increase awareness of the importance of effective patient-practitioner communication among all North Carolinians.** Marcus Plescia, MD, MPH, and Mike Newton-Ward, MSW, MPH, discuss this issue further in "Increasing the Public's Awareness: The Importance of Patient-Practitioner Communication."

Addressing health literacy through patient-practitioner communication is certainly not a cost-free exercise. Practitioners will have to learn new skills, develop new tools, and train staff to be aware of the issue. Although health care providers want to provide the best possible care to all patients, the American health care practitioner today is facing increasing demands on her time in and out of practice. Many of these demands ask practitioners to do more—spend more time with patients, order more tests, or educate oneself more on an issue. Among the myriad of issues the practitioner faces, health literacy may be easy to dismiss. However, in addition to negatively affecting patient health as outlined here, poor communication with patients may negatively affect practitioners' livelihoods. Although the business case for addressing health literacy is still currently unproven, many potential benefits exist. In the increasingly competitive environment, providers compete daily for patients in the health care marketplace. Because patient satisfaction tends to be higher for those practitioners utilizing best practices, a commitment to addressing low health literacy may lead to increased market share. Increased communication leads to a more satisfying work environment and can increase morale and decrease staff turnover. As discussed above and elsewhere in this issue, malpractice liability may be reduced. Perhaps most importantly, the increasing number of initiatives addressing health care quality presents additional leverage on investment in low health literacy mitigation strategies. Outcome measures—such as the percent of diabetics with most recent Hemoglobin A1c less than 7.0%—are affected by patient understanding and compliance. Practitioners who value their performance on these measures are given incentives to develop strategies addressing their low health literacy patients. However, although many of the strategies outlined here may lead to cost savings, the toll on individual patients and their families adversely affected by poor understanding is perhaps the most important reason to improve communication. **NCMJ**

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COMMENTARY

Low Health Literacy:
Epidemiology and Interventions

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Health literacy entered the mainstream medical literature in 1995 with an article published in the *Journal of the American Medical Association*.[1] Since that time, we have witnessed the emergence of a field of research and advocacy that attempts to improve health communication so that all people can understand and act on health information. In this commentary, I will review the epidemiology of low health literacy, our understanding of the relationship between literacy and health outcomes, and emerging interventions to mitigate the effects of low health literacy. As this field rapidly gains new insights, we are beginning to learn how to address the problem.

Epidemiology of Low Health Literacy

Health literacy, as defined by Healthy People 2010 and described in the issue brief in this issue of the *North Carolina Medical Journal*, is a construct which has been elusive to measure as a single variable. Most of the research to date has focused on the ability to read basic health information. However, all of us can identify a friend or colleague who has excellent reading skills, but who has low health literacy. This person has trouble understanding and acting on health information. As such, describing the epidemiology of health literacy requires an explanation of what has been traditionally measured in these studies. To date, researchers have measured reading ability as a proxy for health literacy. Measuring reading ability emphasizes the role of understanding written health information and would likely classify our colleague with excellent reading skills as having "high health literacy." So, although measuring reading ability does not give us the full picture of health literacy, understanding the problems associated with not reading well can help us identify key principles for addressing health literacy.

> *"If close to half of the population we serve is unable to accurately participate in health care, we need to fundamentally restructure how we operate."*

The most up-to-date portrait of reading ability in the United States was the 2003 National Assessment of Adult Literacy (NAAL).[2] The NAAL found that 43% of adults read at basic or below basic levels. Based on analysis by economists and educators, people who read at these levels are not adequately skilled to compete in the current economy or to effectively negotiate much of the health care system.[3] This current state of affairs is astounding and should call close attention to how we provide health care. If close to half of the population we serve is unable to accurately participate in health care, we need to fundamentally restructure how we operate. As we pursue patient-centered care, we must consider the information processing skills of those we serve and adjust our actions to match the skill level.

Health Literacy and Health Outcomes

The importance of health literacy is underscored by its relationship to health outcomes. The research to date has focused on the relationship between reading ability and health outcomes, largely because reading ability is easier to measure than the broader concept of health literacy. Regardless, if poor reading ability translates to poor health outcomes—after controlling for variables like insurance, income, race, ethnicity, and disease severity—then we are more confident that inability to understand health information is an important factor for health outcomes. In 2004, the Agency for Healthcare Research and Quality (AHRQ) released a report on the relationship between literacy and health outcomes.[4,5] This report found that, across several

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areas of health and health care, low literacy was associated with a worse prognosis than higher literacy even after controlling for confounding variables.

Since the publication of the systematic review, several new articles have added to the evidence by evaluating new populations and new outcomes. Two studies have documented that people with lower literacy die at a faster rate than people with higher literacy.[6,7] Patients with low literacy are more likely to misunderstand prescription medication instructions and warning labels.[8-10] Young children with asthma who have parents with low literacy have more days of school missed and more hospitalizations.[11] The body of literature associating low literacy with worse health outcomes becomes more robust each year. Some studies are beginning to explore potential mediating variables such as self-efficacy,[12,13] medication knowledge,[10,14,15] and patient-physician communication.[16] As we begin to understand the mediators between literacy and health outcomes, our intervention design will become more informed and effective.

Interventions to Mitigate the Effects of Low Health Literacy

Interventions to mitigate low health literacy usually fall into one of 4 categories:

(1) Improve health literacy skills in the population
(2) Improve written and multimedia communication
(3) Improve patient-provider communication in health care visits
(4) Alter systems of care

No doubt, such a framework is an oversimplification, but it lays out what we need to think about when addressing health literacy at the state level. I will briefly review each category and the current state of knowledge for each.

1. Improve Health Literacy Skills in the Population

Although the most attractive solution, this may be the most elusive. Improving the reading ability of an adult takes hours of personalized instruction and self-motivation. With one year of intense adult basic education, a person's reading level increases about one or two grade levels. Such improvements, if targeting germane topics, may improve function in the health care environment, but educating 90 million adults with such specificity and intensity is not feasible. No studies have been published that demonstrate improved health literacy over time. As such, we do not know if specific health-related information processing can be improved faster than general reading ability.

We have a small amount of evidence that literacy training programs can improve depression outcomes, regardless of the improvement in literacy. Two studies have enrolled people in adult literacy courses, and both showed an improvement in depression symptoms when compared to a control group.[17,18] The mechanism of the effect may be related to self-confidence and life skills improvement for people who have been struggling to get by. Regardless of the mechanism, the outcome suggests that further study in this area could be promising.

What about the children? Unfortunately, approximately one-third of our nation's children do not graduate from high school, a statistic that has not changed in 30 years.[19] As such, I anticipate that the problem of low health literacy will remain with us in the foreseeable future. Expanding curricula in health literacy for primary and secondary education may help to familiarize students with the health care environment, but improving graduation rates may be more important for the overall health of the population.

2. Improve Written and Multimedia Communication

Most of the research and advocacy related to health literacy has focused on written and multimedia communication. Numerous studies have shown that the readability of health information almost always exceeds the reading ability of its intended audience. If we (health care professionals) were a communications agency, we would be fired. Creating better written messages and using other forms of media (audio or video) have been tested in clinical research and can improve knowledge.[5] Written messages targeting specific illnesses can increase the rate of physician-patient dialogue on a topic and increase the receipt of clinical preventive services.[20,21] Creating health messages that are understandable by most of the intended audience is an imperative for any systematic approach toward addressing low health literacy. Experts have developed guides for creating health messages,[22] and more and more examples are published in the medical literature.[23-25]

Beyond improving specific patient education materials, we need to consider broad-based campaigns to activate people to ask questions and seek clarity. Such campaigns have been created including the Justus-Warren Heart Disease and Stroke Task Force message "Start with Your Heart"[26] and the AHRQ funded message "Questions Are the Answer: Get More Involved With Your Health Care."[27] Although we do not know how much effect these messages have had, they normalize the behavior of seeking clarity in the health care setting. Such social marketing approaches may lead to more efficacious health care encounters.

3. Improve Oral Communication in Health Care Visits

Health communication researchers have known for years that patients remember about 50% of what they are told in a visit with a physician.[28] Even that which is remembered is often remembered incorrectly.[29] This is especially of concern when most health communication takes place orally in the health care setting. Therefore, strategies that improve oral communication may lead to better health outcomes, particularly for those with low health literacy.

People who have strong reading and information processing skills can get by in the current environment because they can seek more information after they leave the health care setting by looking on the Internet or in books. Unfortunately, a large part of society cannot access information so easily and must rely on good information transfer in the clinic or hospital. Although an important area of research, we do not have much empirical evidence on what strategies work best.

The most promising strategy to facilitate understanding in the office setting is the teach-back method. Using this method, the clinician explains a concept or behavior to a person, then asks the person to explain it back in his or her own words. This can give the clinician the opportunity to clarify any areas the person did not adequately understand. This method is the only way a clinician can be certain that the patient or family understands the content. An added bonus to this method is that the patient recall will be better because of having to communicate it to the clinician.

One published study has evaluated the use of the teach-back method by audiotaping visits between patients with diabetes and their physicians.[30] The study found that the teach-back method was used with only 20% of the patients. However, those patients had 9 times the odds of having their blood sugar below the average (a lower blood sugar is good in this context). Although an observational study, it suggests this approach may have benefit. It was also noted that those visits which included the teach-back method were not longer. In addition to this study, the teach-back method and its variants are tried and true pedagogic methods advocated by educators as far back as Socrates.[31]

Another strategy for improving oral communication is to limit the number of topics communicated at one time. In the context of a health care encounter, the clinician often mentions several different ideas, prescribes medications, and suggests specific self-care behaviors. Frequently, there is no summation of the main points, and the clinician is not aware of the elaborate content he or she has just imparted. People have a variety of capacities for remembering things, so the clinician must tailor the amount of information to a given patient. I advocate that clinicians try to limit the number of points they expect the patient to remember to 3. Anything beyond that requires supplementary methods to help the patient remember and reinforce the information.

4. Alter Systems of Care

Lastly, we must consider the role of our care systems in making health care less effective for patients with low health literacy. Most current care systems rely on complex organizations that make lots of errors including problems in scheduling, prescriptions, administering medications, and receipt of self-management support. In these systems, patients with higher health literacy can often get by, but not easily. A patient with low health literacy is left extremely vulnerable and likely receives substandard care. At the time of the 2004 AHRQ systematic review, no studies directly demonstrated whether system changes could mitigate the effects of low health literacy.

Making health care systems responsive to the needs of people with low health literacy is not easy. In many quality improvement programs, the provision of self-management support is the hardest improvement to implement with fidelity and efficacy.[32] Fortunately, models are beginning to emerge,[33] and some practices have shown improved health outcomes for patients with low health literacy.

One system in North Carolina created a diabetes disease management program within the practice that included clinical pharmacist practitioners, diabetes educators, and care assistants to help educate and respond to the needs of the patients with diabetes.[34] This program focused mostly on the patient's desired behavior goals and used the teach-back method when communicating. However, the program also helped patients navigate the health system by teaching them how to get rides to the clinic and how to register for pharmacy benefits when the forms were too complicated. Although patients of all literacy levels benefited from the program, those with low literacy received much greater benefit from the program.[35] In essence, this program reduced disparities in outcomes for patients with low literacy.

The same practice developed a heart failure self-management training program targeted toward patients with low literacy skills.[25] This program offered training for the patient with several follow-up phone calls to reinforce the education. Although this program did not offer specialized medical care or ancillary help like the diabetes program, it did reduce hospitalizations among all patients.[36] Patients with low literacy benefited as much or more than those with higher literacy, but the study was not large enough to explore whether the disparities in fact narrowed.

A large public hospital in California tested 2 forms of diabetes support versus usual care.[37] One of the intervention arms used automated telephone disease management (ATDM) to call patients and gather information on how the patient was doing. If any concerns were elicited, the patient received a call from a nurse educator. The other intervention arm used group visits to provide self-management support. The study found that patients in the ATDM had improved functional status, self-management, and mental health compared to patients in the group visits arm and in the control arm.

System changes to provide more comprehensive care appear promising for patients with low literacy. A system that does not require advanced literacy skills will likely improve care for patients regardless of literacy level. Hence, health literacy meets quality improvement. As we proceed with redesigning our care systems, we should consider the role of the patient and how we can reduce the navigation burden, eliminate clinical inertia, and provide tailored and effective self-management support to reach optimal health outcomes.

Conclusions

Understanding and addressing low health literacy will require further basic research but also implementation science and quality improvement. Basic research in the field is expanding rapidly and we will continue to identify best practices. Implementation has lagged behind because, until recently, we did not have evidence-based methods to improve outcomes. The emergence in the past 3 years of evidence-based approaches should lead to the next phase of implementation science to help us provide health literacy sensitive care to patients in our clinics, hospitals, and public health venues. **NCMJ**

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COMMENTARY

Chasing the Monster

Toni Cordell

While attempting to do the task before her, a young woman stated in frustration, “I am only as good as the information I am given.“ Communication offers an opportunity for understanding and success or misunderstanding and failure. As we all know, the lack of crystal clear health communication can put lives in danger.

Medical professionals have extensive training and education. Face to face with the doctor, health issues can be talked through if both the practitioner and the patient are on the same page while communicating. But some patients also hope that the doctor not only hears their words but also understands the feelings associated with them when they have the courage to express them. That puts a great deal of responsibility on doctors, nurses, and other medical professionals.

> *“Communication offers an opportunity for understanding and success or misunderstanding and failure.”*

About 30 years ago, I visited the gynecologist knowing there was a problem (I later learned it was a prolapsed uterus). During the exam the physician said that the problem had “an easy repair.“ I asked no questions. We just set the surgical date, and I showed up at the hospital for that “easy repair.”

I graduated from high school reading at the fifth grade reading level. When I was in school there was no help for those of us with learning problems. So, I’ve spent my life facing challenge after challenge and attempting to gain enough knowledge so I can feel normal.

Because of my poor reading skills, I simply signed every paper pushed in front of me at the admissions desk before my surgery. This was not my first surgical procedure, and I knew I was required to sign those papers in order to have the “easy repair” procedure. I didn’t read a single word. I didn’t even try because I suspected the medical jargon would make the documents too difficult to understand.

Looking back, it would have been so helpful if the documents needing my signature could have been mailed out ahead of time. Then I could have gone over them at my own pace or asked my husband, an educated man with a high IQ, to check them out. Another option may have been to call ahead of time and request the paperwork so I could familiarize myself with it.

The surgery was a successful “repair.” However, during the 6-week follow–up appointment in the doctor’s office, the nurse walked into the examining room and cheerfully asked, “Toni, how are you doing since your hysterectomy?” Shocked and humiliated, I behaved as normally on the outside as possible. However, it caused an emotional overload with my insides screaming at me for being so stupid. The word hysterectomy meant they cut something out. That is more than a “repair.” How could it happen that I did not know? I just realized part of my body was cut out, and I only thought it was a surgical repair. Although I was not hoping for more children, it was still a traumatic day for me.

Several years ago, after numerous surgeries attempting to correct the organs in my lower abdomen, I was sent to a urologist, Dr Niall Galloway, at Emory University Hospital in Atlanta. His nurse told me that he gets all the train wrecks. Thankfully, he serves as an excellent example of a very positive experience within the medical community.

Of course at the initial appointment I had to deal with the clipboard and the papers needing my signature. By this point in my life I had been to an adult literacy program and my reading level had improved but I still loathed paperwork. I was led back into the examining room. Dr Galloway came in and sat chair to chair and face to face with me. We were both fully clothed. He asked lots of questions. Then as he left the room he instructed his nurse to prepare me for the physical exam.

When I was properly set on that horrible table and fully draped, Dr Galloway returned. Before he laid a hand on me, he spoke with care letting me know what he was doing and even

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warned me to expect the uncomfortable part. After Dr Galloway left the room, the nurse helped me take time to recover and get up right, and she asked if I needed any help to get dressed. So, when Dr Galloway returned, once again I was dressed. That tends to put physician and patient on more of a peer relationship. While in a paper or cloth drape one can feel vulnerable. Being dressed in street cloths takes some of that out of the encounter.

Dr Galloway clearly stated his evaluation and what he believed the treatment should be to correct the current problem. His Picasso-like hand drawings illustrated the places where there would be cuttings, stretching, and stitches. Although I am still not as good at asking questions as I need to be, Dr Galloway communicated so clearly that I went into that surgery very well informed of what to expect.

As a result of my interaction with the medical field and attending conferences on patient safety, I now know about the Ask Me 3 campaign.[a] Ask Me 3 gives a patient a place to start to become better informed and educated about his or her own medical needs. I never want to suggest that all of the responsibility for communication rests on the shoulders of the medical professional. It needs to be a partnership in which the patient also plays a role.

Many of us with low literacy skills or a poor education have emotional baggage from the many years of feeling stupid. After all, many of us sat in high school classrooms alongside of you. I graduated from high school reading at the fifth grade reading level. I know I am not your academic equal. I have a high regard for all who have earned a college education and beyond. But now I have learned that I no longer have to just do as I am told. I suspect one physician has written "noncompliant" on my chart because I argued with him about depression and refused antidepressant drugs. But it is my body and my life, thus it is my choice.

I have lived my life being attached to the stupid monster that is my lack of formal education. No, I am not suggesting I think there are really monsters around every corner waiting to get me. It is just that when I say or do something that reveals my lack of education I get slammed in the face with humiliation. So when a staff member in your office gets frustrated with me, I know it and I tighten up.

Most of the time, I make an effort to be very honest about my reading skill or lack thereof. After I sign the HIPAA papers, I hand the clipboard to the person at the desk and say, "I signed these, but I don't understand them." Most of the time that person just looks at me. Sometimes they will joke that they don't either. I believe at that moment I have just put the ball back in your court, and if there is a problem you could be open to a legal suit. I am not sure, just a guess. I am not personally interested in suing anyone.

Not all patients lack the education to communicate with medical professionals on a peer level. However, even those with advanced educations may not be at peak performance while visiting the doctor. What happens to those with college degrees when their temperatures soar over 100 degrees? Are they able to understand and follow every bit of instructions coming at them when a flu bug has moved in with a bit of diarrhea and vomiting? Okay go one step further. If the word cancer has just come out of the doctor's mouth, can you, at that moment, process all instructions to deal with that life-threatening illness?

Health literacy is not just a problem for those of us with a poor education. No matter how difficult the task, all medical decisions need to be made in partnership with the medical professional and the patient. That requires crystal clear communication with mutual respect. **NCMJ**

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[a] The Ask Me 3 campaign was developed by the Partnership for Clear Health Communication to improve communication between practitioners and patients. It endeavors to teach patients to ask 3 questions of the practitioner during a health encounter: What is my main problem? What do I need to do? Why is it important for me to do this? For more information, visit http://www.askme3.org/for_patients.asp.

COMMENTARY

Lay Health Educators' Roles in Improving Patient Education

Susan Auger, MSW; Sarah Verbiest, MSW, MPH

There is an urgent need to transform our health care system to improve the quality of and access to care, more efficiently use limited resources, and be more cost effective. The convergence of trends, many studied by the North Carolina Institute of Medicine, driving this need for transformation include the alarming increase in chronic diseases across the lifespan, persistent shortages of health care professionals and interpreters, the increasing uninsured population, and limitations of our health care safety net to meet growing demands. Demographic changes, environmental health risks, and health literacy issues further compound these problems. All these factors contribute to health disparities and underscore the need for culturally relevant and linguistically appropriate health education and care. A key to health care transformation is the shift from a traditional hierarchical, clinician-centered approach to a patient or relationship-centered approach in interpersonal communication and service delivery strategies.

> *"Lay health educators are respected and trusted members of a community who know most of the residents they educate. They help translate health information into culturally meaningful, understandable messages that their neighbors can critically think about and act on."*

Given the current milieu, it is time to take a fresh look at the role lay health educators (LHEs), also known as lay health advisors, community health workers, or *promotoras*, can play in improving communication, increasing access to quality care, and reducing costs. Research in health literacy has heightened awareness that it is not enough, from a practical or ethical standpoint, to simply disseminate health information. It is problematic when the information is laden with medical jargon and technical terms and written at too high a reading level. For effective disease treatment and prevention and behavior modification, individuals must be motivated and able to access, understand, and use health information in the context of their daily lives. Lay health educators are respected and trusted members of a community who know most of the residents they educate. They help translate health information into culturally meaningful, understandable messages that their neighbors can critically think about and act on. The LHE model was first endorsed by the federal government in the 1960s as a way to expand access to care for underserved populations. These natural helpers build bridges between systems of government, educational institutions, and medical and social services that might otherwise be out of reach to individuals and their communities. Acting in a spirit of collaboration and mutuality, their work and use of "living room" language embody the principles and best practices of health literacy and relationship-centered care.

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Although currently an underutilized service delivery strategy, the versatility and effectiveness of LHE programs make them an attractive and vital option in today's health care environment. Lay health educator programs are typically used to accomplish 3 interrelated goals: (1) strengthen the therapeutic alliance between health care professionals and community members; (2) improve appropriate health care utilization; and (3) reduce health risks.[1] Diverse program structures and roles and responsibilities of lay health educators reflect the uniqueness of communities and their resources. Amidst this diversity, common program components exist. For example, many programs include outreach to underserved communities through activities such as networking with neighbors, providing simple health screening, and staffing mobile units. Lay health educators often help develop or select health materials for their peers based on their knowledge of language as well as local cultural beliefs and practices. Many LEH models have roots in Paolo Freire's work in adult literacy and seek to empower community members to identify their own needs and then develop and implement a plan that is right for them.[2] Health advocacy, home visits, health promotion, support for lifestyle changes, and the provision of transportation are other program components that are often part of LHE outreach efforts.

Lay health educators' primary allegiance is to their communities and social networks. This is a critical element and must be both respected and maintained by programs. The degree to which LHE programs are integrated within the health system varies. On one end, LHEs are fully integrated into the health care team as paid employees. On the other end, LHEs work autonomously in their community with no connection to the health care community and no compensation. Within these extremes lie a wide variety of partnerships and structures. The level of formal and informal linkages between LHEs and health care providers should be balanced based on the program's focus. In some cases, strong ties with health care providers assist LHEs in their work and health promotion efforts. In other cases, particularly when reaching more isolated and difficult to access communities (such as those with HIV/AIDS), strong links to providers might create a sense of distrust within communities and undermine a LHE's effectiveness. In other circumstances, activities that are integrated with a health center's clinical operations may facilitate better access to comprehensive services.[3] For example, consistent contact between physicians, case managers, and LHE home visitors can help ensure appropriate referrals and more effective follow up. Lay health educator programs must consider ways to respect the contribution of time and expertise of LHEs as well as ways to keep them engaged over time. Cash compensation is one obvious incentive. Increased access to services, training opportunities, respect from their peers, and a deep sense of knowing they have helped their community are other ways that LHEs benefit from their labors.

Programs that actively work with LHEs can build capacity at individual and system levels. Lay health educators commonly report an increased level of self-confidence, assertiveness, and ability to speak their minds as a result of their role. Their increase in knowledge and enhanced health and science literacy skills help increase the capacity of the entire community to take action on behalf of their members. Individuals and communities are empowered to get involved and stay connected with outside systems, a crucial function in times of health crises and natural disasters. Identifying motivated individuals in communities through LHE training can foster opportunities to recruit new talent from underserved communities for possible careers in health care.

With appropriate training and supervision, LHEs can benefit health care systems by providing a cost effective way to address cultural and language differences and more effectively meet the needs of an increasingly diverse patient population. One example of potential system efficiency is to use LHEs with groups of mothers to provide prenatal education as a complement to short physician visits. This can expand and heighten the cultural sensitivity of health care information received by women. The pregnant mothers would also receive greater social support, which has been shown to improve birth outcomes.[4] In addition, sharing the educational responsibilities with LHEs would allow health professionals and clinic interpreters an opportunity to use their time more effectively. In fact, nurse-supervised LHEs provided group prenatal education to high-risk Latinas in a recent study to improve quality of care and reduce health disparities among Medicaid managed care enrollees. They used *photonovellas* (or "photo-stories") and the Teach-With-Stories Method. This innovative approach, developed in North Carolina, is an internationally recognized best practice model for addressing prenatal care, empowerment, and health literacy needs of women. Latinas who received the Teach-With-Stories intervention had higher rates of optimal prenatal care (90.5% vs 64.7%) than the overall prenatal population at Neighborhood Health Plan of Rhode Island, the statewide health maintenance organization conducting the study.[5]

Lay educators have been used successfully with diverse populations to address specific health problems such as cancer, HIV/AIDs, diet and nutrition, prenatal care, environmental health issues, and health disparities within all these issues. The lack of standardization in the program structures, roles, and responsibilities described above as well as differences between community and research cultures pose evaluation challenges. While more research is needed, there are additional studies that demonstrate that LHE interventions can improve access to care, increase client knowledge, and facilitate behavior changes.[5,6,7] Research has also shown that LHEs can improve the health status of individuals with chronic diseases such as diabetes and high blood pressure.[8] The studies available that evaluate the financial impact of LHE programs provide evidence that they are economically sustainable.[9] One study, designed to assess the return on investment of LHEs working with underserved men, examined service utilization, charges, and reimbursements. Primary and specialty care visits increased while urgent care and inpatient and outpatient behavioral health care utilization decreased. Consequently, uncompensated costs decreased; the return on investment was \$2.28 for every \$1.00 in costs.[9]

Meaningful dialog and greater insight into the strengths and needs of communities are needed to improve health literacy, increase access to quality health care, and use limited resources more efficiently. This cannot be accomplished in isolation. Lay health educators offer a unique opportunity to strengthen the relationships between health professionals and patients through more culturally sensitive communication. They are able to adapt and discuss health information with their neighbors in a way that is understandable and encourages improved health promotion and risk reduction. With appropriate training and supervision, these natural helpers can also give community members practical support to navigate systems and make changes in their lives. Despite mounting evidence of their efficacy and cost-effectiveness, barriers exist to the use of LHEs and the sustainability of such programs. For example, while grant funds may be available to start community-based programs, innovative ways to fund LHEs and maintain a program's infrastructure are needed. Also, data systems must be improved to allow better tracking and assessment of LHE programs. Working together, health professionals, community members, researchers, and policy makers can make better use of lay health educators in North Carolina to the benefit of all. **NCMJ**

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COMMENTARY

Incorporating Health Literacy Into Adult Basic Education:

From Life Skills to Life Saving

Sandra J. Diehl, MPH

Our health care system increasingly encourages patient involvement in care, yet patients are often not well-equipped to assume such a role. A contributing factor is having marginal health literacy skills. Health literacy does not just refer to reading and writing skills but a much broader set of communication, cognitive, social, and inquiry skills that allow individuals to meet personal health goals. Approximately half of North Carolina's population has marginal literacy skills.[1] Furthermore, almost a quarter of our state's population has severely limited skills. These individuals can perform tasks such as signing one's name or locating the expiration date on a driver's license but cannot perform more difficult tasks such as locating an intersection on a map, identifying and entering background information on a social security card application, or totaling the costs of a purchase from an order form.[2] Adequate health literacy skills play an integral role in preparing individuals to interact with our health care system. They also have important implications for health promotion, disease prevention, and disease management because they influence actions such as making informed decisions, following health advice and instructions, and seeking and using health information and services.

> *"Adult education principles suggest that learning occurs best when the material being taught is immediately relevant and useful to the student."*

The Role of Adult Education in Improving Health Literacy

Skill building is a critical component of a multidimensional approach to addressing North Carolina's health literacy concerns. Fortunately, we have a community college system that serves all 100 North Carolina counties and has enjoyed a long, stable history of building basic skills among adults. Complementing this system are the efforts of literacy councils and community-based organizations. Basic skills classes at the community college build functional skills that lead to a stronger workforce, and many of these same skills translate to building a more health-literate population. Between 136 000 and 153 000 North Carolinians took part in basic skills classes annually from 2001-2006, according to community college data.[4] Classes are offered free of charge for students attending any of 4 distinct programs under the basic skills umbrella. Two of these programs, English as a Second Language (ESL) and Adult Basic Education (ABE) are especially well-suited for teaching health literacy skills.

Adult Basic Education classes are designed for adults who lack proficiency in reading, writing, speaking, problem-solving, or computation at a level necessary to function in society, on a job, or in the family.[4] English as a Second Language classes are designed to help adults who are limited English proficient achieve competence in the English language.[4] Language and cultural barriers contribute to special health literacy needs among these students.

The adult education setting offers a compelling opportunity for building health literacy skills because of the compatibility between health literacy goals and adult education goals, the flexibility offered to ABE and ESL instructors in choosing a curriculum, teaching methods that are friendly to adult learners, and the potential to reach a high-risk population. Adult education is rooted in a long tradition of encouraging social change and empowerment[5,6] among vulnerable populations, and educators are often passionate advocates for their students. Instructors

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serve as an invaluable resource to adult learners both as links to reliable health information as well as facilitators for building health-related skills.

Qualitative data from a series of recent statewide health literacy workshops offer some insight into the literacy-associated challenges that individuals face. Attendees, representing literacy, health, and human service organizations, named misunderstanding medications, tuning out because a provider uses technical terms, and trouble with paperwork as common concerns among the people they serve. A reading center manager from Fayetteville said, "I work for an adult literacy program and see many people who do not read…they talk about the stack of papers you get to fill out the minute you walk into the doctor's office." A nurse gave another perspective saying, "As a telehealth nurse, I get calls from patients who do not understand the written instructions given to them by their doctor, the emergency department, and/or discharge instructions after hospitalization. This may include how to take their medication or manage chronic diseases such as diabetes or asthma." An adult literacy instructor from Charlotte offered, "Some students read and understand well enough to take meds, the right ones at the right times with (the) correct dosage. However, there are some that do the exact opposite. It's scary." These communication concerns are best addressed through multiple channels such as practice or policy changes to address systems issues and education to strengthen individual skills. Adult education can help complement those efforts not only by enhancing general literacy skills but by also focusing on specific needs such as understanding medicine labels or modeling and practicing communication techniques that may lead to a mutually beneficial conversation among patients and providers.

Classrooms offer a safe place for individuals who share common educational needs to learn new information, practice new skills, and receive feedback. Adult educators employ a variety of teaching methods that appeal to individual learning styles. Furthermore, students usually enjoy a sustained educational relationship with their peers and instructor. This relationship serves to enhance rapport and opportunities for information sharing. Both ABE and ESL classes are guided by a set of national objectives called Comprehensive Adult Student Assessment which outline skills that individuals need to successfully function in everyday life.[7]

Strategies for Building Health Literacy Skills in the Adult Education Setting

Integrating health information into adult education is not a new practice. The adult education arena already builds health literacy skills among adult basic skills learners, albeit framed in an overlapping 'life skills' context. For example, "identify emergency numbers and place emergency calls" is a life skills learning objective; it is also a health literacy skill. The Comprehensive Adult Student Assessment system outlines many other competencies that would also fit under a health literacy rubric. Table 1 presents a small sample of these competencies. Thus, teaching health literacy in classrooms is compatible with existing basic skills standards and helps programs meet progress goals. Because there is compatibility and growing awareness among educators of the importance of health literacy, specialized curricula have been used in adult education classrooms in North Carolina, and more are being developed to help build health literacy skills. Adult Basic Education and ESL classes don't have a set curriculum, thus instructors are able to respond to the needs of their learners and have flexibility to incorporate a variety of learning experiences.

One notable statewide effort is the *Expecting the Best* project which involved curriculum development and evaluation, a project Web site, a multidisciplinary advisory board, and active dissemination efforts. The goals of this project were to introduce teaching material into community college and community-based organizations and facilitate the formation of ties between health and literacy providers. *Expecting the Best* is a 14-lesson curriculum for ESL students that teaches a variety of health-related skills including where to seek health services, how to make an appointment, how to understand medicine labels, and how to understand nutrition labels. It was developed with considerable input from ESL students and community college instructors and administrators, and reviewed by health professionals for accuracy. An evaluation of 14 community college classes randomized to *Expecting the Best*

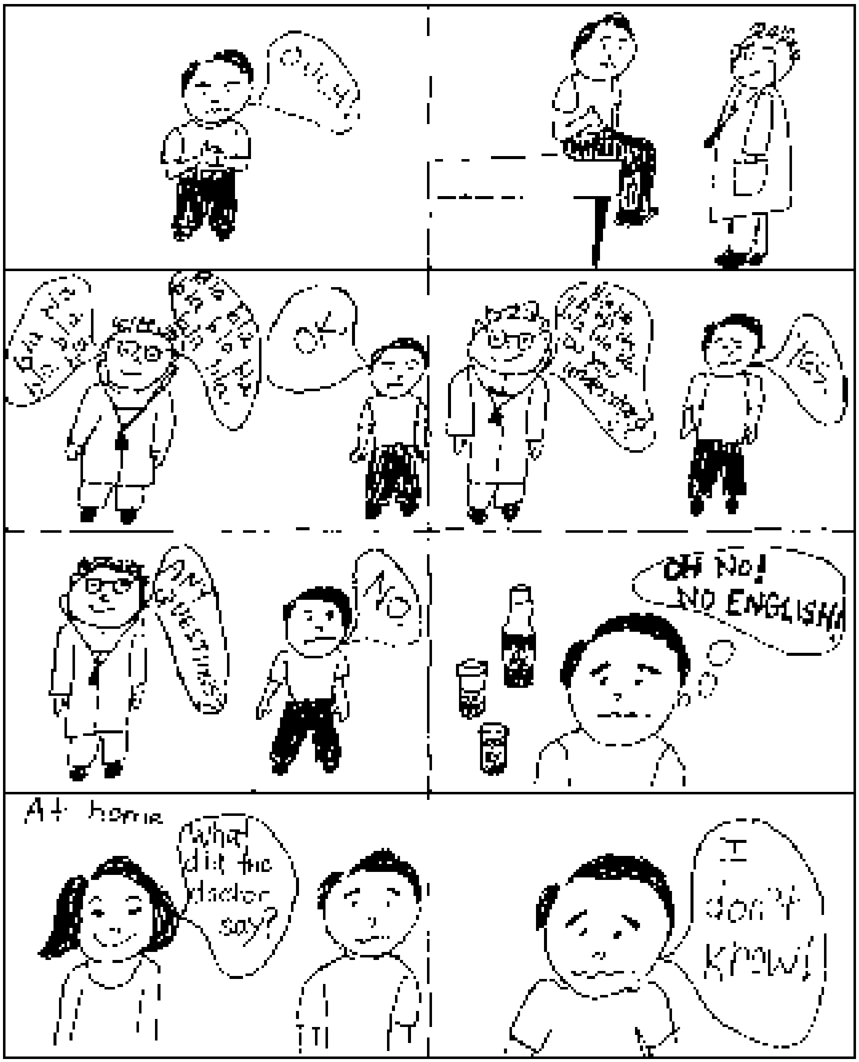
Table 1.
Sample Comprehensive Adult Student Assessment Competencies Related to Health and Literacy

Nutrition Competencies	Health Competencies
■ Select a balanced diet ■ Interpret food packaging labels ■ Interpret nutritional and related information on food labels ■ Compute discounts ■ Use coupons to purchase goods and services ■ Make comparisons, differentiating among, sorting, and classifying items, information, or ideas	■ Locate medical and health facilities in the community ■ Complete a personal information form ■ Identify emergency numbers and place emergency calls ■ Describe symptoms of illness, including identifying parts of the body and interpreting doctor's directions ■ Use a telephone directory and related publications to locate information ■ Fill out medical health history forms

or usual curriculum showed a significant increase in health literacy skills among female students.[8] Other curricula for low-literacy audiences are available on the web.[a] One popular web resource is a series of picture stories for beginner ESL students that can be adapted for audiences of varied literacy levels to generate discussion and teaching moments (Figure 1).[9] Furthermore, a consortium of 5 literacy programs in North Carolina is currently developing a health literacy tool kit that can be used by other programs in the future.

Figure 1.

A Doctor's Appointment



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Adult education principles[10] suggest that learning occurs best when the material being taught is immediately relevant and useful to the student. Adult educators are not limited only to specialized health skills curricula; they can also take advantage of community resources to create a range of relevant and useful learning experiences. The ideas are limitless, and a few are described here to illustrate the possibilities. For example, health educators are often available to visit the classroom and speak about a topic of interest to students.[11] In one case, after a student's child choked and they experienced a distressing trip to the emergency department, a Red Cross trainer visited the classroom and taught students First Aid basics, including rescue skills for choking. This emergency also presented an opportunity for the class to talk about medical bills and the North Carolina Children's Health Insurance Program (NC SCHIP). In another case, at the students' request, a health educator from the local health department visited a class to talk about HIV prevention.

Encouraging civic engagement is often a goal for adult learner programs; this can tie into health literacy efforts by actively involving students in educating others. One promising idea is to consider recruiting lay health advisors from adult education programs. Another idea that has been successfully implemented in an adult education classroom involves asking students to research and create health education materials for their peers. In this program, students presented health information on breast cancer and mammography screening to fellow students.[12] Adult education students might also serve as a potential field testing audience for consumer materials prior to release.

Field trips can be a fun way to teach information in a real-life setting. The Raleigh Farmer's Market has been a popular place to bring students to teach life skills such as making nutritious choices and calculating correct change from transactions. Arranging an introductory visit to a local walk-in or sliding-scale health center can promote health by creating a familiarity with the setting before a medical visit is needed. A trip to the local library can help students build confidence and skills in learning how to research health information.

A key consideration when incorporating health literacy topics into adult education classrooms is student interest. That is, it is crucial to choose curricula, guest speakers, and other activities

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[a] For example, see the Health and Literacy Special Collection at World Education's Web site, http://healthliteracy.worlded.org.

that are of interest to students. If students do not actively participate in selecting what they learn, then it is unlikely they will be engaged. Worse, the intent can be misinterpreted. An advocate in the Latino community explained, for instance, how students felt alienated when a health educator visited their ESL classroom to talk about sexually transmitted infections. While the intention was good, it ended up as a stigmatizing experience because the students did not ask for this information nor did they have any particular interest in it. Another suggestion, based on formative data from the *Expecting the Best* program, is to include health literacy skills as part of a diverse curriculum rather than creating a class that focuses only on improving health skills.

Finally, instructors themselves must feel confident in incorporating health literacy skills into their classes. Understanding that health literacy is a part of general literacy and life skills can help, as can viewing themselves as a link rather than a primary resource of health information. Arranging meetings between health educators and literacy organizations to share resources is mutually beneficial and can also help acquaint educators with local health resources. Literacy workers can learn how to incorporate health materials into their classrooms, while health care workers can learn how to reach low-literacy groups and can refer patients to adult education classes. Making health literacy curricula widely accessible and easy to use, accompanied by teaching workshops that orient and encourage instructors to implement new materials and which include pointers on how to link with health resources, may be a useful dissemination strategy.

Adult education is a context where meaningful learning occurs among individuals at high risk for low health literacy. It is an easily accessible, positive environment to not only provide information but to practice and reinforce skills. Best of all, it is a stable system that offers a sustainable point for intervention and which serves to contribute to a diverse approach to meeting the health literacy needs of North Carolinians. **NCMJ**

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COMMENTARY

Improving Prescription Drug Labeling

Michael S. Wolf, PhD, MPH; Stacy Cooper Bailey, MPH

According to a 2006 report by the Institute of Medicine of the National Academies, *Preventing Medication Error*, approximately 1.5 million preventable adverse drug events occur each year.[1] Attention to the root causes of medication errors leading to adverse events has most often been attributed to the provider's or health care system's contributing role in errors during the prescribing, ordering, dispensing or administering of a medicine.[2,3] The reason attention was focused on those causes may be that most studies investigating medication error have been conducted in inpatient hospitals or nursing homes.[4] However, more than one-third of adverse drug events take place in outpatient settings at a cost approaching $1 billion annually.[1] It has been estimated that a large proportion of outpatient medication errors occur as a result of patients themselves not administering a medicine as intended.[3] For ambulatory care, the patient, rather than the provider, is ultimately responsible for correctly administering a medicine as prescribed. Therefore, the processes of quality control and monitoring of medication error shift from provider to patient.

The current body of evidence detailing the incidence and causes of outpatient medication error is limited. Yet problems are likely to intensify as patients increasingly self-manage greater numbers of prescription and over-the-counter medications. Chronically ill patients and the elderly are at greatest risk for experiencing medication errors as they take more prescription drugs annually than younger and healthier patients, and visual/cognitive impairments by age may limit reading ease and comprehension.[5-9] The risk for miscommunication and error may be further compounded since the average older adult sees several different health care providers annually.[10]

Health Literacy as a Medication Safety Concern

Limited health literacy is another significant risk factor that could account for outpatient medication errors that are the result of improper dosing administration. Numerous studies have found low health literacy to be significantly associated with a poorer understanding of medication names, indications, and instructions.[11-14] More recently, health literacy skills have been linked to requisite knowledge for adherence to treatment regimens.[15] This current and well-publicized body of research has focused on the ability of patients to read, understand, and demonstrate instructions on drug container labels. The line of inquiry has been supported by parallel work in human factors research.[5,6] Davis and colleagues conducted a multisite study among adults receiving primary care at community health centers and found a high prevalence of patients, especially those with limited literacy, misunderstanding seemingly simple dose instructions provided on the primary label of medication containers.[11] In this study, 46% of adults misunderstood at least one prescription container label they encountered. The problem extends to the auxiliary sticker labels that provide accompanying warnings and instructions for use of the medicine. Another study demonstrated over half (53%) of patients, especially those with limited literacy, had difficulty interpreting text and icons commonly used on these auxiliary warning instructions.[12]

Beyond the container, drug labeling also includes accompanying medication information materials that provide indications for use and

> *"...the manner in which the current health care system delivers necessary medication information to patients is clearly inadequate."*

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further detailed precautions that can not fit on the container due to space constraints. Studies have found that these materials, as with the container label, are not useful for a majority of patients, particularly those with limited health literacy.[16] This includes consumer Medication Guides (aka Med Guides) that are required by the Food and Drug Administration to be dispensed along with certain prescribed medicines that have been identified as having serious public health concerns. Patients with limited health literacy were significantly less likely to attend to these materials. These findings are supported by earlier research studies that suggest consumer medication materials are too difficult for most patients to read.[17] As a result, the patient information leaflets and Med Guides that accompany many prescription medications may be ignored.

A System Failure

The 2004 Institute of Medicine of the National Academies report on health literacy, *A Prescription to End Confusion*, aptly identified the problem of health literacy as encompassing more than limitations in individual abilities.[13] Rather, the complexity of demands placed upon the individual by the health care system must clearly be addressed. While patients must have adequate cognitive capacity and proficiency to read, understand, and act on medication label instructions to ensure proper and safe use, the manner in which the current health care system delivers necessary medication information to patients is clearly inadequate. Physicians, who are legally responsible for delivering important drug information directly to patients, frequently miss opportunities to adequately counsel their patients on how to self-administer their medicines.[19] Pharmacists, next in line to counsel patients, also frequently fail to verbally communicate detailed information to patients at the point of dispensing medicines.[20]

In light of these failures, patients must depend more on the print drug labeling materials (ie, the container label, consumer medication information, Med Guides, patient information leaflets) that are challenging for patients across all health literacy levels.[17,18] With the exception of Med Guides and a very limited set of similar patient package inserts that are available for only a select number of drugs, no national standards or regulations exist for the development and oversight of consumer medication information or container drug labels. Informational leaflets are industry-generated, and state laws minimally govern content and format on prescription container vials. This all leads to what can best be described as a fragmented system of patient information.

Taking Action

Improving the readability and understanding of instructions and supplementary information for prescription drugs is warranted as it may ultimately stimulate appropriate and safe medication use among patients. Evidence is available now supporting the design of better drug labeling.[21] This includes considerations for both the container label and accompanying materials. Based on recent health literacy studies and work by the American College of Physicians Foundation (ACPF) on prescription drug labeling, certain general recommendations can be issued that espouse the importance of promoting health literacy as a medication safety issue.[22]

First, seemingly simple dosage instructions printed on the container label should be written in the most clear and concise manner. Previous research has found that patients have more difficulty understanding vague medication directions as compared to more explicit ones.[23,24] The less a patient is required to make inferences, the more easily medication schedules can be comprehended (ie, "take every 6 hours" vs "take at 8am, 2pm and 8pm"). This is especially important for more complex dosing schedules, where patients may become easily confused or more prone to errors if instructions are read in haste.

Second, Shrank and colleagues examined the variability in content and format on prescription drug container labels.[25] They found that pharmacies consistently emphasized provider-directed content versus information most pertinent to the patient. The use of bolding, highlighting, and larger font should be directed solely to label content that is most salient to the patient. Information such as prescription number or the pharmacy logo should be de-emphasized and segregated from dosage instructions, warnings, or indications so as to not detract from the most important label content detailing its appropriate use. Every effort should be made to organize the container label in the most patient-friendly manner. It likely will be the most tangible source of drug information repeatedly used by patients.

Third, accompanying materials should abide by core principles upheld by adult literacy practitioners.[17,26] Consumer medication information should keep to simple language and avoid medical jargon. The scope of information should be limited and summaries more frequently used to highlight actionable messages. Shrank and colleagues further describe the type of content that is desired by patients to support appropriate use.[21] Surveys have shown that patients want to know, in addition to dosage instructions, the indications for use of a prescribed medicine, any precautions, and the duration of treatment. Information on the benefits and side effects of drugs is also sought after by patients, and providing this information has been found to improve adherence.[20]

Finally, steps should be taken to ensure that these separate elements of drug labeling, the container label and accompanying materials, are developed together as an integrated and complimentary set of information sources. Patients should be included in this process so materials are appropriately organized, and they accurately reflect the common schemas imposed by patients of all literacy levels when seeking to understand how to use prescribed medicines.

Conclusion

System change is urgently needed to promote health literacy for greater medication safety. Patients must be able to easily understand how to use prescription drugs correctly. Standardizing and integrating drug labeling must be a central goal to ensure that best practices are implemented because evidence is already available to target improvements. This should be viewed as a short-term goal for policymakers, and some states have already made progress to this end.

In the long term, additional challenges for drug labeling include efforts to seek labeling concordance in other languages because not all prescription drug information and instructions are currently available to non-English speakers. A formative response to labeling problems would also extend to addressing how health care providers communicate to patients the information that is necessary to safely administer prescribed medicines. More broadly, health technology used by an increasing number of providers at the point of writing the prescription should be integrated with the software used by dispensing pharmacies to fill it and print out the labeling components. This would provide another layer of quality assurance that could minimize variability and the risk that instructions become lost in translation. **NCMJ**

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COMMENTARY

Medication Instruction by Pharmacists:
Making Good on an Offer

Michael D. Murray, PharmD, MPH

Medications are often the most effective treatment alternative for chronic diseases. Because most of the 3 billion prescription medications are self-administered by patients in their homes, appropriate use of medications requires careful instruction tailored to a patient's level of health literacy and comprehension. Unfortunately, many patients are not getting such instruction, which increases their risk of treatment failure or otherwise preventable adverse medication events. There are many reasons for this lack of instruction. However, the primary reason is that health professionals lack sufficient time to communicate needed instruction, and they are driven by the inertia of existing practice behaviors to the extent that inadequate instruction of patients is largely ignored. Patients also have time constraints, and they expect their prescriptions to be filled quickly so they can dash to the next thing on their list. While pharmacists are legally bound to *offer* medication counseling to patients, little counseling is actually *provided* in most pharmacies. However, the general void in medication counseling presents an important opportunity for pharmacists to play a greater role in patient care by reinforcing physician-to-patient medication instructions and improving the effectiveness and safety of self-administered medications. This commentary reviews salient factors and recent research involving medication instruction by pharmacists.

> *"While pharmacists are legally bound to offer medication counseling to patients, little counseling is actually provided in most pharmacies."*

Risks of Inadequate Medication Instruction

Insufficient medication information carries a risk of harm to the patient. This, in itself, must be considered as an impetus for better medication instruction. Patients who lack adequate information about their medications are more likely to experience treatment failures due to poor adherence, medication errors, and adverse events. Gandhi and colleagues[1] conducted a prospective cohort study of 661 outpatients responding to a survey to determine the rates, severity, and preventability of adverse drug events. Of the 661 participants, 25% (162) experienced adverse drug events of which 13% were serious and 39% could have been made less severe or entirely prevented. Physician-patient communication about new somatic complaints was a major factor in mitigating or preventing many of these adverse events.

The results of the study by Gandhi et al are consistent with a study of spontaneous reports of medication errors occurring in the home that were submitted to the United States Pharmacopeia's MedMarx and Medication Errors Reporting programs.[2] Of the 802 reports submitted, 11% (87) were classified as severe and resulted in permanent harm in 3 cases, a life-threatening situation in 4 cases, and death in another 4 cases. The most frequent causes of the 802 errors were performance deficit in 34% (246), poor communication in 21% (151), knowledge deficit in 19% (135), and not appropriately following a medication-related procedure or protocol in 13% (91). These results reinforce the importance of good communication involving in-home administration of medications and remind us of the potentially catastrophic results of not providing sufficient education about medications and not monitoring their use.

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North Carolina State Counseling Rule

Pharmacists are required to offer, as opposed to actually provide, medication counseling.

> Patient Counseling shall mean the effective communication of information, as defined in this Rule, to the patient or representative in order to improve therapeutic outcomes by maximizing proper use of prescription medications, devices, and medical equipment. An offer to counsel shall be made on new or transfer prescriptions at the time the prescription is dispensed or delivered to the patient or representative.[3]

While the offer to counsel may be made by nonpharmacist personnel, the counseling must be conducted by a pharmacist. The reality is that the amount of time spent by pharmacists (or others) providing medication instruction or counseling is minimal.

Lack of Time

Physicians often provide to each patient a brief overview of the rationale and directions for each medication they prescribe. However, their time is limited due to the many other important matters that must be addressed during a visit including a review of the objective findings from the physical examination, a description of the rationale for laboratory tests, interpretation of the results of previous laboratory tests, an outline of the next steps in the patient's care, and consideration of new somatic complaints. Bodenheimer termed this a "tyranny of the urgent" whereby constant attention to acute needs leaves little time for matters pertinent to the patient's chronic care planning.[4] Given that the typical visit with the physician is approximately 15 minutes (with multiple interruptions), time and attention are barriers to more comprehensive medication instruction by physicians.

Pharmacists are also pressed for time. The legal requirement to offer medication counseling prompts an all too familiar near monologue from a pharmacy assistant to the patient: "Do you have any questions for the pharmacist? Please sign here. That'll be $58.25 for today's medications. Thank you." An offer to counsel made—check; legal requirements satisfied—check; business requirements satisfied—check; written information about the prescribed medications included on the bag containing the medications—check; patient appropriately instructed on medications—likely not.

Patients are also sometimes impatient when it comes to timely filling of their prescriptions and getting out the door of the pharmacy. Ironically, for many patients, their lack of adequate medication counseling is often because they are too rushed. Additionally, pharmacies are confusing places. Patients who get their prescriptions filled at busy pharmacies often do not know which person—among several wearing a white coat behind the counter—is the pharmacist. Furthermore, the lack of a private area for counseling in many pharmacies is also an important barrier to comprehensive instruction and communication.

Recent Studies

Recent studies suggest that spending more time with patients at the pharmacy translates into important improvements in their health status and in cost reductions. In North Carolina, the success of the Asheville Project has resulted in its imitation throughout the country. The project was a prospective cohort study of workers from 2 large employers in Asheville, Mission Health and Hospitals and the City of Asheville, who were serviced by 12 pharmacies. The clinical protocol promoted intense self-care education, financial incentives to participants such as free medication copayments, and frequent follow-up by pharmacists and nurses. Specially trained pharmacists scheduled free personal consultations to provide medication education, encourage adherence to the doctor's prescription, and provide treatment monitoring. For example, pharmacists trained patients on the use of home glucose monitors (for patients with diabetes) and measured peak flow (for patients with asthma). Patients were referred to physicians as needed.

Results of studies involving patients with diabetes[5] and asthma[6] indicated favorable changes. Patients with diabetes (n=85) had lower values of hemoglobin A1c over 7 to 9 months. While the costs of diabetes-specific services and medications were increased, the total costs considering all diagnoses were lower after implementation of the program. Furthermore, participants were quite satisfied with the program.[5] Recent results involving 207 Asheville Project participants with asthma (n=207) followed for up to 5 years suggested reductions in emergency department visits, hospital admissions, and total health care costs of approximately $2000 per year.[6] While these results are generally encouraging and have been embraced by the broad pharmacy community, they must be considered in light of limitations such as participant loss to follow-up and missing data.

We recently reported a randomized controlled trial involving 314 low-income participants with heart failure.[7] The intervention involved a pharmacist who had access to patient-centered materials aimed at persons with low health literacy. We were particularly interested in whether more pharmacist time spent instructing patients would lead to improved medication adherence, which in turn could result in decreases in expensive health care utilization and associated costs. To measure adherence to cardiovascular medications for heart failure, we used a special prescription lid that contained a battery and computer chip that recorded the time and date when the medication bottle was opened and closed. Compared to the 192 participants assigned to the usual care group, the 112 participants in the intervention group took more of their medications with less day-to-day variability in the timing of their medication dosing. Intervention participants had fewer emergency department visits or hospital admissions and approximately $3000 lower total direct annual health care costs. Study participants in the intervention group were satisfied with the information provided by the pharmacist and preferred the patient-centered materials compared to the densely written medication information that is provided by most pharmacies.[8] In summary, we found that addressing the heterogeneity in health literacy among patients is important: The one size fits all written medication information for patients is not appropriate for many patients, at least not without sufficient accompanying verbal instruction.

Improving Medication Instruction and Implementation

Pharmacy practice is undergoing a transformation that will favorably influence medication instruction for patients. The forces of change surrounding this transformation include the widespread recognition that patients:

- Need more information about the potent drugs they are prescribed.
- Have more prescriptions filled than ever before.
- Are serviced with faster, more sophisticated automation and information systems.
- Have access to pharmacists and pharmacy technicians who are serving broader roles.

Implementation of any successful program to improve medication instruction for patients will require more time and individualized service from pharmacists. While time-consuming, pharmacists should consider a teach-back method for making sure the patient can understand and explain instructions in the terms he or she comprehends.

In any profession or business, more time means more money. If the returns on investment of the aforementioned studies are generalizable to broader health care settings, then it would be more feasible to consider greater remuneration for cognitive services by pharmacists. Indeed, several North Carolina pharmacies have taken progressive steps to engage its pharmacists in nondispensing aspects of pharmaceutical care, have reconfigured many of their dispensing areas to include space for private counseling, and have successfully received remuneration for nondispensing services. However, increasing cognitive services by pharmacists in the setting of increased competition for the health care dollar will more likely require a transfer of some pharmacist dispensing activities to highly trained technicians. For example, shifting the role of pharmacist work functions (dispensing, checking, adjudicating insurance claims, etc) to the pharmacy technician could allow more time for pharmacist counseling and other cognitive services. Such a redistribution of pharmacy workload between pharmacists and technicians would clearly require revision of the Board of Pharmacy's pharmacy practice rules. Notwithstanding any direct action by the Board on the medication counseling rule, the near hope would be that pharmacists will take it upon themselves to make a more concerted effort to provide medication counseling to willing patients rather than simply making an offer to do so. **NCMJ**

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Increasing the Public's Awareness:

The Importance of Patient-Practitioner Communication

Marcus Plescia, MD, MPH; Mike Newton-Ward, MSW, MPH

Effective communication among professionals, patients, and communities is a significant public health concern. With up to one-third of individuals in some health care settings struggling with limited understanding of health issues and instructions, health literacy has emerged as an important cause of health disparities and a significant public health issue.[1] Effective communication to bring about behavior change requires a focus on both communities and individuals. From a public health perspective, communication must capture the collective nature of community health while recognizing individual health literacy issues. Successful communication within communities requires community involvement, the use of nontraditional approaches, and a focus on social norms. In this commentary we discuss specific public health approaches to working in communities with low levels of health literacy and the use of the social marketing process to develop an array of interventions that can impact all the determinants of a health problem in a population.

The best strategy to increase effective communication and improve health knowledge and skills is to increase health literacy levels overall. This requires significant time and resources. In the interim, the emphasis must be on working within existing levels of health literacy to develop more effective prevention and self-management of acute and chronic illness. Best practices in the medical setting have been described throughout this issue of the *North Carolina Medical Journal*. In the public health setting, promising community practices include the use of lay health advisors and engagement of important community institutions.

Lay Health Advisors as Community Change Agents

Since many causes of racial disparities have strong social etiologies, the use of lay health advisors has emerged as a focus of many interventions, particularly those in racial and ethnic minority communities. Lay health advisor projects seek to identify and recruit "natural helpers" in a community and provide training and support for them to advise and assist their neighbors and peers with a variety of health issues. Lay health advisor models enhance empowerment and capacity building by promoting and supporting individuals who assume responsibility for community improvement, seek new knowledge and skills, and actively engage and recruit others. Lay health advisor programs have demonstrated changes in the attitudes of community members about their control over health issues and their willingness to consider behavioral changes.[2,3]

> *"From a public health perspective, communication must capture the collective nature of community health while recognizing individual health literacy issues."*

A number of lay health advisor and other natural helper programs have been implemented in communities across North Carolina. The NC Office of Minority Health and Health Disparities' Community Health Ambassador Program works with faith and community-based organizations across the state to train trusted leaders and community volunteers to improve communication about access to care and self-management for

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diabetes and cancer prevention. Over the last 7 years, the Charlotte REACH 2010 project has maintained a cohort of 15 to 20 lay health advisors who focus on diabetes and heart disease among African Americans in the Northwest Corridor neighborhoods of Charlotte.[4] Lay health advisors serve as an effective source for health communication by acting as peer role models, increasing community capacity, and forming new social support networks.

Community Settings to Promote Health Behavior Change

The medical setting is a good venue for health-related communications. Health care professionals are credible, highly respected, and expected to provide advice and instruction on health issues. However, other community settings are equally valuable, particularly in communities with low health literacy levels. The faith community plays a central role in many cultures and is an important source of social capital and influence. In many communities, priests and ministers are highly influential and have been effective communicators about important public health issues.[5] Many interventions in the African-American community have focused on the faith setting because the church is such an important source of social support and community leadership, especially among older women.

Numerous programs in North Carolina have engaged the faith community in effective health communication. Some of these have been highly effective. For example, the Black Churches United for Better Health project showed a significant improvement in daily servings of fruits and vegetables following a multicomponent, multichurch intervention in 10 rural counties.[6] Project Direct, a multiyear diabetes demonstration project in southeast Raleigh, has collaborated with multiple faith-based projects in North Carolina to create a manual for health communication in the faith setting.[7]

A Social Marketing Approach to Health Communication

The social marketing approach was first introduced in 1971 as a way to apply commercial marketing principles to improve social issues. It has been applied to a range of health, environmental, and social issues including breastfeeding, family planning, and tobacco control. The social marketing process provides a powerful tool to improve health and well-being at the population level. It offers a logical framework to link multiple interventions such as those described above. Behavior change at the community level requires more than increased knowledge and awareness, and individuals and populations frequently encounter barriers to engaging in desired behaviors. A consensus conference of behavioral scientists, sponsored by the National Institutes of Mental Health, identified a variety of external and internal determinants of health behavior ranging from access, policy, and cultural beliefs, to knowledge, perceived consequences, and self-efficacy.[8] A social marketing approach augments communication efforts by identifying and addressing these determinants.

Social marketing is an evidence-based approach. Commercial marketing research and planning processes are used to identify all the determinants of a given behavior in a target audience and then implement interventions that lower barriers or increase facilitators for the desired behavior. Social marketing is characterized by an emphasis on voluntary behavior change and attention to the costs and benefits of engaging in a behavior. A variety of interventions are customized for specific audiences based on an understanding of the target audience. The ultimate goal is to make a behavior "fun, easy and popular."[9] Such an approach targets 3 important determinants of behavior: (1) rewards and consequences; (2) adequate skills and knowledge; and (3) impact of family, friends, and culture. Social marketing employs the same intervention strategies as commercial marketing: product, price, place, and promotion—referred to as the "marketing mix." Product strategies include any tangible services or items that make the behavior easier and emphasize benefits that are meaningful to the audience. Price interventions include activities, outreach, policy changes, or messages that decrease barriers to the targeted behavior. Place strategies include offering times and locations that are convenient or occur where and when the audience is likely to be thinking about the issue. Promotion strategies are intended to persuade or inform. These include public service announcements, news stories, media advocacy, and word of mouth.

To illustrate how the social marketing process can integrate multiple communication strategies to impact a health problem, consider how a traditional media campaign could be enhanced with other intervention activities. The Lost in Translation campaign uses television public service announcements to raise awareness among African Americans about the role hypertension plays as a risk factor for heart disease and stroke. To augment the public service announcements, the campaign developed brochures and revised its Web site to include a section with consumer information on reducing heart attack and stroke risks. The campaign addresses two barriers to action identified in research with the target audience: lack of knowledge of one's blood pressure numbers and lack of awareness of the connection between high blood pressure and stroke.

A social marketing approach would expand this campaign beyond increased knowledge and awareness—to health promotion interventions. A social marketing approach might augment the public service announcements with a product intervention such as supplying free or low cost blood pressure cuffs and training family members how to use them. Place promotions would expand interventions beyond the medical practice setting to churches; community centers, and African-American owned businesses. Price interventions would address access and cultural barriers and could include using lay health advisors, parish nurses, or formal and informal community leaders. A price intervention might also include role playing how to ask questions of a medial provider to overcome possible social norms about questioning authority figures.

Social marketing combines the knowledge of the public health practitioner with the experiences of the community to create a unique mix of services, outreach, messages, policy change, and tangible products that make the behavior easier, more rewarding, and more acceptable. In populations with low levels of health literacy, the social marketing approach includes specific interventions to increase effective communication. These include lay health advisors or other trusted agents and outreach in important community institutions such as faith-based settings. **NCMJ**

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COMMENTARY

Effective Practitioner-Patient Communication in Long-Term Care

Dennis W. Streets, MPH, MAT, LNHA

"Have you ever thought just a wee little bit, of how it would seem to be a misfit; and how you would feel if you had to sit *on the other side of the desk*."[1] This is the first stanza of a poem entitled *The Other Side of the Desk*, a copy of which I secured many years ago. While I don't know the author or the origin of this poem, its message is not unlike how my dad would describe his approach to medicine. As a general practitioner in Pennsylvania, Florida, and then North Carolina for over 50 years, he spoke of 3 keys to treating patients—gathering a solid medical history, conducting a thorough physical, and putting yourself in the other person's shoes. Although he did not have as much specialized education and training as some of his colleagues; at his funeral service this past June both former patients and fellow physicians shared their high regard for his medical practice. The thing that made his practice so good was that it was based on effective communication.

> *"There is no well-kept secret to effective practitioner-patient communication in long-term care; rather, it involves the routine application of practices that are well known."*

When I became administrator of the state's second largest nursing facility in the late 1980s, I tried to heed my dad's advice. I actually taped *The Other Side of the Desk* to my desk's pull-out extension so I would have a constant reminder of how important effective communication is in any situation and especially in long-term care where there can be many barriers. Still, I sadly recall too many situations where we provided less than ideal care to patients and less than adequate support to families largely because we failed as communicators. Here is a partial list of issues that can interfere with the exchange and understanding of information in all long-term care settings:

- Functional illiteracy is a reality for many of our state's residents of all ages. It can be particularly troublesome when people become vulnerable due to compromised health and social isolation. According to the Centers for Medicare and Medicaid Services Active Resident Information Report for the first quarter of 2007, more than one-fourth of North Carolina's nursing home residents have obtained no more than an eighth grade education.[2] While we should be careful in linking schooling to functional literacy, it may still be an indicator of risk for effective communication. A recently released article in the *Archives of Internal Medicine* made national news with the finding that medically illiterate older patients were 50% more likely to die within the 6 years of the study than patients who understood basic written medical information and instructions about such conditions as asthma, diabetes, and heart disease.[3]
- Dementia itself denotes a cognitive impairment associated with a broad set of symptoms such as memory loss, confusion, compromised judgment, and, sometimes, personality changes or unusual behavior. Alzheimer's disease is the most common cause of dementia, affecting 1 in 10 people over age 65 years and nearly half of those over age 85 years.[4] More than one-half (57%) of North Carolina's nursing home residents have a dementia diagnosis, including about 20% diagnosed with Alzheimer's disease.[5] Struggling with depression or anxiety and other mental health issues can compound the effect of dementia and present significant communication challenges in their own right. Nearly one-half (46%) of nursing facility residents are diagnosed as depressed.[6]

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- Even patients with well-functioning cognitive skills can find themselves at high risk of exclusion from care decisions and possible mistreatment due to sensory losses, especially sight and hearing. As reported in our *2007-2011 State Aging Services Plan*, more than 1 in 4 North Carolinians age 75 years and older have severe visual and/or hearing impairment.[7] About one-quarter of North Carolina's nursing home residents are hearing impaired and nearly half are visually impaired.
- The high turnover rate among both professional and paraprofessional direct care workers creates higher risk for mistakes and an atmosphere of instability and unfamiliarity for workers and care recipients alike. In 2005 average turnover rates for direct-care staff were 116% in nursing facilities, 111% in adult care homes, and 46% among home care agencies.[7]
- The increasing presence of workers and patients for whom English is their second language can further aggravate other existing communication barriers. While a caring attitude can help overcome this barrier, a linguistic disconnect can nonetheless jeopardize quality of care. Beyond language, there are many other cultural differences associated with increasing racial and ethnic diversity. We cannot allow diversity to contribute to disparity in health care.
- With long-term care patients, physicians can find themselves especially dependent on how well other professionals convey and act upon information. Most often responding offsite to requests from multiple caregivers such as long-term care nurses, social workers, and pharmacists, the physician must trust that information is shared accurately through multiple sources and acted upon appropriately. The complexity of health care and health insurance only makes matters more risky for providers and patients in long-term care.

The importance of health literacy vis-à-vis long-term care will surely increase as North Carolina's population ages. Already 28 of our counties have more people age 60 years and older than 17 and younger—it is projected that seniors will outnumber young people in 75 counties by 2030.[7] Those working in the health and long-term care sector will be especially challenged with meeting the needs and demands of an aging population. The increasing interest in consumer-directed care is just one example of the changing landscape in the provision of services as more boomers join the ranks of those needing long-term care for themselves or their parents.

In this commentary, I focused more on residents of nursing facilities because descriptive data are generally more available on this population than those receiving services and supports in other settings. I want to emphasize, though, that the issues are certainly no less important—and in some ways more important—for those in assisted living or receiving home and community care where there is not likely to be around-the-clock professional assistance.

So the practitioner is left with many challenges—most, if not all, of which are well-known and experienced daily. The question, then, is how to respond in providing the best possible care for consumers of long-term services and supports in all settings. I propose 5 basic elements representing the fingers of a hand extended to assist the most vulnerable:

(1) *Don't assume—take time to know the person*. I recall another poem among my collections that many senior groups have appreciated. The key message is captured in the following verses: "You tell me that I'm getting old; I tell you that's not so. The 'house' I live in is worn out, and that, of course, I know…You only see the outside, which is all that most folks see. You tell me that I am getting old? You've mixed my 'house' with me."[8]

(2) *Show empathy for vulnerability and dependency*. The idea of putting yourself on the other side of the desk or bed should be a guiding principle. People with compromised health conditions and living environments should not have to also forego the patience and respect of others. Rather we should encourage and facilitate their participation in decisions whenever possible.

(3) *Recognize and appreciate the family caregiver*. The North Carolina Institute of Medicine's 2001 Task Force on Long-Term Care acknowledged that most long-term care is provided informally by family and friends.[9] In 2006, nearly one-quarter (24%) of adults in North Carolina reported providing regular care or assistance to a family member or friend.[10] Family caregivers are a vital conduit in the communications between patients and providers.

(4) *Encourage and support effective communication*. We need to practice what we know: give information in as simple and straightforward a manner as possible; give important information verbally and in writing; don't assume understanding—use the "teach back" method and ask questions to confirm it; be a good, reflective listener—"Now, Mrs. Jones, from what you have told me, you are mainly concerned about …."

(5) *Follow up*. For patients receiving long-term care in any setting, there is no substitute for following up on interactions with and for those patients to assure understanding and implementation of care plans, address patient confusion and anxiety, and identify and respond to any other issues. Effective relationships with facility staff are essential as is an understanding of the so-called aging and adult services network (eg, councils and departments on aging, senior centers, and county departments of social services) that assists the majority of those still living in the community who need long-term services and supports.

There is no well-kept secret to effective practitioner-patient communication in long-term care; rather, it involves the routine application of practices that are well known. While communication becomes more critical and yet more difficult with patients receiving long-term services and supports because of the many barriers, the practitioner's goal must remain to extend a caring hand to the most vulnerable who face chronic diseases, disabilities, losses, and end-of life decisions. **NCMJ**

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COMMENTARY

Developing an Informed Consent Process With Patient Understanding in Mind

Mary Ann Abrams, MD, MPH; Barb Earles, RN, MHA, CPHRM

As part of its 2003 Clinical Performance Improvement Strategic Plan, Iowa Health System incorporated health literacy as a cross-cutting, system-wide quality initiative.[1,2] With 10 senior hospital affiliates in 7 cities, a 14 rural hospital network, and 430 primary care physicians, Iowa Health System provides health care for a third of Iowans. Health literacy teams have been established at hospital affiliates, outpatient clinics, and home health agencies using the Model for Improvement,[3] learning sessions, conference calls, training workshops, and electronic communication to test and implement a variety of health literacy interventions. Iowa Health System's overarching health literacy goals are targeted toward improving interpersonal and written communication and creating a patient-centered care environment that welcomes questions and encourages dialogue.

Teams chose to improve consent documents and processes as part of their goals to improve patient understanding through plain language, teach back, and reader-friendly print materials. This was predicated on the increasing prominence of health literacy as a health care quality and safety priority; on case law involving communication of risks wherein claims have involved a lack of informed consent; and on concern that consent forms are written in language that patients cannot understand. Below we describe our rationale, experience, and lessons learned.

Building the Case

Health Literacy as a Quality and Safety Priority

Recognizing and communicating that a diverse set of leading health care organizations identify improving patient understanding during the informed consent process as an important quality and patient safety strategy helps garner support among physicians, staff, and organizational leaders.

The National Quality Forum (NQF) published *Safe Practices for Better Healthcare*[4] *in 2003.* Updated in 2006,[5] the report presents evidence-based practices that should be used universally to reduce the risk of harm in the health care setting. Safe Practice 2 (originally Safe Practice 10) states: "Ask each patient or legal surrogate to 'teach back' in his or her own words key information about the proposed treatments or procedures for which he or she is being asked to provide informed consent." Additional guidance is provided about teach back; reading level and language for consent documents; engaging in a dialogue about the procedure for which consent is being sought; and use of qualified medical interpreters or readers to assist those with limited English proficiency or health literacy, or visual or hearing impairments. Safe Practice 2 is relevant to practitioners in multiple clinical areas and to patient-centered care, especially for those who are particularly vulnerable to medical errors associated with communication barriers, including low health literacy.

> *"Iowa Health System's overarching health literacy goals are targeted toward improving interpersonal and written communication and creating a patient-centered care environment that welcomes questions and encourages dialogue."*

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The Safe Practices are included in the Hospital Quality and Safety Survey of the Leap Frog Group, an organization working to mobilize employer health care purchasing power to achieve breakthrough improvement in safety, quality, and affordability.[6]

The Joint Commission and Centers for Medicare and Medicaid Services promulgate standards and regulations related to informed consent. The Joint Commission standards address informed consent as stated in Standard RI.2.40—"Informed consent is obtained," and Standard PC.6.30—"The patient receives education and training specific to the patient's abilities as appropriate to the care, treatment, and services provided by the hospital." There are Centers for Medicare and Medicaid Services requirements related to informed consent for hospitals in several Conditions of Participation (CoP) (Patients' Rights CoP at 42 CFR 482.13(b)(2); Medical Records CoP at 482.24(c)(2)(v); Surgical Services CoP at 482.5 1(b)(2)). Revisions to interpretive guidelines in 2007 demonstrate continued emphasis on the importance of informed consent and patient involvement with informed decisions:

> The right to make informed decisions means that the patient or patient's representative is given the information needed in order to make 'informed' decisions regarding his/her care…The patient or the patient's representative should receive adequate information, provided in a manner that the patient or the patient's representative can understand, to assure that the patient can effectively exercise the right to make informed decisions. (Interpretive Guidelines §482.13(b)(2))

The American Medical Association (AMA) states, "Informed consent is more than simply getting a patient to sign a written consent form. It is a process of communication between a patient and physician that results in the patient's authorization or agreement to undergo a specific medical intervention."[7] In *Health Literacy and Patient Safety: Help Patients Understand. Reducing the Risk by Designing a Safer, Shame-Free Health Care Environment*,[8] the AMA states:

> Patient understanding is the first patient right and without such understanding there are limitations on the ability to exercise all other rights customarily credited or formally contracted to patients. This right is not one that physicians confer, but one they assist patients in exercising freely. It is neither just nor fair to expect a patient to make appropriate health decisions and safely manage his or her care without first understanding the information needed to do so.

This is underscored in the 2005 White House Conference on Aging proceedings:

> "Patients have the right to understand healthcare information that is necessary for them to safely care for themselves, and to choose among available alternatives. Healthcare providers have a duty to provide information in simple, clear, and plain language and to check that patients have understood the information before ending the conversation."[9]

Case Law

National case law addresses the way risk is communicated and recognizes that claims have involved lack of informed consent. Informed consent is a process, not merely the signing of a document. Consent documents, in conjunction with provider documentation, are used as evidence that informed consent was given. Studies have shown that 18% to 45% of patients are unable to recall the major risks of their surgery; 44% do not know the exact nature of their operation; and 60% to 69% do not read or understand the information contained in a hospital consent form.[10] Legally, a signed consent form is not proof of informed consent. If the patient does not understand, the form is meaningless.

Readability

In Health Literacy: A Prescription to End Confusion, the Institute of Medicine of the National Academies found that the readability levels of informed consent documents for research and clinical practice exceed the documented reading levels of the majority of adults in the United States, and that this has important ethical and legal implications that have not been fully explored.[1] Readability analyses from representative Iowa Health System senior hospital affiliate consent forms demonstrated that many were written at or above 17th grade level.

The Iowa Health System Experience

In 2004, the trends described above led Iowa Health System to embark on its work to create a reader-friendly written consent document to prompt action on the informed consent process using teach back. Beginning with the Consent for Surgery/Procedure document, an iterative process was used to develop a plain language consent that improved readability and patients' understanding, ability to make informed choices, and satisfaction. The revised document was also intended to help providers ensure that patients understand their procedures and have the ability to ask questions as needed while not adding complexity to the perioperative care environment. The consent was developed in collaboration with Iowa Health System health literacy teams, risk managers, health care providers, the Iowa Health System Law Department, and adult learners who reviewed multiple drafts, clarifying terms, content, and design. A cardinal feature of the consent is a space for description of the procedure not only in medical terms, but also in the patient's own words—a form of teach back. Plain language characteristics of the new consent include: simple words; short sentences; short paragraphs; minimal medical terms; clear headings, bullets, and numbering; generous white space; 12-14 point serif fonts; key uses of bold text; and 1.5 line spacing. The final document has a seventh to eighth grade reading level calculated manually using the Fry formula and electronically using *Readability Calculations* software.[11]

When team members had agreed on a near-final draft, an evaluation tool was developed for pilot testing at a single hospital. Data were collected using the original consent form followed by the new consent form on patient demographics and procedure type; time to complete the document; whether the consent was actually read; who read it (eg, patient, family, and/or nurse to patient/family); ease of patients in recounting the name of the surgery in their own words (teach back); questions asked by patients or their families during the consent discussion; and patient/family and nurse satisfaction with the process and new consent form.

Results were positive for all types of patients and procedures. Patients and staff reported high satisfaction with the reader-friendly form and process. Nurses did not find that asking for teach back (description of the procedure in the patients' own words) during the consent process was awkward; all respondents moderately/highly valued this use of teach back. Nurses also reported it was much easier to clearly evaluate patients' knowledge about their surgery, and patients' comfort level in asking questions was enhanced by the "permission" wording on the form. Patients/families reported appreciation of the easier-to-read format and being asked to state in their own words the description of their surgery. Increases in time, interruptions, or extra calls to physicians for clarifications or answers to questions that arose when patients actually read and understood the consent document have not been reported.

Following communication with key departments, senior administration, physicians, and thought/opinion leaders, the first pilot hospital adopted the new consent document for all surgical procedures. Three hospitals followed, and a fifth hospital recently initiated pilot testing. Testing is repeated at each hospital, somewhat more rapidly, to build will, acquire local data, and problem solve at the local level. Each affiliate is asked to chronicle their experience so others can learn from their work. As support for the new consent increases, widespread implementation at other affiliate hospitals occasionally has to be tempered as pilot testing, communication, and staff and provider education are conducted.

Additional health literacy-related consent work continues. The new Surgery/Procedure consent has been translated into Spanish with additional pilot testing. English and Spanish versions of a Blood/Transfusion consent have been developed and are being pilot tested by the hospitals. Work has begun on a Consent for Procedure by Non-Physician Providers.

Lessons Learned and Keys to Success

Building support among physicians, staff, and senior leaders requires underscoring the increasing focus on health literacy by professional, payer, accrediting, and regulatory organizations; health literacy's relationship to risk management; and evidence demonstrating the impact of low health literacy and its integral role in the informed consent process.

Documenting the processes of testing and adopting new forms, conducting pilot tests, communicating proactively with affected leaders, departments, and committees, and continuously learning from others' experience build will, provide local data to support the effort, and help navigate potential roadblocks. It is important to involve all those with roles in the consent process, organizational change, and quality of care. It is equally and vitally important to include patients and adult learners. Patient input and feedback helped structure the ultimate content and layout of the new consent and provided an effective counterpoint to arguments against simplification.

All providers must be educated about the difference between the informed consent process and the consent form. Signing the consent form alone is not sufficient to meet legal requirements for informed consent. It is the role of the provider to discuss, through a process of shared decision making, the recommended surgery, procedure, treatment plan, anesthesia, or other service. Physicians then need to be sure patients understand what is being recommended, its risks and benefits, other options and their risks and benefits, and risks and benefits of no treatment before patients make a decision.

Providers and staff also should be educated about the need to use simpler language and teach back. Building capacity on use of teach back should be part of improving the informed consent process because asking patients to describe or repeat back in their own words what they understood they have been told is our way to make sure they really understand. If gaps or misunderstandings are heard, further teaching can be done. Ultimately and ideally, teach back will be interwoven throughout the entire informed consent discussion, even if additional assistance (eg, trained interpreters) must be provided to help patients understand.

Other health care organizations are also working to improve the consent process.[12,13,14] Their efforts include standardized education using employee orientation and ongoing educational and peer reinforcement and requiring documentation of teach back on the consent form or in the health care record prior to the procedure.

As additional Iowa Health System affiliates adopt the reader-friendly consent, continuing emphasis will center on moving beyond use of the new form toward incorporating teach back to check for and ensure understanding and documenting these discussions during everyday interactions with patients and families. In the context of patient-centered care, consent is a shared decision-making process between the patient and their provider, not an event or a signature on a form. True informed consent is a core component of quality health care.

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Cultivating Patient-Centered Communication Skills Training Across the Medical Education Continuum:

A Model for Practice

Gail S. Marion, PA-C, PhD; Sonia J. Crandall, PhD; Frank Celestino, MD; William McCann, PsyD; Julienne Kirk, PharmD

Effective patient-centered communication improves trust, patient satisfaction, health literacy, and health outcomes and reduces health disparities and law suits that occur due to poor communication.[1-3] For these reasons competency guidelines outlined by the Accreditation Council for Graduate Medical Education,[4] the Liaison Committee on Medical Education, Accreditation Review Commission on Education for the Physician Assistant,[5] and the Association of American Medical Colleges[6] require that communication skills training be mandated in undergraduate and graduate medical education. The Institute of Medicine of the National Academies report "Improving Medical Education" concluded that basic and complex communication skills are a "high priority"[2] in medical education.

Despite growing evidence that patient-centered care improves health outcomes, medical students receive mixed messages.[7] In preclinical communications courses in US medical schools, educators use available evidence to teach students to be open, reflective, and patient-centered, while in clinical clerkships students often witness directive, doctor-centered communication by those who have not had the training that current students receive.[8,9] At Wake Forest University School of Medicine Department of Family and Community Medicine our goal is to cultivate culturally competent, patient-centered communication skills across the continuum of medical education to more effectively address health literacy needs, reduce health disparities, and improve health outcomes. Since 2000, 5 Title VII Health Resources and Services Administration grants have facilitated the development of a culturally competent, patient-centered communication curriculum for faculty, family medicine residents, and medical and physician assistant (PA) students. Each grant was envisioned as a step towards the long-range process necessary to create patient-centered teachers, clinicians, and students. This article presents an overview of curricular innovations, the evaluation process, early outcomes, and next steps.

> *"Despite growing evidence that patient-centered care improves health outcomes, medical students receive mixed messages."*

The curriculum across learner groups (faculty, residents, medical and PA students) was developed using Common Ground,[10] a criteria-based training model derived from the Kalamazoo Consensus Statement.[11] This model was adopted for

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its ease of use in the clinical setting and for the associated Common Ground Assessment Instrument (CGAI) which has construct validity, internal consistency, test-retest reliability, and generalizability across clinical cases.[10] The model includes 6 core skills: rapport building, agenda setting, information management, active listening, addressing feelings, and reaching common ground. The curriculum was incorporated into faculty development, residency training, and medical student training in the Department of Family and Community Medicine and also into the curriculum of the Department of Physician Assistant Studies. The following sections describe the activities into which the curriculum was included.

Department of Family and Community Medicine Activities

Faculty Development

An Administrative Units award provided infrastructure support for patient-centered communications research and funded 6 faculty pilot projects. Outcomes of this grant led to several other communications research projects including 2 National Cancer Institute grants, and to numerous presentations, publications, and curricular innovations.

Residency Training

A residency training award facilitated development of a cultural competency curriculum for residents and medical Spanish and immersion training in Guatemala for faculty, staff, and residents. It also fostered ties with 2 Latino clinics. Outcomes of this grant included the addition of 20 hours of communication skills training provided during the Human Behavior Rotation for first-year residents. Evidence indicates mindfulness training may improve a physician's self-awareness and other-awareness, help decrease anxiety, and help develop a relaxed alertness that might contribute to the incorporation of communication skills in clinical practice.[12-14] The new training includes (1) relaxation/ mindfulness training and practice including an examination of their roles in development of higher order communication skills; (2) introduction to and practice with the CGAI; and (3) videotape reviews of residents' patient encounters using the CGAI. Common Ground skills are reinforced during the required geriatric outpatient rotation in the second year. During the second and third years, residents attend a Balint support group which provides an opportunity to consider how patient-centered communication can facilitate patient care.

Medical Student Curriculum

A predoctoral training grant allowed us to develop a collaborative project with the Departments of General Internal Medicine and Pediatrics to implement a communication skills curriculum in 3 third-year clerkships. This grant facilitated a continuity experience for clinical students to further develop and refine patient-centered communication skills taught in the preclinical years to better serve diverse and vulnerable patient populations.

We worked with the course and clerkship directors to revise the first-year communications course and with the family medicine clerkship patient simulation to reflect the Common Ground skills. All evaluation instruments and the interview skills template used by the students are explicitly linked to the Common Ground skills domains. Three new standardized patient assessments focusing on vulnerable and high-risk patients were designed for and implemented in the third year ambulatory care clerkships. In the last 2 years we trained nonfaculty raters to reliably assess students' communication skills using the Common Ground criteria.

Outcomes of this grant led to the training of over 90 faculty, nonfaculty, and community preceptors as raters to reliably assess communication skills throughout 4 years of the curriculum. Use of the CGAI has helped to ensure that we are evaluating communication skills objectively across multiple assessments in preclinical and clinical years. To evaluate effectiveness of the communications curriculum, the trained nonfaculty raters were randomly assigned student interviews from the standardized patient assessments to rate. To date, they have reviewed over 3000 videotaped interviews to find that skills have significantly improved across 3 classes of first-year medical students. The next step is to evaluate longitudinal data which include a total of 14 digitally recorded video encounters per student from baseline to graduation.

Department of Physician Assistant Studies Activities

A recently completed grant established a culturally competent, patient-centered curriculum. For first-year students, core communications elements were incorporated. Students are oriented to Common Ground while reviewing DVDs of clinician-patient dyads using the CGAI. In small groups, students practice using patient-centered skills with standardized patients. To further improve communication skills students participate in a required medical Spanish course and are trained and evaluated on effective use of medical interpreters. Eight standardized patient assessments over both years and site visits in the clinical year are used to evaluate these skills. Outcomes include (1) significantly improved patient-centered communication skills across the last 2 classes (nonfaculty raters have reviewed over 1000 randomly assigned recorded interviews); (2) effective student interaction with interpreters and an increased student ability to use medical Spanish in the clinical setting; and (3) completion of an international Spanish language immersion program by 17 students.

Because we know there is no one factor more predictive of poor health status than low health literacy,[3] the current grant is devoted to integrating health literacy throughout both years (preclinical and clinical) of training; this new component will be embedded in the well-established patient-centered communications curriculum within the clinical applications and professionalism courses. Skill 6 of the Common Ground model trains learners how to (1) summarize the patient's problems and concerns; (2) check for understanding; (3) check for feasibility; (4) check for agreement;

and (5) establish mutual responsibility for the plan. Using this guide, students will consider health literacy as well as cultural, financial, and other factors as they develop a plan with the patient that effectively ties the visit to what happens when the patient leaves the office. Among other teaching strategies, standardized patient instructors (portraying patients who need to stop using tobacco or alcohol, lose weight, exercise more, or manage diabetes) will provide the students with multiple opportunities to practice and receive feedback (using validated instruments) to further develop these skills to care for patients in the clinical year. All students are required to review and self-assess their video recorded encounters after they receive feedback from the standardized patient assessments to improve future performance. These skills will be assessed and reinforced during site visits and standardized patient assessments in year 2 on at least 4 occasions.

Conclusion

Common Ground is highly transportable. Currently, among others, it is used in the California medical schools. We have trained faculty at other medical schools and physician assistant programs in North Carolina and Virginia. The model and its associated criteria-based instrument make it feasible to provide basic training for faculty in about 4 hours. With schools looking for ways to provide communication skills training in undergraduate and graduate medical education, this model offers an ideal method to incorporate patient-centered communication into clinical training programs. Health Resources and Services Administration or other medical education funding to incorporate this curriculum is helpful, but not essential because the model and curriculum materials lend themselves to relatively short training.

Future goals of the Wake Forest University School of Medicine include translating these curricula and outcomes to other health disciplines, providing an advanced communication skills elective for fourth-year medical students, and developing patient-centered communication curriculums for practicing clinicians to address health literacy assessment and use. Goethe wrote, “Knowing is not enough: we must apply. Willing is not enough; we must do.” Growing evidence suggests that we are not applying what we know and are failing to provide adequate care for millions of patients in a country with the most expensive health care system in the world using doctor-centered models of care.[15] We must be willing to do what is necessary to produce effective patient-centered clinicians to improve health outcomes for our patients. **NCMJ**

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COMMENTARY

Communicating Health Information to English as a Second Language Patients

H. Nolo Martinez, MS, PhD

Large numbers of immigrants have settled in North Carolina in recent years. The immigrant population grew 58.1% (373 000 to 590 000) between 2000 and 2005. Most immigrants are unfamiliar with the basics of the US health care system and lack adequate knowledge to make informed decisions about their own health. These difficulties block many immigrants from attaining self-sufficiency and becoming full participants in our society. Basic health literacy and assistance gaining access to community resources could prevent these families from becoming mired in poor health for generations.

The University of North Carolina at Greensboro Center for New North Carolinians Immigrant Health ACCESS Project recognizes language and cultural barriers as principal health care problems for over 50% of new immigrants in North Carolina, as defined by both the providers and the limited English speaking community. Most newcomers have limited English proficiency, utilize traditional health practices from their cultures, live close to the poverty level with inadequate health insurance, work in hazardous jobs, and have limited familiarity with our health systems or preventive health practices.

With more than a dozen different major ethnicities in the state and an immigrant population that represents several different demographic profiles, languages, cultures, and needs, North Carolina health providers face extraordinary challenges. How well and how rapidly we replenish the bilingual and bicultural health care practitioner workforce in our state determines our ability to eliminate language barriers, improve health behavior of new immigrants, and save on scarce financial resources in order to reach more residents, newcomers, and the uninsured.

The state of North Carolina does not yet have enough bilingual health care personnel and culturally appropriate policies in place to fully tackle disparities among immigrants in the state. Title VI of the Civil Rights Act of 1964 requires that limited English proficiency populations have access to "culturally and linguistically appropriate services" at no cost to the client. Health providers, including both public and private entities that receive federal funds, are required to take reasonable steps to ensure meaningful access to the information, programs, and services they provide. Very few North Carolina providers offer services in multiple languages through qualified interpreters. Some rely on family members, including children, or use untrained or unqualified interpreters, thus creating ethical and confidentiality issues.

> *"Health care practitioners are often unfamiliar with the traditional practices of their patients and may not ascertain what interventions the patient is already using or willing to use, thus creating an additional health hazard."*

Cultural competency gaps magnify the health communication problems. Health care practitioners are often unfamiliar with the traditional practices of their patients and may not ascertain what interventions the patient is already using or willing to use, thus creating an additional health hazard. Newcomer immigrant patients who are unfamiliar with US health practices do not know how to best access health systems, put into practice preventive

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health behavior, or use medications as directed.

A large number of new North Carolina immigrant residents do not have the English-speaking capabilities to fully access health care, and practitioners cannot communicate in the patients' languages. As a consequence, patients are not able to speak freely with their practitioners and do not receive information on how they can better take care of themselves or their families. If the practitioners cannot explain to their patients their conditions, they cannot tell the patients why or how to follow lifestyle changes or explain why medication is necessary. Limited English proficiency immigrant patients cannot ask questions or make agreed upon changes to their treatments with their practitioners.

Communication barriers are not only connected to the inability to speak English. Immigrant residents in North Carolina show some cultural behaviors that interfere with health communication:

- Some immigrants have identified the stigma of being a refugee as a detriment. It destroys their sense of being part of the general community and may create barriers of mistrust with the health care provider, which makes communication difficult.
- Immigrant patients may be troubled when health care practitioners ask many personal questions, take notes of conversations, and fill out forms
- Men may particularly feel that talking about suffering is a sign of weakness and may be reluctant to talk about psychological dimensions of pain.
- Due to misunderstanding the role of some health care professionals (eg, nurses), some patients may feel discriminated against and refuse communication.
- People who are not confident with their English proficiency may refuse to disclose information to medical professionals.
- Many find it difficult to follow the legal procedures in North Carolina but may not ask for advice.

The key to ensuring meaningful health access for limited English patients is the ability to reach effective communication between the patient and the health provider. One strategy to achieve more effective communication, in addition to complying with the terms of Title VI to provide culturally and linguistically appropriate services, includes using trained and culturally competent interpreters. Improving the quality of interpreter services can reduce health costs, increase prevention efforts, and decrease primary care use by non-English speaking residents. Another strategy is to assist case management efforts of safety net providers by using lay health advisors to support immigrant clients' better understanding and navigation of the health care system. Lay health advisors are trusted members of the communities in which they serve. Their assistance can help immigrant clients develop stronger relationships with their practitioners.

Cultural competence means the capability and will of a provider or service delivery system to respond to the unique needs of an individual considering the culture of the person. Using interpreters and lay health advisors as cultural brokers can help health providers attain knowledge regarding beliefs, cultural values, and preferences. This knowledge becomes critical when a practitioner creates interventions to meet a person's needs. Immigrant lay health advisers have the ability to use the individual's culture as a resource or tool to aid in the intervention and explain the health needs or problems. The capacity to provide equal access to individuals from different cultural and linguistic populations results from the new understanding of immigrants' distinct needs which is gained through collaboration with lay health advisors. Culture gives meaning to health communication and provides the context for understanding health information. Health literacy education programs must be developed to reflect the unique language and cultural backgrounds of North Carolina's immigrant populations.

Communicating with patients who have limited English proficiency requires more than just finding someone who speaks their language to assist with interpretation. According to the Civil Rights Act of 1964 and Executive Order 13166, patients with limited English proficiency have the right to a trained interpreter. Trained language interpreters have formal education in interpreting and abide by a professional code of ethics that includes confidentiality, impartiality, accuracy, and respect. Good medical interpreters are not only fluent; they are also familiar with medical terminology and have experience in health care. Although there are several accredited training programs for medical interpreters, there is no national certification. Only the state of Washington offers state testing and certification. The University of North Carolina at Greensboro Center for New North Carolinians has developed curricula and testing to certify that North Carolina health interpreters have received training and certification.

A great obstacle to the practitioner-patient relationship or therapeutic bond happens when a language barrier exists between the practitioner and patient. More attention needs to be given to the process of language translation during this interaction. Some have suggested increasing the number of Spanish and other language courses for practitioners as an option for reducing the language barrier. I encourage the learning of other languages, but a quick or survival language course can also lead to significant mistakes on the part of the practitioner. Unless the practitioner is fluent in the language, it is prudent to always use an interpreter, especially following the exam, to ensure and document patient understanding. The interpreter should ask the patient if he or she has any additional questions and then request that the patient repeat back any instructions from the practitioner.

Most providers use translation of messages, documents, and materials into other languages to reach nonnative speakers of English. This process is flawed because the English language, especially technical language concerning complex medical topics, does not always translate well into other languages and may result in misrepresentations and misunderstandings. Furthermore, translating documents is also complicated by the sheer number of different languages used by residents in North Carolina. It is a tremendous and expensive challenge to translate health communication materials into a range of different languages, and meaning can be lost in translation.

Nevertheless, language is important for both access to and quality of care. Using trained and qualified interpreters can and should be implemented to improve access to health information for consumers who are not native English speakers. Health literacy is a complex issue, and improvements in the health literacy of limited English proficient clients require a variety of approaches. Health literacy not only involves the communication skills and abilities of immigrants to understand spoken, written, and mass-media communication about health and health care, but it also involves the communication skills and disposition of health care providers and the support of those that understand the client's culture and language. Effective health communication with thousands of new North Carolinians must be interactive and adaptive, utilizing many different channels of communication.

North Carolinians are well aware of the increasing diversity across the state. In grocery stores in any county one can hear multiple languages and dialects spoken. Visiting reception areas of any of our health service agencies, one will encounter people from many cultural backgrounds. The public schools report that more than 90 different languages are spoken in the home of children enrolled throughout our state's educational system. Human service providers and educators are challenged to find the best way to meet the needs of an increasingly diverse population. Partnerships between lay health advisors, qualified interpreters, health care providers, and consumers who desperately need relevant health information can help overcome many problems related to health literacy. **NCMJ**

Identifying and Addressing Communication Failures as a Means of Reducing Unnecessary Malpractice Claims

Gerald B. Hickson, MD; A. Dale Jenkins

Substantial research provides clear evidence of the relationship between communication failures and malpractice claims. Communication failures among health care practitioners are associated with most avoidable adverse outcomes.[1,2,3] Poor communication skills also adversely impact patient-provider relationships, increasing the likelihood that families sue when faced with adverse outcomes whether or not errors have occurred.[4,5,6]

In spite of the research, many within medicine cling to myths concerning why they get involved in claims, asserting, "Everyone in my specialty gets sued," or "It's just a cost of doing business." Others contend they attract litigation-prone patients or attend to the most challenging cases. Unfortunately, such myths pose a stumbling block to one approach to reducing malpractice claims that everyone should support: identifying and addressing ways to promote improved patient-practitioner communication.

Our goal is to focus on just one factor promoting lawsuit generation—poor practitioner communication skills. We will review research concerning why families file suit, why some practitioners have a "dark cloud," and the role that poor provider communication skills play in observed claims' disproportionality. Finally, we will offer suggestions concerning what health care practitioners can do to identify and address risk.

Studies reviewed widely in the media by researchers at Harvard focused national attention on errors in medicine. Their studies involving chart review suggested that 1% to 2% of hospitalized patients in the US experience adverse outcomes due to medical errors.[7,8] Study results should convince us that we share a duty to make medicine safer. How to make medicine safer is beyond the scope of this commentary, but we do want to focus on an often overlooked finding that suggests another problem needing attention. In completing thousands of reviews, the Harvard team identified cases where errors caused adverse outcomes and where families filed suit. However, for every family who filed a "valid" claim, the Harvard team identified 5 families who sued with no evidence of negligence.[9] Such findings are consistent with information from state-based claims reporting. Data from the state of Tennessee reveals that in 2006 over 80% of closed malpractice claims were dropped without an award or settlement.[10]

When such data are reviewed, many practitioners fall back on their old myths or seek to blame the plaintiff bar without asking two questions: Why are so many nonvalid claims filed, and is there anything we can do? Nonvalid claims create burdens for the families filing them because many relive painful experiences, for the practitioners who are named because they may experience emotions from anger to depression, and for members of society who ultimately pay the bill.

To understand why people sue, you begin by asking families who have filed claims. Although such studies are subject to recall bias, they provide evidence of how communication failures prompt some families to sue. When asked what prompted them to seek legal advice 25% of families interviewed mention the need for money.[4] Most, however, cited noneconomic reasons

> *"...risk is predicted by the practitioner's inability to communicate effectively and establish and maintain rapport with patients, especially in the face of an adverse event."*

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including belief in cover-ups and the need for information.[4,5] Results also highlight how often families believe that no one ever expressed concern about the family's loss or offered an apology in the face of what the family believed was an error.

Studies examining why some physicians attract more than their fair share of lawsuits offer additional insight into how poor communication skills promote claims. Sloan and colleagues reported that physicians can be sorted into 3 risk groups: those with no suits, those with an occasional claim, and a third group with high claims. Between 2% and 8% of physicians by specialty account for more than one-half of all malpractice-related costs.[11] In a follow-up study, Bovbjerg identified that claims experience is constant over time such that physicians at high malpractice risk today will be at high risk tomorrow.[12] Study results raise an obvious question: Why do certain physicians generate so many suits? Multiple hypotheses have been proposed, but studies reveal that individual claims experience is not predicted by patient characteristics, illness complexity, or even the physician's technical skills.[13,14] Instead, risk is predicted by the practitioner's inability to communicate effectively and establish and maintain rapport with patients, especially in the face of an adverse event.[4,6,13,14] In a study examining perceptions of care, patients seeing high-risk obstetricians were 3 times more likely to assert that their physicians would not answer questions or listen when compared with families seeing obstetricians with no malpractice claims.[14] Over 30% of study subjects seeing high-risk physicians voiced dissatisfactions with care even after delivering healthy newborns.

In spite of evidence linking poor communication skills with claims experience, the question remains: Is there really anything that can be done to reduce risk? In response to this question, researchers with the Vanderbilt Center for Patient and Professional Advocacy developed 2 hypotheses. First, high-risk providers are unaware of their status. Second, if made aware, many will seek to change their practices or communication behaviors in ways to reduce risk.

To help make high-risk physicians aware of their status, the team sought a proxy for malpractice claims that is linked to risk events but occurs frequently enough to be counted and fed back to the at-risk clinicians. Many groups, clinics, and hospitals have patient advocates, called ombudsmen, who listen to families who are dissatisfied with care. Advocates record the stories and attempt to address what is perceived as wrong. Analysis of thousands of stories reveals that unsolicited complaints are not randomly distributed. Just like malpractice claims, 30% to 50% of practitioners never attract a complaint. An equal number get an occasional complaint. However, when coded for complaint type (34 separate categories) by practitioner, the complaint reports can be used to reliably identify a small subset of physicians (4% to 8% of any group) who account for over 40% of claims and 50% of all malpractice-related costs.[15,16]

The Vanderbilt team then turned its attention to how complaint data could be used to promote awareness. At each study site, peer messengers are trained to deliver intervention materials to their at-risk colleagues, including (1) a report card illustrating the individual's relative ranking, (2) a table illustrating the complaint type distribution, and (3) the actual complaint text so physicians can review and gain insight.[17,18] Visits average just over 30 minutes and are mostly received professionally. Currently, the identification and intervention model is operational in 25 geographically-distributed sites (from free-standing group practices to major medical centers) with over 16 000 medical practitioners assessed yearly.

Intervention results are encouraging and reveal that many high-risk practitioners, when made aware, address recurring sources of patient dissatisfaction within their practices.[18] Just under 60% of those receiving awareness interventions respond. Unfortunately, approximately 20% depart their practices, some seeking what is referred to as a "geographic solution," while an equal number require an authority-based intervention that mandates anything from a practice review to a comprehensive mental health evaluation.

The intervention study affirms that practitioners can act to reduce sources of patient dissatisfaction that promote risk within their practices. The study also provides important insight into common communication failures that promote risk. Review of over 200 000 unsolicited patient complaint reports leads us to a few suggestions that should benefit any provider who wants to improve patient-practitioner communication even if only for the purpose of reducing personal malpractice risk. These include making patients feel respected, using the informed consent process to build practitioner-patient relationships, and letting patients know the practitioner cares about feedback.

The first important strategy is for practitioners to send clear messages to their patients that they are respected as fellow humans. For a host of reasons, including anxiety, illness complexity, and the pressures of modern medical practice, patients sometimes can perceive a loss of connectedness with their health care providers. Such a loss impacts quality of medical history-taking, adherence with medical care plans, and risk of litigation. Practical means of sending a message of respect were identified in a study by Levinson.[19] They include attention to body language (Do you look rushed?), efforts to solicit patients' opinions ("Which option seems most workable for you?"), and encouraging patients to talk ("What can we talk about today?" followed by a mandatory pause). Such strategies take time. However, in the Levinson study, providers modeling respect-generating strategies averaged just over 3 minutes more per encounter than their colleagues who did not but who were subjects to suits.

Another strategy for improving communication suggests the practitioner view the informed consent process as an opportunity for relationship building. Review of unsolicited complaint reports reveal that families often express uncertainty about the intended procedures including what they should expect, risks versus benefits, and specifically, when they will get follow-up information. One predictor of malpractice risk is a patient's assertion that the practitioner involved failed to show up after the procedure. We commend national efforts to promote teach back in association with informed consent.[20] Patients should have an opportunity to describe back to the practitioner the proposed procedure, the most common complications, and when they should expect a follow-up discussion.

The final recommended step for improving communication is for practitioners to send the message that they want to hear from their patients, especially if the patients are dissatisfied. Both marketing and medical studies reveal that most families who experience significant dissatisfaction with care are hesitant to speak up to the provider involved or a representative of the group.[21,22] Consequently, hospitals and medical groups may fail to recognize recurrent sources of dissatisfaction that put them at risk. Most of us tend to be defensive in the face of a complaint, but complaints, if seen as an opportunity to learn, offer an important key to identifying and addressing unnecessary malpractice risk as well as a way of allowing patients to have a role in improving care for everyone. **NCMJ**

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COMMENTARY

A Perspective on Doctor-Patient Communication in the Dental Office

M. Alec Parker, DMD

> *"Think like a wise man, but communicate in the language of the people."*
> W. B. Yeats

The awareness of the importance of health literacy has synergistically combined with concerns regarding disparities in access to care, questions relative to patients rights, and the growth of consumerism to initiate a reevaluation of how the various health professions communicate with their patients on a daily basis. Practitioners are beginning to examine not only how they communicate but how well the information is being received, understood, and applied to create a more positive outcome for those they counsel and serve. These types of questions have been debated for several years within the dental community, and due to that ongoing discussion I believe the dental profession may be more advanced in this arena than other health professions.

Dentistry has been exploring this issue for quite some time since most people view dental treatment decisions as being more elective than those made in medical offices. Up until recently, this has seemed to be a reasonable assumption given that most dental problems were not perceived as being directly related to systemic disease or as potentially life-threatening. However, new research strongly suggests that there are indeed associations between chronic oral infections and heart and lung diseases, diabetes, stroke, and preterm low birth weight. Therefore, the ability to clearly communicate with patients has taken on a new level of importance from the perspective of the practitioner as well as the patient and other health professionals.

Communication Styles

Currently, dentists use a variety of approaches to help patients understand their oral health status and ways to help make it better. Since most dental school curriculums do not include courses to improve communication skills, most practitioners graduate without any guidance as to how to effectively deliver the information they have acquired. Many dentists don't go any further than merely telling the patient the results of the exam and the recommended treatment. There is no attempt to involve the patient in the discovery or decision-making process. While the paternalistic style of doctor-patient communication may have produced the desired outcome for patients of previous generations, members of the current generations want to be more involved in their health care. The rise of consumerism coupled with a more informed public has sown the seeds for a more interactive communication dynamic. In fact, many dentists have begun to define the people they serve as "clients" rather than "patients." This change in perspective serves to remind dental teams that the people they serve want to be more involved in decisions regarding the care they receive. Many

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patients arrive in the practitioner's office having already done research on the Internet. They are better prepared to ask questions and no longer want to abdicate treatment decisions to the dentist or other members of the dental team. Today, clients seeking dental care expect to have proposed treatment plans presented in an understandable format and to have the opportunity to discuss the merits of possible alternative procedures. They want to be informed consumers and expect practitioners to provide the facts they need to make a decision that best fits their personal goals and values.

In order to assist patients in the decision-making process, some dentists have realized that they need to make a more concerted effort to deliver their findings in a comprehensible form. In fact, one of the more frequently cited barriers to oral health literacy identified by consumers is the practitioners' use of technical dental terminology during their conversations with patients. Although the use of dental jargon seeks to provide clarity when used among dental professionals, its use with consumers tends to widen the communication gap. Unfortunately, most dental teams have not been trained to convey technical thoughts using less intimidating terminology. In many instances, while the dental team may have spent an adequate amount of time informing a patient about their oral conditions and making sound treatment recommendations, the overusage of technical jargon results in patients leaving the office more bewildered than when they arrived.

To further complicate the issue, most patients are reluctant to admit they do not fully understand the explanation delivered by the practitioner. Exacerbating this is the fact that many dentists tend to be introverts and are not comfortable with confrontation. This lack of confrontational tolerance may imply to some patients that their questions are not welcome, thus setting up additional barriers to further understanding by both parties. To counterbalance this situation, many dentists who possess an introverted personality elect to utilize dental auxiliary personnel with more open communication styles to help patients feel more comfortable asking for additional information.

Dental Technology

The ever-expanding use of dental technology has greatly contributed to the ability of the dental team to bridge some of the communication gaps that previously existed in dentistry. Most of these new technologies seek to provide patients with the ability to better comprehend their oral health status. Others provide an opportunity for patients to view possible treatment options that may provide solutions. The first technological breakthrough in this arena was the intraoral camera. This device consists of a small camera lens and a light source positioned in a wand-like device that enables the operator to capture magnified, high resolution intraoral images that are instantly visible to both the patient and the practitioner on a video monitor. Using a close focusing lens, the camera captures views of the oral cavity that have previously gone unnoticed by the average patient. From a patient education and communication perspective, one of the more useful features is the use of split screen views to illustrate and compare normal, healthy oral structures with those that may exhibit pathology. These images seem to stimulate both curiosity and concern from most observers. It provides the practitioner the opportunity to answer questions that, perhaps for the first time, are truly meaningful to patients since they can relate the images uniquely to their own personal situations or symptoms. When patients are presented with personalized health information and given the opportunity to ask more questions, an environment is created that is much more conducive to learning than situations where patients are presented with a generic brochure that may be poorly written and difficult to understand.

Another technological innovation is the use of digital radiography. In addition to allowing dental personnel to take radiographs at a much lower exposure level than that of traditional radiographs, the instantaneous viewing of captured radiographic images is a major step in assisting clinicians in their diagnostic procedures. These images are magnified and projected on a computer monitor providing greater detail and legibility than the small intraoral films used in the past. Dental team members utilize computer monitors located in the treatment rooms to assist patients in learning what structures are visible on the image and why they are relevant. Like the images taken by the intraoral camera, digital radiographic images may be used as a baseline measurement as well as an adjunct to dentists when helping patients to understand their current dental conditions. Conditions such as decay, abscessed teeth, impacted teeth, and periodontal disease are readily visible on digital radiographs.

Specially configured digital cameras have also become available and are a wonderful communication tool. Using a macro lens and specialized flash designs, these cameras can capture oral conditions in great detail. Those images are useful in many ways to the practitioner for the benefit of the patient. A growing number of dentists use the digital camera as frequently as radiographs to render a diagnostic opinion, especially when the area of concern includes a soft tissue component. Examples of soft tissue parameters that are better illustrated using a photograph include gingival inflammation, swelling, recession, or the presence of exudate. Prior to rendering a diagnostic opinion, those images may be sent to other practitioners, including dental specialists, to provide the most comprehensive information to the patient.

The field of dentistry that has experienced the most growth in recent years is cosmetic dentistry. Practitioners who provide cosmetic services have become highly dependent upon digital photography to communicate with patients. Sophisticated software programs utilize imported digital photographs that permit dental personnel to provide clinically accurate renderings of various cosmetic procedures for patient consideration. Dentists also use these images to illustrate desired cosmetic changes to laboratory personnel who may not have the benefit of direct communication with the patient.

Any discussion of technology relating to patient communication would be incomplete without mentioning the growing use of software programs that allow patients to better understand treatment options. These programs usually provide visual presentations of treatment choices delivered in easily understandable terms by a professional vocalist. Some vendors even offer interactive software that allows the viewer to control not only the subject of the information but also how the message is delivered. Although these new technological advances can come with a steep price tag, most dentists feel that the expense is justified since it invariably helps patients make better choices. It also provides the patient with a consistent message, thereby eliminating the possibility that important points might be inadvertently omitted from the discussion by the dentist or auxiliary personnel.

While technology has definitely had a positive impact on dentistry's ability to communicate with patients, there is no substitute for the personal touch. In fact, any attempt on the part of the practitioner to humanize the health care experience will be appreciated. Most people prefer health care professionals who are truly interested in them as persons rather than just being remembered as a number or a name on a chart. The challenge for the practitioner is to develop a delivery model that allows this interaction to take place without sacrificing timeliness and efficiency. Many practitioners have come to appreciate the value of incorporating a brief interview into their new patient experience. The dentist or a trained auxiliary can spend this time reviewing the patient's health history, clarifying prescription drug information, and asking open-ended questions that will help discern the patient's expectations for the day's visit as well as their oral health literacy level. A highly trained and intuitive person can gather a great deal of information in this short time frame that will support the rest of the dental team in their efforts to personally connect with this particular patient. Following the interview, some patients will appreciate a brief office tour. This affords an opportunity for the staff to familiarize the new patient with the physical layout of the office while also providing the chance to meet other team members. It is also a great time to introduce some of the technology that is available. The astute auxiliary will not only explain what the technology does but also how it helps patients better understand and participate in their treatment.

Some Ideas Enhancing Communication

There are several ways dentists can help patients make better decisions relating to their oral health. First, we need to realize that most patients are not well-informed about their oral health. Since the oral cavity is not readily visible, and many dental disease processes remain asymptomatic for long periods of time, dentists and auxiliary personnel need to make sure that they schedule enough time to allow patients to ask questions and learn more about their conditions. Second, dentists should consider purchasing various technologies that enable the patient to learn via the modality that is most effective for their individual learning style. Third, dentists and their teams need to evaluate their own ability to communicate with their patients. How well are they able to assess a patient's literacy level? Do they have a "one size fits all" approach or are they able to adjust their communication style to one that best serves the patient's level of understanding? During my years in private practice, the ability to individualize and tailor my communication was clearly the most challenging for me. Remember that dentists usually have contact with every patient who walks in the door, even those who are there for their routine continuing care visit. This means that the dentist must be able to change his or her style of personal interaction several times within a relatively brief time frame. With experience, practitioners will be able to identify those patients who want to "get in and get out" as well as those who look at their dental appointment as a social occasion.

Conclusion

The May 2000 document, *Oral Health in America: A Report of the Surgeon General*, drew national attention to the importance of oral health and provided scientific evidence of the integral relationship between oral health and general health. It alerted the entire medical and dental community that the gap between the oral cavity and the rest of the body needed to be addressed in a way that informed patients and changed behavior in an effort to improve the quality of life for all Americans. Seven years later, oral health literacy remains a challenge. America continues to become a more diverse country. Each ethnic background exhibits its own unique culture, customs, and communication preferences. Recognizing those challenges, dental education has begun to incorporate communication training into its curriculum. Dental technology continues to be developed that will help enhance the ability of patients to understand more about their oral health. It is incumbent on those who did not receive formal communication skills training to assess their own abilities. Then, they can take the appropriate steps to ensure they have done everything possible to provide their patients with the information they need to become partners in both their dental treatment and the prevention of future oral health problems. **NCMJ**

Health Professions Education to Promote Health Literacy:

Leverage Points and New Opportunities

Karen D. Stallings, RN, MEd; Thomas J. Bacon, DrPH

The issue brief makes a case for the increasingly important role the patient plays as part of the health care team in managing chronic illness, improving health outcomes, and navigating the complex health system. This commentary discusses the history of patient engagement in care decisions to show that empowering the patient to play a stronger role cannot be done in isolation. Health care practitioners must be taught new ways of relating to patients and incorporate those practices into their day-to-day routines.

One of the challenges and opportunities the North Carolina Area Health Education Centers Program (AHEC) has is to work with health professions schools and other educators to incorporate these new approaches to care into the curricula for undergraduate and graduate students, residents, and practicing health professionals. This is no simple task since students and practitioners are already stretched to the limit. They are asked to assimilate new material about medications and treatments, understand the changing economic realities of health care, and develop new ways to deliver services. As a result, AHEC looks for practical ways that we can introduce evidence-based practices for patient education and practitioner-patient communication throughout the spectrum of health professions education and practice.

Several key regulatory and policy changes over the past 35 years have had a major influence in advancing evidence-based practices in patient education and improved practitioner-patient communication. These include the American Hospital Association's Patient's Bill of Rights (1972), Medicare's prospective payment with Diagnosis Related Groups (1983), and the Joint Commission on the Accreditation of Health Care Organizations making patient and family education a focus area (1993). Each has raised awareness of the professional responsibility for teaching and the skills needed to communicate effectively with patients and families. Throughout these developments in accreditation and federal regulation, health care providers and institutions have called on the AHEC Program for continuing education and clinical training to prepare health professionals and students with the knowledge and skills they need to meet agency and public expectations for patient and family education. Many of the first patient education programs were hospital-based. The health care delivery system has changed dramatically, and clinicians practice in many different roles and settings. Patient education is integrated into care delivery in each of these.

> *"Many health professionals continue to struggle with what to teach, how to identify survival skills, and how to pare down instruction to make teaching practical."*

Professional Responsibility for Patient and Family Education

In 1972, in response to the American Hospital Association's Patient's Bill of Rights, hospitals emphasized informed consent as the way to ensure the patient's "right to know." Specifically, the patient had the right to know about his illness, the diagnostic

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and therapeutic processes to be used, and the prognosis for physical recovery. The patient had a right to refuse treatment and to be informed about the consequences of those actions. This led to formal statements by professional groups including physicians, nurses, and pharmacists that addressed patient teaching responsibilities in their practice standards. The Area Health Education Centers Program responded by offering continuing education programs to teach health care practitioners the legal and ethical responsibilities for patient education.

The curricula for students in the health disciplines, whether medicine, nursing, allied health, pharmacy, dentistry, social work, or others, underscore the professional, legal, and ethical responsibilities they will have to share their medical knowledge in a way that is understandable and usable in the daily management of health. Student and resident learning about patient-practitioner communication begins in the classroom. The Area Health Education Centers Program facilitates community-based clinical experiences in a variety of settings including home care, free clinics, health departments, schools, senior centers, and long-term care facilities where students are able to learn that health care encounters extend beyond basic evaluation and diagnosis; they also require communicating health care information to patients and teaching them the skills and knowledge for self-management. This process involves a relationship between patient and practitioner that is long-term and takes advantage of every encounter with the health care system to promote healthy behaviors.

Developing Patient Education Materials

In developing consent forms and patient education brochures, patient reading ability, understanding, language, and culture must be addressed by replacing medical terminology with plain language, basic concepts, and illustrations. AHEC has advised and continues to advise students and practitioners to develop materials that are at the fifth grade reading level, in the patient's native language, and sensitive to cultural and religious beliefs. While great strides have been made, researchers continue to find that patient education materials are written far above the reading levels of most patients and contribute to problematic low health literacy. Patients cannot understand directions, lack self-care skills, misuse medications, and are unable to access needed services. Health care professionals are frequently not aware of the gap in reading level and patient understanding and of how to rectify it. In light of the report of the North Carolina Institute of Medicine task force on low health literacy, the AHEC Program understands that we must continue to raise awareness among health care practitioners about the prevalence and impact of low health literacy in North Carolina. The new Center for Health Literacy Excellence proposed by the task force offers North Carolina an excellent opportunity to create a central source for the best evidence-based tools and curricula for practitioners so that these resources don't have to be developed locally.

Discharge Planning and Patient Safety

In 1983, Medicare's prospective payment with Diagnosis Related Groups tied financial incentives to shorter hospital stays. Patient education efforts focused on discharging patients safely with the ability to manage some aspects of care at home, especially medications, modified diets, and use of medical equipment. The pressure to teach more in less time and impart skills (such as insulin injection) needed for self-care initially meant that more staff were teaching patients, and teaching was started earlier, often when patients were too ill to absorb the information. The Area Health Education Centers Program continuing education workshops teach practical strategies to coordinate teaching provided by various health disciplines, document patient learning, and provide consistent information to patients and families. Practitioners are urged to reduce the number of handouts and facts to be taught and actively engage patients in learning using teach back, role play scenarios, and return demonstration of skills. Many health professionals continue to struggle with what to teach, how to identify survival skills, and how to pare down instruction to make teaching practical.

In 1993, the Joint Commission on the Accreditation of Health Care Organizations (JCAHO) made patient and family education a focus area, insisting that all patients and families receive the education necessary to acquire survival skills, utilize community resources, and understand the role patients must play in their treatment plans. The Joint Commission's patient safety initiatives place patients and families at the center of the health care team and open lines of communication among patients and practitioners which are viewed as essential. Many hospitals have called on AHEC to assist with staff development efforts for managers and front-line staff related to JCAHO mandates for accreditation.

Chronic Illness and Disease Management

Today there is a growing awareness of the improvements in health outcomes that can be realized by incorporating evidence-based prevention and disease management strategies into the patient care practices of physicians and other primary care practitioners. Patient involvement and empowerment are essential for the success of these approaches, however, and patients with chronic diseases who also have low health literacy have less knowledge about their disease, more complications, and worse health outcomes. Patients and families may seek health information from other sources including the Internet, relatives and neighbors, and cultural or religious communities. The ability to exchange ideas, identify inaccurate information, and acknowledge patient choice requires openness and flexibility. The Area Health Education Centers Program continuing education efforts bring health librarians to teach practitioners about information patients find in lay literature and on the Internet and how to help patients access reliable sources.

The cornerstones of chronic illness management include smoking cessation, weight loss, regular exercise, stress reduction, and adherence to medication regimens. Patient education efforts drive home in a forceful way the changes that patients need to make.

Health professionals tend to view cooperation or compliance as a single choice. Following a therapeutic diet, however, involves multiple choices throughout every day. Being compliant with a treatment plan for chronic illness may be costly, painful, or socially isolating. It is important to acknowledge the frustration that many practitioners feel when patients are unable or unwilling to comply with all the behavioral changes that are prescribed and to stress that patient teaching for effective management of chronic illness should have broader goals than compliance. As we prepare present and future health care practitioners to teach patients, AHEC student and continuing education programs should stress that helping patients understand their disease is a good beginning, but self-efficacy also relies on very specific action plans and daily strategies that patients choose to engage in which will ultimately lead to achieving long-term goals. Practitioners can incorporate practical strategies such as limiting the number of changes, making easier changes first, and working with families to anticipate barriers such as the cost of medications. Patient education is a partnership in which professionals must also strive to be role models and coaches for these health practices.

Future Opportunities

New initiatives currently underway in North Carolina to improve quality and patient safety in physician offices, hospitals, health departments, and other settings offer exciting opportunities to incorporate better patient-practitioner communication techniques, improve patient education materials, and create a better system of care that includes the patient as a critical part of the health care team. Incentives to improve outcomes will include moves by Medicare, Medicaid, and private insurers to begin rewarding physicians and other practitioners through pay for performance programs. The new climate will enhance motivation for health professionals to utilize the most advanced techniques in educating patients, simplifying processes of care, and incorporating the patient into the process.

North Carolina is on the cutting edge in developing programs to enhance quality and patient safety. The national program Improving Performance in Practice, funded by the Robert Wood Johnson Foundation and others, selected North Carolina as one of 2 pilot states. The project, a collaborative effort of the Community Care Networks, AHEC, the medical professional societies, and state health agencies has been successfully implemented in 2 regions this year and will be developed in 3 more regions this fall. The program seeks to support physician practices in collecting data on how chronic illness is managed in the practice and then offer assistance through a regional quality improvement coach to make improvements that lead to better health outcomes for patients.

The North Carolina Center on Hospital Quality and Patient Safety of the North Carolina Hospital Association engaged more hospitals than any other state in the national 100 000 Lives Campaign and now leads North Carolina hospitals in participating in the 5 Million Lives Campaign. Both initiatives seek to improve outcomes in hospital quality through quality collaboratives, educational programs, and greater transparency of data on quality measures of care.

Particularly in the outpatient setting, these quality initiatives require new approaches to managing chronic illness and fostering prevention at both the individual patient level and the practice level. Practitioners will be required to learn new skill sets, but patients will also have to be more engaged in the process if successful outcomes are to be achieved.

AHEC Statewide Initiatives to Promote Patient-Practitioner Communication

The Area Health Education Centers Program is committed to playing its traditional role of incorporating educational materials and curricula into all phases of the educational process in collaboration with the educational institutions of the state. The following recommendations address new efforts to meet the needs and challenges mentioned in the preceding paragraphs:

(1) AHEC can assist the health science schools in identifying and utilizing community-based clinical experiences that advance students' skills in patient education. Our mutual goal is to help students take concepts introduced in the classroom and apply them with the guidance of skilled community preceptors. The Area Health Education Centers Program can offer grant funding to support the development or expansion of new clinical experiences for health science students and would place priority for funding decisions on projects that include interdisciplinary collaboration, use of effective written patient instructions, patient and family teaching, and assessment of learning outcomes. Patients and their family members can be incorporated into training programs by sharing their stories about living with and managing chronic illness. This will add another dimension to what is taught in the classroom.

(2) AHEC will continue to offer continuing education programs that address how to evaluate and rewrite materials and that identify practical ways to screen patients for low health literacy. Interdisciplinary AHEC continuing education workshops with case studies and role play can help practitioners become more skillful using the teach-back method. It is important for each discipline to consider the unique contributions it can make to teaching. For example, when practitioners confirm the diagnosis and the daily management needs with patients, this sets the stage for ongoing teaching by other disciplines. Sharing experiences among different disciplines illustrates the gap between what patients need and what is provided. For example, when nurses make home visits, they become aware that a written action plan is critical to activating patients for self-care.

(3) AHEC librarians can provide health care practitioners with information about resources available on the Internet, how to evaluate Web sites for reading level and illustrations, and how to steer patients to reliable and accurate sources. At the same time, we must look for new ways to make this information available when practitioners and patients need it. Online resources, materials developed through the proposed Center for Health Literacy Excellence, and other nationally developed tools need to be available in real time, and practitioners need to be educated to use them most effectively. The Area Health Education Centers Program can highlight these resources in continuing education programs and include links to them via the AHEC Digital Library. The North Carolina Institute of Medicine Task Force on Health Literacy has identified many experts and agencies with valuable resources that can assist us in transforming patient education practices to address low health literacy, and AHEC can raise awareness among health care professionals.

(4) AHEC can develop learning collaboratives and invite practitioners to participate in the sharing of best practices and practical strategies for patient-practitioner communication in the management of chronic illnesses. In caring for children with asthma, the consistent use of daily management plans, family teaching, and consistent follow-up with asthma registries are effective. These effective techniques can be shared to improve care for other chronic illnesses.

For over 3 decades, the AHEC Program has been actively engaged in efforts to promote patient partnership and patient education. Incorporating communication and patient education techniques in continuing education and patient training has gained momentum as the result of new regulatory measures. The current climate places a much greater emphasis on better patient outcomes, including establishing uniform standards of care for managing chronic illnesses and assisting practitioners in measuring and improving the outcomes of their practices. This serves as a catalyst for greater strides in patient education. If we are to realize fully the kinds of improved health outcomes that everyone wants, it will be essential for patients to be fully engaged in the process of managing chronic illness and to play a greater role in making better decisions about lifestyle issues. **NCMJ**

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North Carolina MEDICAL JOURNAL

COMMENTARY

A Failure to Communicate

Timothy W. Lane, MD; J. Carson Rounds, MD

Most people who have seen the classic movie *Cool Hand Luke* will never forget the famous admonition by the chain gang's boss, played by Strother Martin, to Paul Newman, just after he submits him to a vicious beating for insubordination. The boss justifies his psychopathic actions by informing Newman and his fellow inmates, "What we have here is a failure to communicate." Our profession has heard from multiple quarters over the past decade that we have failed to communicate in many ways with our patients and with one another. When we hear such accusations, we recall this iconic scene and the dreaded punishment for so failing. We certainly do not want be beaten up nor do we advocate beating up on ourselves. In the best spirit of professionalism, we need to examine communication problems and actively seek and apply solutions.

Some observations are obvious. We glibly use the vocabulary of medicine that took several years of intense study and repetition to master to communicate with our colleagues and, too frequently we admit, with our patients. We have all been guilty of using seemingly simple words or phrases such as "lesion," "bronchoscopy," or "intravascular catheter" and then winced at our insensitivity when our patients' eyes glazed over or faces grimaced in confusion. Sensitivity on our part would go a long way in helping our message in such circumstances. Many of our medical schools are now addressing sensitive and patient-centered methods of doctor-patient communication.

Research in the growing field of health literacy demonstrates better patient understanding when words are carefully chosen in speech or written communication and are targeted at 4th to 6th grade reading levels even when formal education may be at a much higher level.[1] Current estimates indicate that nearly one-third of our population, or over 90 million Americans, read at this basic level. Another 15 million have extremely limited to no ability to read.[1] This is not a small or isolated problem.

"We have all been guilty of using seemingly simple words or phrases such as 'lesion,' 'bronchoscopy,' or 'intravascular catheter' and then winced at our insensitivity when our patients' eyes glazed over or faces grimaced in confusion."

One immediately visible area where reading literacy affects health literacy is in administration of prescription medicines. Recent investigations show significant patient confusion over medication use and prescription directions, and this work has led to recommendations and policy actions to improve written materials for patients and parents or guardians of children.[2] Confounding this are the confusing ways pharmacies label medicine containers; there is no systematic pattern to the labels and the print is not large enough for much of our elderly population to read without magnification. Since most pharmacy laws are specific to each state, we need to advocate for change that will improve patient understanding and readability of medication labeling and of all things that we share in writing with our patients.

We also have to increase our current glacial slouching toward the broad adoption of electronic medical records. With electronic medical records, we will see a comprehensive assessment of the

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quality of care we provide in terms of process and outcomes. The hope is that electronic medical records will promote legibility, monitoring of chronic disease management programs, sharing of important information with other practitioners, and, not least, delivery to our patients of literacy-sensitive documents summarizing and educating them about their health.

As professionals we have always philosophically held to the principles of accountability, quality, and fairness and now, as never before, our work is cut out for us. However, despite the burdens and tasks of practicing medicine in the 21st century, we must never lose sight of our common goal and most important outcome: the well-being of our patients. As Harvard physician Francis Weld Peabody so succinctly said in 1912, "...the secret of the care of the patient is in caring for the patient."[3] New approaches to health literacy, evidence-based application of our skills, and our own sensitivity are just some of the tools of caring that we must have in our metaphorical black bags. **NCMJ**

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Spotlight on the Safety Net

A Community Collaboration
Mike Darrow, CFRE

Practitioner Volunteerism at Free Clinics: A Critical Need

According to recent estimates 1.4 million people in North Carolina, or over 17% of the adult population, have no health insurance. North Carolina's uninsured population is growing at a rate faster than the national average. Free clinics act as a safety net by attempting to bridge the gap in health care access for the state's uninsured. Because free clinics are local, volunteer-based organizations, the supply of practitioner volunteers is critical to their survival and success in serving the needs of the uninsured. Free clinics struggle with obtaining sufficient practitioner volunteers to meet the demands for services.

What Is a Free Clinic?

A free clinic is a private, nonprofit, community-based organization that provides medical care at little or no charge to low-income, uninsured, and underinsured persons through the use of volunteer health care professionals and partnerships with other health care providers. The North Carolina Association of Free Clinics (NCAFC) has 69 member clinics—more free medical clinics than any state in the country. The first free clinic in North Carolina was the Open Door Clinic in Raleigh, which was established in 1985.

No 2 free clinics are alike. They are custom designed by communities to meet identified health care needs using the community's unique health care assets and resources. Free clinics are governed by volunteer boards of directors that represent a broad cross section of the community. They may provide acute and/or chronic health care, laboratory, dental, pharmacy, substance abuse, and/or mental health services. Licensed professional practitioners render all services to the clinics' uninsured patients.

Because they are private, nonprofit organizations supported primarily by cash and in-kind contributions from the private sector, volunteerism is a central feature of free clinics. Clinic services are provided primarily or exclusively by volunteer health care professionals serving in the clinic's own facility or in their own private practice settings. Lay volunteers also perform a variety of administrative and clerical tasks, which keeps overhead costs low.

In North Carolina, low-income, uninsured, and underinsured adults have the greatest difficulty accessing affordable health care services. While eligibility criteria vary from one clinic to the next, free clinics conduct rigorous eligibility screenings to ensure that the patients they serve are truly in need. Free clinics believe that inability to pay should not prevent people from receiving quality health care. To this end, the clinics provide services at little or no charge. Free clinics place a strong emphasis on providing nonjudgmental, compassionate care that respects the dignity and self-worth of every patient.

Volunteer Practitioner Trends

In 2005 free clinics in North Carolina reported utilizing 6443 volunteers, of which 1167 were physicians.[a] The total number of physician volunteers in free clinics actually declined from 2004 to 2005 by 10.3% while the total number of hours volunteered increased by 3.8%. It appears that clinics are losing volunteer physicians, but the ones who continue to support the work of free clinics are volunteering more hours. The decrease in North Carolina's practitioner volunteers reflects a nationwide trend.[1]

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[a] It is important to note that these numbers are most likely underreported. They do not include 12 new clinics added to NCAFC since 2005, and 7 clinics reported no data. The latter reflects the difficulty clinics have in tracking volunteer hours.

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There are a number of reasons why fewer practitioners may choose to volunteer in free clinics. First, the number of the uninsured and the proportion needing chronic care is increasing. Managing the growing demand for the complex services needed to treat those with chronic diseases adds additional strain and stress on volunteer physicians. There is also increasing economic pressure on active physicians who are facing reduced third-party payments and increased operating costs in their private practices. This requires physicians to spend more time seeing patients in their practice, thus reducing the amount of time available to volunteer.

There are also a number of actual and perceived barriers to volunteering. Physicians often cite malpractice or insurance issues as compelling factors in deciding not to volunteer. Additionally, retired physicians cite maintaining continuing medical education hours as another barrier. Physicians also mention confusion about maintaining their licenses, unaware of the volunteer license specifically designed for volunteering at a free clinic.

Strategies to Increase Volunteerism by Practitioners

There are several strategies that NCAFC is undertaking to increase the number of physician volunteers in free clinics. The first is to increase recruitment of retired physicians. The NC Association of Free Clinics is working with the American Health Initiative on a project entitled TAP-IN, which is a Web-based project focusing on increased awareness of volunteer opportunities for retired medical providers in free clinics. This program was piloted in 3 clinics and resulted in additional volunteer practitioners in those clinics. The program went statewide as of April 2007.

The NC Association of Free Clinics is also focusing on marketing free clinics to raise awareness of their work and the people they serve. On April 24, 2007 NCAFC sponsored a Statewide Open House in which all 69 NCAFC member clinics were open to the public on the same day. The Open House received statewide media attention as well as local exposure. Raising overall awareness of free clinics and publicizing the need for volunteers should have a positive effect on practitioner recruiting.

The NC Association of Free Clinics views its partnerships with the North Carolina Medical Board and the North Carolina Medical Society as critical to the success of free clinics. Both organizations are very supportive of the work of free clinics and have been instrumental in streamlining the volunteer licensing application, informing retiring physicians about changing their licenses from active to volunteer, and working with clinics and retired physicians from out of state to obtain volunteer licenses. The NC Association of Free Clinics also works in partnership with these organizations to enhance the volunteer experience for the practitioner.

Finally, NCAFC is collaborating with insurance providers to offer special professional liability policies for volunteer practitioners at very affordable rates. This is a very important factor in recruiting more practitioner volunteers.

Conclusion

With 1.4 million uninsured in North Carolina, free clinics cannot be the solution to providing health care to our friends and neighbors. However, with the assistance of practitioner volunteers, our clinics can continue to help bridge the gap for the uninsured in our state while long-term solutions are developed. Rather than wait for those solutions, the North Carolina Association of Free Clinics is acting now to engage North Carolina's communities and enlist thousands of volunteer practitioners.

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Mike Darrow, CFRE, is executive director of the North Carolina Association of Free Clinics.
For information on volunteering at a free clinic, go to www.ncfreeclinics.org or www.TAP-IN.org.

Health Promotion and African-American Baptist Churches in North Carolina

M. Anita P. Holmes, JD, MPH; John Hatch, DrPH, MSW

The General Baptist State Convention of North Carolina (GBSC) has actively sponsored disease prevention and health promotion services since 1978. The Faith and Health Initiative, sponsored by Kate B. Reynolds Charitable Trust, is the most recent of several area-based health promotion efforts. While the focus of GBSC health initiatives vary, including maternal and child health, smoking cessation, nutrition education, enhancement of parenting skills, and reduction in incidence and control of diabetes, faith-driven values and strategies motivate and direct the development, implementation, and ongoing work of each project.

Project efforts utilize the historic role of the African-American church as initiator, enabler, and sponsor of activities to improve life at the community level. Programs are initiated by discussing specific health concerns with pastors and selected lay leaders and asking them if programs focused on these concerns seem right for their congregations. Potential benefits to participants are considered as well as the role the church will be asked to play in implementation. A long tradition of lay leader participation in setting congregation priorities benefits program implementation. Each church has a structural authority to select priorities independently of central governance structures. A key component of these programs is the selection and training of volunteers who will be responsible for recruiting participants, coordinating church and community resources, facilitating participation, and providing specialized training when appropriate.

The Faith and Health Initiative, a primary and secondary prevention program, was designed to significantly change risk behaviors through encouraging nutritionally sound dietary practices, increasing physical activity and exercise, and utilizing the intersection between faith and health to strengthen and increase project viability and sustainability. Four GBSC Associations (regional subunits of the statewide Convention) serving rural underserved counties in the northeastern part of the state served as the targeted intervention points. Although the geographic area may be characterized as socioeconomically challenged, it is rich in human, cultural, and spiritual resources.

To build on this strong infrastructure, center leadership first enhanced the relationship between the Associations' pastoral faith leaders (called moderators) while seeking a shared vision as the springboard for the project. These leaders were instrumental in assisting the project in identifying 4 project facilitators (1 for each association) to coordinate the project at the regional level. Facilitators were diverse in demographic background (eg, education, age, sex, and occupation). However, the common denominator was their active involvement with their associations and the way in which they were respected by other parishioners and the community in general.

From the beginning of the project, the faith leaders of the participating associations were engaged. Recognizing the critical role pastors play in supporting project efforts and in translating health teachings in relation to theological understandings, the project continued to actively include pastors in project planning and updates through quarterly meetings of participating churches' pastors. These meetings provided an opportunity to expose pastors to the project curriculum and selected activities, allowing them to better assist in the diffusion of information to parishioners. Also key to parishioner involvement and support, were the lay volunteers and natural helpers recruited for the respect they receive, the guidance they are sought for, and the helping role they play in the lives of fellow parishioners and others in their network.

An essential component of the Faith and Health Initiative and other GBSC projects is the development of partnerships with local human service agencies. These partnerships are critical in the continued support and sustainability of these locally owned projects. The Faith and Health Initiative enjoyed partnerships with both public and private entities. These working relationships not only maximized the resources available to the project and community, but also resulted in some of the relationships between resource staff and project leaders surviving past the formal project funding period.

Positive project outcomes were evident at both the individual and organizational level. Individuals experienced increased knowledge and behavioral modification (eg, increased fruit and vegetable consumption and increased physical activity) and became advocates within their social networks for health promotion policy and environmental changes. At an organizational level, churches and associations made system-level policy and environmental changes including establishment of health committees as ongoing organizational components, changing to healthier menu selections at congregational meal functions, and establishing walking trails on church grounds. The groundwork laid by the Faith and Health Initiative continues to provide fertile soil for addressing health disparities in these communities.

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Running the Numbers

A Periodic Feature to Inform North Carolina Health Care Professionals
About Current Topics in Health Statistics

From the State Center for Health Statistics, NC Department of Health and Human Services
http://www.schs.state.nc.us/SCHS

Selected Data Related to Health Literacy in North Carolina

Health literacy is the ability of people to understand basic health information, communicate with health practitioners, and properly use health services. Low health literacy might be associated with, for example, the inability to read and comprehend basic health-related materials such as prescription bottles and appointment slips. Studies suggest that people with low health literacy are less likely to take their medications as prescribed or follow treatment protocols, less able to manage their chronic conditions, and more frequently hospitalized.[1] There is new evidence that people with low health literacy have higher death rates.[2] Health literacy problems are more common among racial and ethnic minorities, the elderly, and people with lower education achievement or lower income, but people from all walks of life struggle with health information.

Some of the surveys fielded by the State Center for Health Statistics in North Carolina provide information about the level of health knowledge on certain topics. Health knowledge deficits may reflect underlying health literacy problems. Low rates of health knowledge could reflect that the population had difficulty understanding the message, but it could also reflect a failure of message dissemination.

The data summarized in this article are drawn from 2 surveys. The Behavioral Risk Factor Surveillance System (BRFSS) is a random telephone survey of persons ages 18 years and older in the state. The Pregnancy Risk Assessment Monitoring System (PRAMS) is a random mail and telephone survey of new mothers in North Carolina. Below are selected data from these surveys that give insight into health knowledge in our state.

Table 1.
North Carolina Health Knowledge

Measure	Source	Year	Percentage
Percentage of new mothers who have ever heard or read that taking the vitamin folic acid can prevent some birth defects	PRAMS	2004	83.1
Percentage of diabetics who check their blood for glucose or sugar every day	BRFSS	2005	62.2
Percentage of diabetics who check their feet for sores or irritations every day	BRFSS	2005	71.9
Percentage of diabetics who have ever taken a course or class in how to manage your diabetes yourself	BRFSS	2005	54.7
Percentage of adults who identified all 5 heart attack symptoms correctly	BRFSS	2005	10.0
Percentage of adults who identified all 5 stroke symptoms correctly	BRFSS	2005	16.6
Percentage of adults age 50+ years who think that people their age or older who do not have symptoms should be tested for colon or rectal cancer	BRFSS	2005	94.9
Percentage of men age 40+ years who rated their understanding of the advantages and disadvantages of PSA tests as excellent or very good	BRFSS	2005	49.0

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The low percentages shown in the table for individuals who practice proper diabetes management, correctly identify heart attack and stroke symptoms, and report they understand PSA tests suggests substantial problems with health knowledge in the overall population of adults in North Carolina. More detailed data (for example, broken out by demographic categories) can be found at www.schs.state.nc.us/SCHS (click on BRFSS or PRAMS on the left side of the page under Health Data). For example, the 2005 percentage of adults who identified all 5 stroke symptoms correctly was 6% for those with less than a high school education compared to 26% for those with a college degree.

A study on a North Carolina heart failure self-management program showed that an intervention designed for patients with low literacy reduced the rate of hospitalization and death in the intervention group as compared to a control group.[3] In another study, patients with diabetes and low literacy benefited more from a disease management intervention compared to those with diabetes and higher literacy skills.[4] These studies suggest that well-designed programs to engage and educate patients about their own chronic illness and disease self-management will help reduce morbidity and other problems associated with low health literacy.

Health literacy depends not only on individual capacity to communicate and understand health information but also on the demands posed by society and the health care system.[5] For example, health care professionals have a responsibility to reduce the complexity of their speech and written materials and simplify access to health care services. Finally, improving the levels of literacy, education, and income in the general population will have the effect of increasing health literacy in North Carolina.

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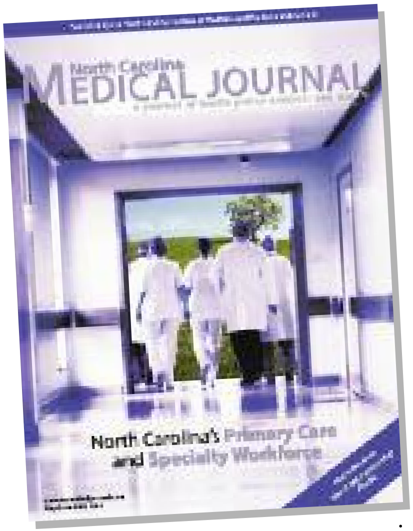
Contributed by Paul A. Buescher, PhD, State Center for Health Statistics; Alexander E. White, JD, MPH, Heart Disease and Stroke Prevention Branch, NC Division of Public Health; Darren A. DeWalt, MD, MPH, Division of General Internal Medicine, University of North Carolina at Chapel Hill

Readers' Forum



North Carolina MEDICAL JOURNAL

North Carolina's Primary Care and Specialty Workforce

To the Editor:

The North Carolina Institute of Medicine should be commended for its timely recognition of the issues relating to medical manpower as addressed in the May/June 2007 issue of the *North Carolina Medical Journal*. The North Carolina Academy of Family Physicians published similar concerns over a decade ago in its publications *Who Will Take Care of Our People?* and *Who Will Care for Our Communities?* These were red flags to the NC General Assembly and the academic community from family physicians in this state who realized that the population was increasing while growing more aged and sickly, and that fewer medical students were choosing primary care and family medicine as a career. Sadly, there was no response, but this was the age of managed care, and we did see a small increase in family medicine match rates. Since that time the state's population has more than doubled and become on average older, and we find significant maldistributions of health care. Many of our state's citizens are underserved and face health care disparities. Unfortunately, both of our calls went unheeded. Perhaps your efforts will meet with more success in arousing public awareness of this urgent issue.

It is not surprising the NC Institute of Medicine found that even if we begin training more primary care and family physicians today, there will still be a deficit in the providers of first line care in the foreseeable future. Our answer: THERE ALREADY ARE too few primary care physicians to provide a medical home for all of the citizens of our state. Unless there is a change in the number of students choosing careers in primary care, the crisis threatens to be catastrophic.

There has been significant discussion about increasing class size at each of the four academic institutions as well as proposals for a fifth training site in Charlotte. None of the suggestions include an increase in the number of primary care providers in North Carolina. For many years the legislature has required that our universities report the specialty selection of the senior class of each school. However, this is an accounting of merely the intern year and does not consider matches in general internal medicine/pediatrics for a preliminary year where many go on to subspecialize. Strong consideration should be given to a change in legislation that requires accountability upon completion of residency. The American Association of Medical Colleges and the American Medical Association have recommended a graduation rate of 50% primary care and 50% specialty care physicians. This is not happening in our state and has contributed to the current shortage of primary care providers.

If past history is a predictor of the future, the plight of health care in this state will only worsen, and North Carolina citizens will have to pay more for a system in which they receive care that is fragmented and reactive rather than preventative or comprehensive.

Why do countries such as Cuba and Great Britain rank higher in quality of care despite spending significantly less on health care than the United States? The answer is quite simple. It is the uncomplicated access to well-trained primary care physicians. The data in Barbara Starfield's research supports this premise. We have in this state demonstrated—through the work of Community Care of North Carolina—a system which achieves better access and improved quality of care while also achieving a cost savings. The basis of this system is that each patient is assigned a primary care medical home. The model utilizes care managers, pharmacists, nutritionists, and project specialists to assist in education of patients and improve standards of care. This is the model that has the potential to achieve the desired improvements in health outcomes sought by the NC Institute of Medicine. We do not need academic centers to create another model of inefficient, costly care.

I challenge our academic leaders to study the Community Care of North Carolina model, embrace the concepts of quality-based and accessible care, and provide physicians who can serve those needs in this state.

The North Carolina Academy of Family Physicians stands ready to aid in achieving this lofty goal.

Respectfully,
Michelle F. Jones, MD, FAAFP
President
North Carolina Academy of Family Physicians

To the Editor:

I would like to comment on some issues that were touched upon in the article by Dr Harvey Estes in the May/June issue of the *North Carolina Medical Journal*. I feel compelled to say that it was through Dr Estes' diligent efforts and pioneering work at Duke that the Physician Assistant Program came into being in North Carolina and subsequently became a vital link in health care delivery in our state and a model to the nation—with the Nurse Practitioner Program to follow.

I think the real core of dissatisfaction in the general public about the health care delivery system centers around concerns of expense, the limited availability (not the quality) of health care, and the general perception of diminished interest in the individual patient by physicians. It is my perception that the public would readily accept the expense and logic for the creation of another state-owned medical school. I have always felt that there has been an abundance of qualified North Carolinians for medical training.

Since the advent of the Brody School of Medicine at East Carolina University, North Carolina has grown 2 million in population. It is interesting to recall that this school was violently opposed during its inception by the state's then 3 medical schools.

I also feel that economic and social changes are apparent in the culture of the medical profession. There is a willingness to accept more professional regimentation in order to escape the added hours and business aspects of practice and a seeming desire to escape close personal relationships with clientele.

This capitalistic approach is, to me, the excessive zeal for the accumulation of wealth which leads to unfettered capitalism, control through ownership, and favoritism to hospital employed or affiliated physicians. This situation serves as a deterrent to physicians with the same credentials and staff memberships to enter private or small group practices; ergo, establishing a private or small group practice starts out more risky, and its growth and survival is problematic.

Here in my hometown there is a strong feeling or recognition in private practices that if the hospital's ownership doesn't extend to your practice, you probably won't get equal opportunity to share in the patient pool. New physicians do not come to a community expecting to be discriminated against by the management of local hospitals. Equal opportunity should be applied to physicians regardless of affiliation.

Respectfully,
John R. Gamble Jr, MD
Lincolnton, NC

To the Editor:

The May/June 2007 issue of the *NC Medical Journal* defined the challenges faced by North Carolina in providing primary care, obstetric care, and psychiatric services to individuals across the state. As a clinical specialist in child and adolescent psychiatric and mental health nursing since 1990, and a recently licensed family psychiatric and mental health nurse practitioner (PMH-NP), I would like to respond from an individual practitioner perspective.

In my work with children and families, I became acutely aware of the impact of limitations in the availability of psychiatric practitioners. Primary care practitioners (PCPs) have been instrumental in filling the gap when medication was part of the treatment plan. However, with publicized warnings about possible side effects of some psychiatric medications and a growing demand for PCP services, some PCPs became less willing to manage psychiatric medications. In my experience, it was not unusual to see a child wait months to see a child psychiatrist, which often resulted in major implications for the child's academic and social functioning. These experiences motivated me to obtain post-masters education as a family PMH-NP at the University of North Carolina at Chapel Hill School of Nursing.

I am fortunate to work for an organization that supported my ability to pursue the education and clinical placements necessary for training. FirstHealth of the Carolinas has also facilitated my ability to arrange collaborative practice agreements and supervision time with three highly skilled and experienced psychiatrists. This has been vital in my transition to this expanded role.

As resources for psychiatric and mental health services continue to be stressed, it is important that psychiatrists and community organizations be willing to provide the kind of facilitation that I have experienced. I also support Erin Fraher's recommendation to develop innovative models of interdisciplinary care that incorporate advanced practice psychiatric nurses into the psychiatric team. It is my hope that educational institutions, psychiatrists, and nursing leaders will continue to work toward developing models that serve to expand clinical resources to our citizens.

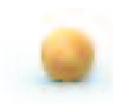
Sincerely,
Elizabeth Watson, MSN, PMH-NP
FirstHealth of the Carolinas
Outpatient Behavioral Services
Pinehurst, NC

To the Editor:

Your recent issue on physician supply indicated that there may be an emerging shortage of general surgeons. I have decided to pursue general surgery in my residency next year, and it may be useful for others to know why.

There are many reasons that I have decided to apply to general surgery residency programs this fall. During medical school, I discovered that I like the intensity of the interaction between patient and surgeon, the variety of health care issues faced while working in a clinic and an operating room, and the opportunity to master technical skills in addition to the diagnostic skills required of all physicians. Becoming any kind of surgeon could satisfy these interests, but I have chosen to practice general surgery. Although the old paradigm of general surgeons being similar to family doctors on the front lines of primary care is probably no longer true, except for in the most rural settings, the concept still appeals to me. I respect the communication and shared decision making skills that many primary care physicians possess, and I hope to emulate them in my own practice. I value practicing in a field of medicine that is accessible and comprehensible to patients. And, it is fulfilling to know that my career as a general surgeon might help fill an unmet need in the country's health care system.

Katharine L. McGinigle
Medical student
The University of North Carolina
at Chapel Hill



ACIPHEX® \a-sa-ˌfeks\
(rabeprazole sodium)
Delayed-Release Tablets

BRIEF SUMMARY
Before prescribing ACIPHEX®, please see full prescribing information.

INDICATIONS AND USAGE
Healing of Erosive or Ulcerative Gastroesophageal Reflux Disease (GERD)
ACIPHEX® is indicated for short-term (4 to 8 weeks) treatment in the healing and symptomatic relief of erosive or ulcerative gastroesophageal reflux disease (GERD). For those patients who have not healed after 8 weeks of treatment, an additional 8-week course of ACIPHEX® may be considered.

Maintenance of Healing of Erosive or Ulcerative Gastroesophageal Reflux Disease (GERD)
ACIPHEX® is indicated for maintaining healing and reduction in relapse rates of heartburn symptoms in patients with erosive or ulcerative gastroesophageal reflux disease (GERD Maintenance). Controlled studies do not extend beyond 12 months.

Treatment of Symptomatic Gastroesophageal Reflux Disease (GERD)
ACIPHEX® is indicated for the treatment of daytime and nighttime heartburn and other symptoms associated with GERD.

Healing of Duodenal Ulcers
ACIPHEX® is indicated for short-term (up to four weeks) treatment in the healing and symptomatic relief of duodenal ulcers. Most patients heal within four weeks.

Helicobacter pylori Eradication to Reduce the Risk of Duodenal Ulcer Recurrence
ACIPHEX® in combination with amoxicillin and clarithromycin as a three drug regimen, is indicated for the treatment of patients with *H. pylori* infection and duodenal ulcer disease (active or history within the past 5 years) to eradicate *H. pylori*. Eradication of *H. pylori* has been shown to reduce the risk of duodenal ulcer recurrence. (See **CLINICAL STUDIES** and **DOSAGE AND ADMINISTRATION** in full prescribing information.)

In patients who fail therapy, susceptibility testing should be done. If resistance to clarithromycin is demonstrated or susceptibility testing is not possible, alternative antimicrobial therapy should be instituted. (See **CLINICAL PHARMACOLOGY, Microbiology** in full prescribing information and the clarithromycin package insert, **CLINICAL PHARMACOLOGY, Microbiology**.)

Treatment of Pathological Hypersecretory Conditions, Including Zollinger-Ellison Syndrome
ACIPHEX® is indicated for the long-term treatment of pathological hypersecretory conditions, including Zollinger-Ellison syndrome.

CONTRAINDICATIONS
Rabeprazole is contraindicated in patients with known hypersensitivity to rabeprazole, substituted benzimidazoles or to any component of the formulation.

Clarithromycin is contraindicated in patients with known hypersensitivity to any macrolide antibiotic.

Concomitant administration of clarithromycin with pimozide and cisapride is contraindicated. There have been post-marketing reports of drug interactions when clarithromycin and/or erythromycin are co-administered with pimozide resulting in cardiac arrhythmias (QT prolongation, ventricular tachycardia, ventricular fibrillation, and torsade de pointes) most likely due to inhibition of hepatic metabolism of pimozide by erythromycin and clarithromycin. Fatalities have been reported. (Please refer to full prescribing information for clarithromycin.)

Amoxicillin is contraindicated in patients with a known hypersensitivity to any penicillin. (Please refer to full prescribing information for amoxicillin.)

WARNINGS
CLARITHROMYCIN SHOULD NOT BE USED IN PREGNANT WOMEN EXCEPT IN CLINICAL CIRCUMSTANCES WHERE NO ALTERNATIVE THERAPY IS APPROPRIATE. If pregnancy occurs while taking clarithromycin, the patient should be apprised of the potential hazard to the fetus. (See **WARNINGS** in prescribing information for clarithromycin.)

Amoxicillin: Serious and occasionally fatal hypersensitivity (anaphylactic) reactions have been reported in patients on penicillin therapy. These reactions are more likely to occur in individuals with a history of penicillin hypersensitivity and/or a history of sensitivity to multiple allergens.

There have been well-documented reports of individuals with a history of penicillin hypersensitivity reactions who have experienced severe hypersensitivity reactions when treated with a cephalosporin. Before initiating therapy with any penicillin, careful inquiry should be made concerning previous hypersensitivity reactions to penicillins, cephalosporins, and other allergens. If an allergic reaction occurs, amoxicillin should be discontinued and the appropriate therapy instituted. (See **WARNINGS** in prescribing information for amoxicillin.)

SERIOUS ANAPHYLACTIC REACTIONS REQUIRE IMMEDIATE EMERGENCY TREATMENT WITH EPINEPHRINE. OXYGEN, INTRAVENOUS STEROIDS, AND AIRWAY MANAGEMENT, INCLUDING INTUBATION, SHOULD ALSO BE ADMINISTERED AS INDICATED.

Pseudomembranous colitis has been reported with nearly all antibacterial agents, including clarithromycin and amoxicillin, and may range in severity from mild to life threatening. Therefore, it is important to consider this diagnosis in patients who present with diarrhea subsequent to the administration of antibacterial agents.

Treatment with antibacterial agents alters the normal flora of the colon and may permit overgrowth of clostridia. Studies indicate that a toxin produced by *Clostridium difficile* is a primary cause of "antibiotic-associated colitis".

After the diagnosis of pseudomembranous colitis has been established, therapeutic measures should be initiated. Mild cases of pseudomembranous colitis usually respond to discontinuation of the drug alone. In moderate to severe cases, consideration should be given to management with fluid and electrolytes, protein supplementation, and treatment with an antibacterial drug clinically effective against *Clostridium difficile* colitis.

PRECAUTIONS
General
Symptomatic response to therapy with rabeprazole does not preclude the presence of gastric malignancy.

Patients with healed GERD were treated for up to 40 months with rabeprazole and monitored with serial gastric biopsies. Patients without *H. pylori* infection (221 of 326 patients) had no clinically important pathologic changes in the gastric mucosa. Patients with *H. pylori* infection at baseline (105 of 326 patients) had mild or moderate inflammation in the gastric body or mild inflammation in the gastric antrum. Patients with mild grades of infection or inflammation in the gastric body tended to change to moderate, whereas those graded moderate at baseline tended to remain stable. Patients with mild grades of infection or inflammation in the gastric antrum tended to remain stable. At baseline 8% of patients had atrophy of glands in the gastric body and 15% had atrophy in the gastric antrum. At endpoint, 15% of patients had atrophy of glands in the gastric body and 11% had atrophy in the gastric antrum. Approximately 4% of patients had intestinal metaplasia at some point during follow-up, but no consistent changes were seen.

Steady state interactions of rabeprazole and warfarin have not been adequately evaluated in patients. There have been reports of increased INR and prothrombin time in patients receiving a proton pump inhibitor and warfarin concomitantly. Increases in INR and prothrombin time may lead to abnormal bleeding and even death. Patients treated with a proton pump inhibitor and warfarin concomitantly may need to be monitored for increases in INR and prothrombin time.

Information for Patients
Patients should be cautioned that ACIPHEX® delayed-release tablets should be swallowed whole. The tablets should not be chewed, crushed, or split. ACIPHEX® can be taken with or without food.

Drug Interactions
Rabeprazole is metabolized by the cytochrome P450 (CYP450) drug metabolizing enzyme system. Studies in healthy subjects have shown that rabeprazole does not have clinically significant interactions with other drugs metabolized by the CYP450 system, such as warfarin and theophylline given as single oral doses, diazepam as a single intravenous dose, and phenytoin given as a single intravenous dose (with supplemental oral dosing). Steady state interactions of rabeprazole and other drugs metabolized by this enzyme system have not been studied in patients. There have been reports of increased INR and prothrombin time in patients receiving proton pump inhibitors, including rabeprazole, and warfarin concomitantly. Increases in INR and prothrombin time may lead to abnormal bleeding and even death.

In vitro incubations employing human liver microsomes indicated that rabeprazole inhibited cyclosporine metabolism with an IC_{50} of 62 micromolar, a concentration that is over 50 times higher than the C_{max} in healthy volunteers following 14 days of dosing with 20 mg of rabeprazole. This degree of inhibition is similar to that by omeprazole at equivalent concentrations.

Rabeprazole produces sustained inhibition of gastric acid secretion. An interaction with compounds which are dependent on gastric pH for absorption may occur due to the magnitude of acid suppression observed with rabeprazole. For example, in normal subjects, co-administration of rabeprazole 20 mg QD resulted in an approximately 30% decrease in the bioavailability of ketoconazole and increases in the AUC and C_{max} for digoxin of 19% and 29%, respectively. Therefore, patients may need to be monitored when such drugs are taken concomitantly with rabeprazole. Co-administration of rabeprazole and antacids produced no clinically relevant changes in plasma rabeprazole concentrations.

In a clinical study in Japan evaluating rabeprazole in patients categorized by CYP2C19 genotype (n=6 per genotype category), gastric acid suppression was higher in poor metabolizers as compared to extensive metabolizers. This could be due to higher rabeprazole plasma levels in poor metabolizers. Whether or not interactions of rabeprazole sodium with other drugs metabolized by CYP2C19 would be different between extensive metabolizers and poor metabolizers has not been studied.

Combined Administration with Clarithromycin
Combined administration consisting of rabeprazole, amoxicillin, and clarithromycin resulted in increases in plasma concentrations of rabeprazole and 14-hydroxyclarithromycin. (See **CLINICAL PHARMACOLOGY, Combination Therapy with Antimicrobials** in full prescribing information.)

Concomitant administration of clarithromycin with pimozide and cisapride is contraindicated. (See **PRECAUTIONS** in prescribing information for clarithromycin.) (See **PRECAUTIONS** in prescribing information for amoxicillin.)

Carcinogenesis, Mutagenesis, Impairment of Fertility
In a 88/104-week carcinogenicity study in CD-1 mice, rabeprazole at oral doses up to 100 mg/kg/day did not produce any increased tumor occurrence. The highest tested dose produced a systemic exposure to rabeprazole (AUC) of 1.40 μg•hr/mL which is 1.6 times the human exposure (plasma $AUC_{0-\infty}$ = 0.88 μg•hr/mL) at the recommended dose for GERD (20 mg/day). In a 104-week carcinogenicity study in Sprague-Dawley rats, males were treated with oral doses of 5, 15, 30 and 60 mg/kg/day and females with 5, 15, 30, 60 and 120 mg/kg/day. Rabeprazole produced gastric enterochromaffin-like (ECL) cell hyperplasia in male and female rats and ECL cell carcinoid tumors in female rats at all doses including the lowest tested dose. The lowest dose (5 mg/kg/day) produced a systemic exposure to rabeprazole (AUC) of about 0.1 μg•hr/mL which is about 0.1 times the human exposure at the recommended dose for GERD. In male rats, no treatment related tumors were observed at doses up to 60 mg/kg/day producing a rabeprazole plasma exposure (AUC) of about 0.2 μg•hr/mL (0.2 times the human exposure at the recommended dose for GERD).

Rabeprazole was positive in the Ames test, the Chinese hamster ovary cell (CHO/HGPRT) forward gene mutation test and the mouse lymphoma cell (L5178Y/TK+/-) forward gene mutation test. Its demethylated-metabolite was also positive in the Ames test. Rabeprazole was negative in the *in vitro* Chinese hamster lung cell chromosome aberration test, the *in vivo* mouse micronucleus test, and the *in vivo* and *ex vivo* rat hepatocyte unscheduled DNA synthesis (UDS) tests.

Rabeprazole at intravenous doses up to 30 mg/kg/day (plasma AUC of 8.8 μg•hr/mL, about 10 times the human exposure at the recommended dose for GERD) was found to have no effect on fertility and reproductive performance of male and female rats.

Pregnancy
Teratogenic Effects. Pregnancy Category B: Teratology studies have been performed in rats at intravenous doses up to 50 mg/kg/day (plasma AUC of 11.8 μg•hr/mL, about 13 times the human exposure at the recommended dose for GERD) and rabbits at intravenous doses up to 30 mg/kg/day (plasma AUC of 7.3 μg•hr/mL, about 8 times the human exposure at the recommended dose for GERD) and have revealed no evidence of impaired fertility or harm to the fetus due to rabeprazole. There are, however, no adequate and well-controlled studies in pregnant women. Because animal reproduction studies are not always predictive of human response, this drug should be used during pregnancy only if clearly needed.

Nursing Mothers
Following intravenous administration of ^{14}C-labeled rabeprazole to lactating rats, radioactivity in milk reached levels that were 2- to 7-fold higher than levels in the blood. It is not known if unmetabolized rabeprazole is excreted in human breast milk. Administration of rabeprazole to rats in late gestation and during lactation at doses of 400 mg/kg/day (about 195-times the human dose based on mg/m^2) resulted in decreases in body weight gain of the pups. Since many drugs are excreted in milk, and because of the potential for adverse reactions to nursing infants from rabeprazole, a decision should be made to discontinue nursing or discontinue the drug, taking into account the importance of the drug to the mother.

Pediatric Use
The safety and effectiveness of rabeprazole in pediatric patients have not been established.

Use in Women
Duodenal ulcer and erosive esophagitis healing rates in women are similar to those in men. Adverse events and laboratory test abnormalities in women occurred at rates similar to those in men.

Geriatric Use
Of the total number of subjects in clinical studies of ACIPHEX®, 19% were 65 years and over, while 4% were 75 years and over. No overall differences in safety or effectiveness were observed between these subjects and younger subjects, and other reported clinical experience has not identified differences in responses between the elderly and younger patients, but greater sensitivity of some older individuals cannot be ruled out.

ADVERSE REACTIONS
Worldwide, over 2900 patients have been treated with rabeprazole in Phase II-III clinical trials involving various dosages and durations of treatment. In general, rabeprazole treatment has been well-tolerated in both short-term and long-term trials. The adverse events rates were generally similar between the 10 and 20 mg doses.

Incidence in Controlled North American and European Clinical Trials
In an analysis of adverse events assessed as possibly or probably related to treatment appearing in greater than 1% of ACIPHEX® patients and appearing with greater frequency than placebo in controlled North American and European trials, the incidence of headache was 2.4% (n=1552) for ACIPHEX® versus 1.6% (n=299) for placebo.

In short and long-term studies, the following adverse events, regardless of causality, were reported in ACIPHEX®-treated patients. Rare events are those reported in ≤1/1000 patients.

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Coming in the November/December 2007 issue of the

North Carolina Medical Journal

a look at:

Arthritis

Index of Advertisers

North Carolina
MEDICAL JOURNAL

CLASSIFIED ADS: RATES AND SPECIFICATIONS

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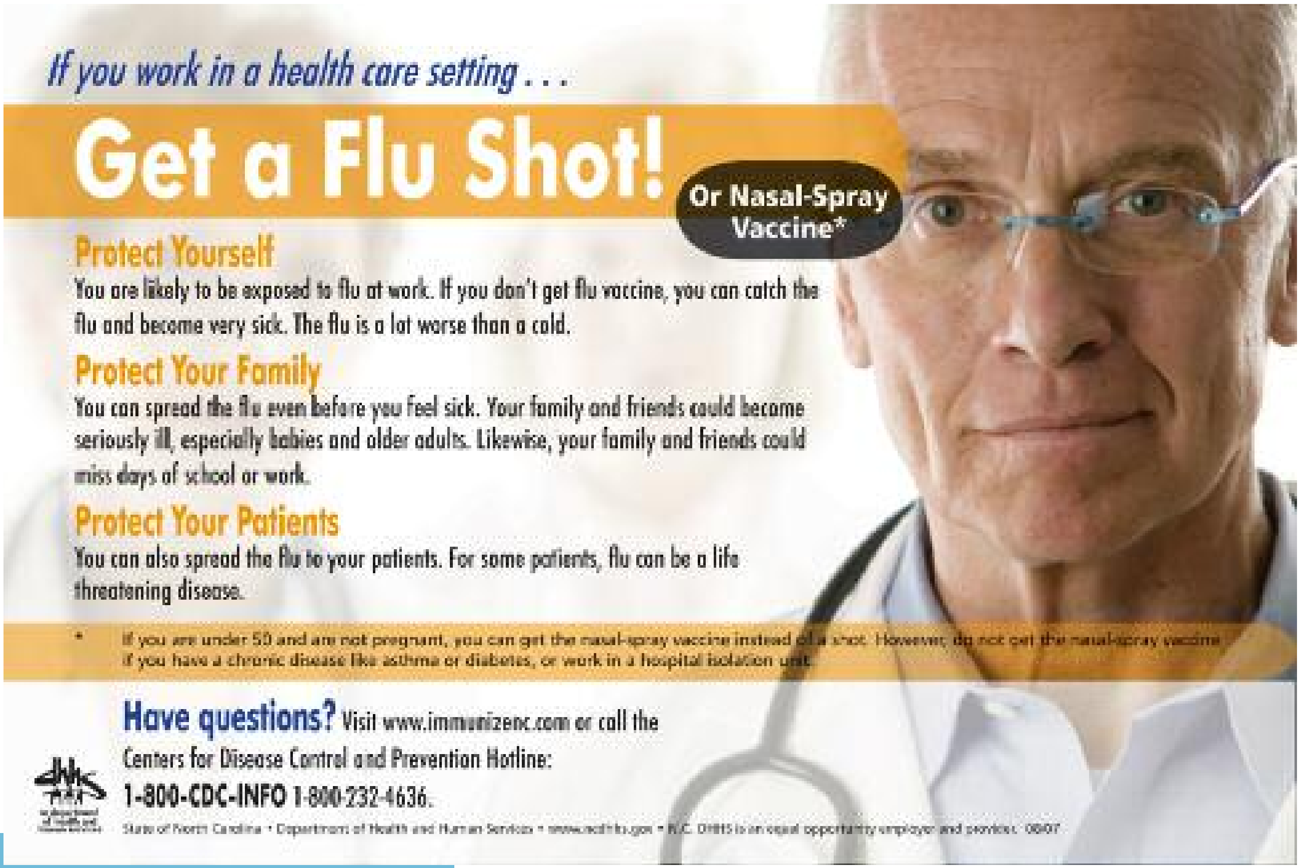

Compassion transformed into art.

Compassion and caring come in many forms, but perhaps none as expressive as The Southeastern Hospice Festival of Trees. Each year, the visions of local artists are displayed through dozens of trees themed in unique combinations of satin bows, glistening tinsel, and one-of-a-kind ornaments.

Even more enchanting is knowing behind each tree is a sponsor whose contribution helps fund the efforts of Southeastern Hospice and our new center for end-of-life care, Southeastern Hospice House.

'Tis the season for giving, and few expressions of kindness mean more than helping someone be at ease during life's most difficult time.

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Sandra Inman
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For 23 years, Sandra has been leading church choirs.

Now she's singing our praises.

Sandra Inman has a gift for music, and it's a gift she's happy to share. Just about every week, you can find her at nursing homes in her hometown of Reidsville, leading the residents in songs of faith. Then on Sundays, there are the two church services, plus the Wednesday meeting . . . it goes on and on, and she loves every minute of it.

In the spring of 2006, however, Sandra feared her days of sharing music might soon be over. She began having difficulty concentrating and remembering things. At first, she tried to hide her problems; she just thought it was the inevitable effect of getting older. But an MRI scan revealed a large tumor spreading over nearly half her brain.

Fortunately, she was under the care of a world-class team at Moses Cone Neuroscience Center. She went into her operation buoyed by their confidence. Her doctors removed the tumor safely and told her she'd be okay. Now Sandra is back at the nursing homes every week, once again bringing music to the people she loves.

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North Carolina MEDICAL JOURNAL

a journal of health policy analysis and debate

Quality Of Life Scale

A Measure Of Function
For People With Pain

0 Non-functioning	Stay in bed all day Feel hopeless and helpless about life
1	Stay in bed at least half the day Have no contact with outside world
2	Get out of bed but don't get dressed Stay at home all day
3	Get dressed in the morning Minimal activities at home Contact with friends via phone, email
4	Do simple chores around the house Minimal activities outside of home two days a week
5	Struggle but fulfill daily home responsibilities No outside activity Not able to work/volunteer
6	Work/volunteer limited hours Take part in limited social activities on weekends
7	Work/volunteer for a few hours daily. Can be active at least five hours a day. Can make plans to do simple activities on weekends
8	Work/volunteer for at least six hours daily Have energy to make plans for one evening social activity during the week Active on weekends
9	Work/volunteer/be active eight hours daily Take part in family life Outside social activities limited
10 Normal Quality of Life	Go to work/volunteer each day Normal daily activities each day Have a social life outside of work Take an active part in family life

Arthritis in North Carolina

Also in this Issue:
Marking a Milestone in Access to Health Care

www.ncmedicaljournal.com
November/December 2007, 68:6


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She deserves to know it's in good hands today.

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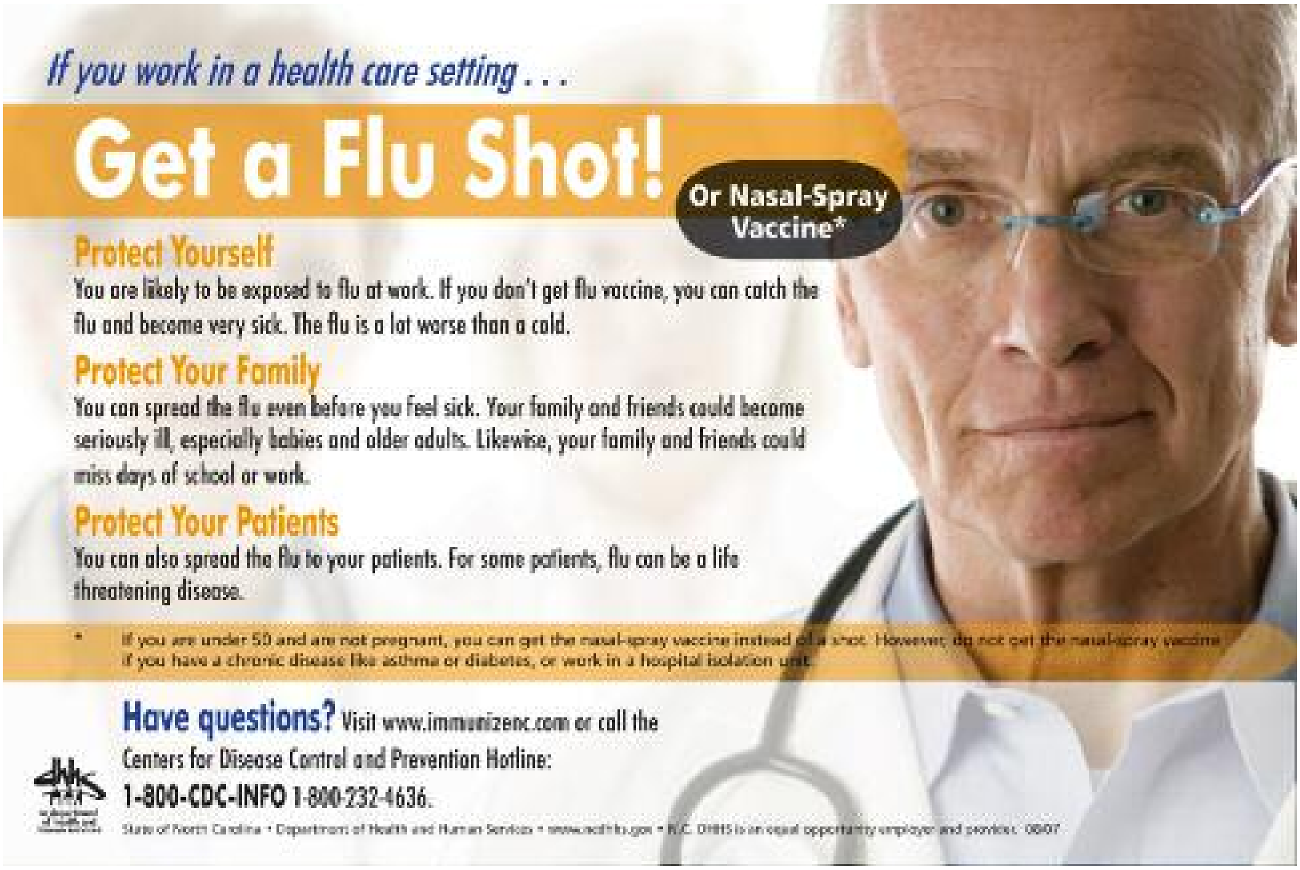

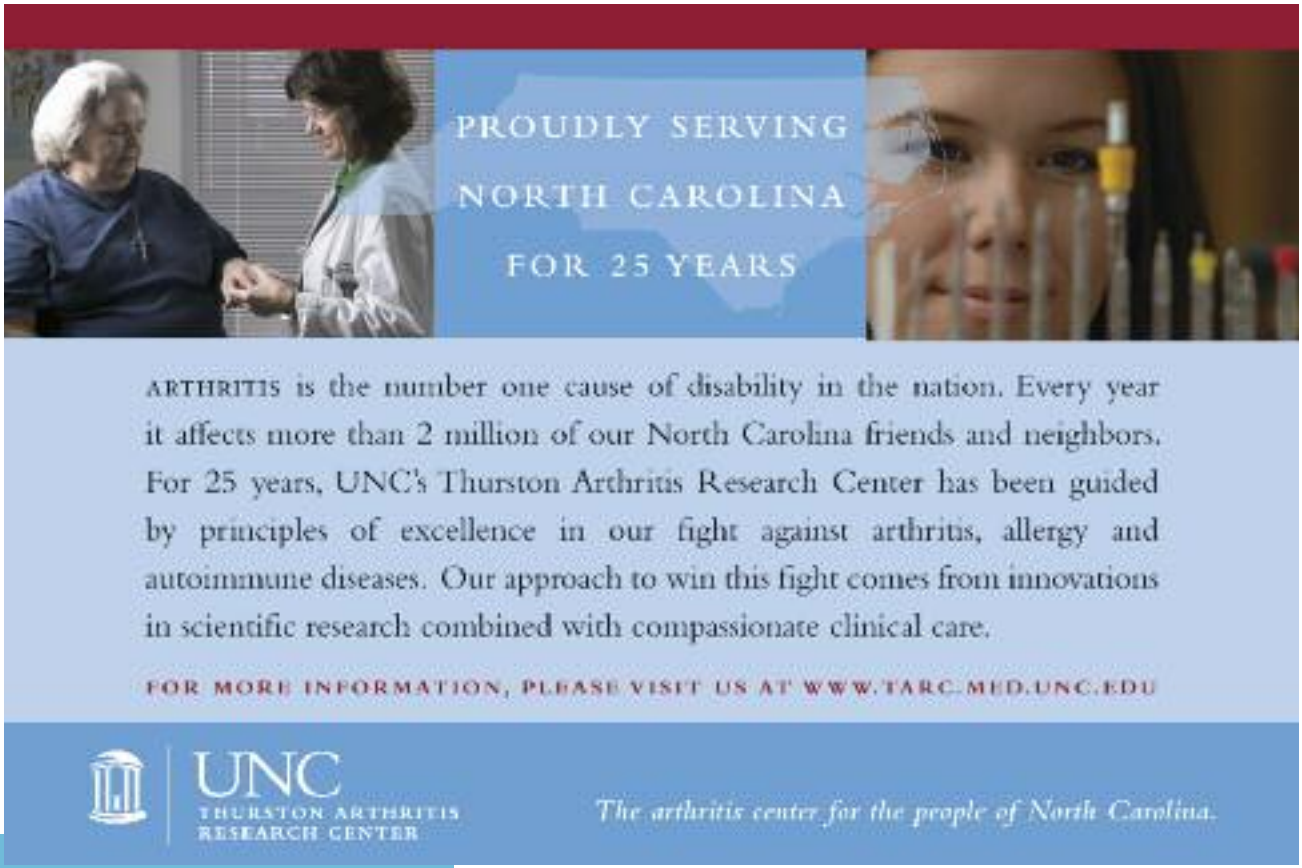

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Tarheel Footprints in Health Care

Recognizing unusual and often unsung contributions of individual citizens who have made health care for North Carolinians more accessible and of higher quality

Recognizing Jean Zoda, BSN, RN

The quote from writer and humorist Leo Rosten, "I cannot believe that the purpose of life is to be happy. I think the purpose of life is to be useful…," could have been attributed to Jean Zoda, registered nurse and arthritis program instructor and advocate. But to those who know her work with the Arthritis Foundation and her advocacy on behalf of people with arthritis, Jean would probably modify the quote to say, "I believe that the purpose of life is to be happy AND to be useful." Jean has found a unique way to blend being useful to others while harvesting joy and good health for herself.

A few years ago Jean found herself 100 pounds overweight, in poor health, and unable to do more than the activities of daily living. Exercise discouraged her because it made her joints sore. Enter the Arthritis Foundation Aquatic Program. Jean decided to give water exercise a try. The water exercise classes helped Jean lose weight, recover her health, and renew her spirit. The instructor was supportive and encouraging and even suggested that Jean train to become a water fitness instructor herself. This ended up giving Jean a new life journey and a new career path.

Because of her own personal journey, her newfound commitment to exercise, and as a testament to the benefits of water exercise, Jean forged ahead with becoming an Arthritis Foundation Aquatic Program instructor. Jean's philosophy from her days of nursing, "seeing the whole person," flows into the classes she teaches. She believes it's important to support the whole person by not only providing the benefits of being in the water and exercising, but by connecting people to support groups, providing resources, and, most of all, having fun. According to Jean, "Water fitness…has to be all about FUN to keep people motivated and coming back."

Jean continues her life journey as she works to become the best instructor she can be. Jean is now a Master Trainer for the Arthritis Foundation Aquatic Program and conducts instructor courses around the state. She has become an instructor for the Arthritis Foundation Exercise Program and is always looking for opportunities to be useful to others. Jean has become an advocate for evidence-based programs for people with arthritis. She wants people to have access to exercise and self-help programs proven to be beneficial for arthritis sufferers so they do not get discouraged by ineffective programs.

Jean continues her usefulness by serving on the NC Arthritis Program Advisory Board and helping to craft the State Arthritis Plan which directs arthritis resources and services for North Carolinians through 2010. Jean also contributed as an aquatic exercise expert and advocate for the UNC TV program HealthWise: Arthritis in July 2006, and her community outreach includes promoting the Triangle Arthritis Walk for 2007. As an Arthritis Foundation volunteer, Jean promotes arthritis programs with a local continuing care retirement community and is a frequent guest speaker at Triangle-area arthritis support groups, school programs, and health fairs. Jean is particularly proud of a tremendously successful Disability Day at an area elementary school where she taught elementary-age children about arthritis and the importance of taking care of their bodies. Jean has also committed to continuing her professional growth as an arthritis advocate by attending arthritis-related conferences and seminars.

Word is getting out about Jean's advocacy and aquatic classes. Many community agencies have contacted her to come and speak. Her expertise in aquatic fitness has now broadened to include being a multiple sclerosis aquatic instructor and American Red Cross lifeguard, lifeguard instructor, and water safety instructor. She is also a member of the Aquatic Exercise Association and is a certified Aquatic Fitness Professional. In addition, she teaches weekly Arthritis Foundation Aquatic exercise classes and works part-time for the NC Arthritis Program providing technical and data support and follow-up with newly trained instructors.

Not everyone has the privilege of combining their passion and their work. Jean is one of the lucky ones. Jean will tell you, "The greatest blessing and reaffirmation of my work comes when a new participant joins my class. For example, one student recently started my arthritis aquatics class saying she couldn't do much. She had tried unsuccessfully with other types of physical activity, suffered with arthritis and fibromyalgia, and had extra weight and other health factors that barely allowed her accomplish the activities of daily living. She heard about the arthritis class at the pool and knew she needed to do something and wondered if this class would help. I just smiled at her, knowing first-hand about her journey and told her that she had come to the right place. And I began my work."

The *North Carolina Medical Journal* is proud to recognize volunteer, advocate, and professional Jean Zoda for her passion, caring, and commitment to citizens in North Carolina living and being physically active with arthritis.

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POLICY FORUM

Arthritis in North Carolina

COMMENTARIES

DEPARTMENTS

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Racial/Ethnic Variation in Perceptions of Medical Information Sources in Durham County, North Carolina

Jason E. Williams, MD, MPH; Kevin J. Anstrom, PhD; Joëlle Y. Friedman, MPA; Kevin A. Schulman, MD

Abstract

Background: *Concerns about health and health care disparities have led some groups to promote better communication of medical information as a potential means of empowering patients to overcome barriers to health care and to practice healthy behaviors. We examined the independent effect of race/ethnicity on perceptions of the usefulness of different sources of health information.*

Methods: *We analyzed data from a cross-sectional telephone survey of black, Latino, and white adults (n = 515) in Durham County, North Carolina, in 2002. Respondents rated the usefulness of medical information sources, nonmedical information sources, and media. We used logistic regression to determine the effect of race/ethnicity on ratings of information sources, adjusting for demographic, socioeconomic, and health status factors.*

Results: *Compared to white respondents, Latinos and black respondents were more likely to perceive as useful the local health department, ministers/churches, community centers, television, and radio. Latinos were less likely than white and black respondents to report the pharmacy as a useful source of medical information.*

Limitations: *Some findings may be particular to Durham County, especially those based on the Latino subgroup. Also, the response rate (43%) suggests that nonresponse bias may have affected our results. Finally, perceived usefulness may affect one's intent to act on information but may not correlate with the benefit gained from a particular source.*

Conclusions: *There are substantial racial/ethnic differences in perceptions of certain medical information sources. Medical information designed for minority populations may be more effective if disseminated through particular sources.*

Key Words: *Attitude to health; ethnic groups; health services accessibility; mass media; North Carolina; public opinion; social perception; social support*

Racial/ethnic minorities experience a greater burden of preventable morbidity and mortality and poorer quality of care than white patients in the United States even after controlling for access-related factors.[1-4] Concerns about health and health care disparities have led some groups to promote better communication of medical information as a potential means of empowering patients to overcome barriers to health care and to practice healthy behaviors.[1,3,5] Improved dissemination of medical information may lead to greater demand for and receipt of preventive care and other services; greater awareness and understanding of risk factors, screening tools, and treatments; greater patient and provider satisfaction; and better health outcomes.[3,5-9] Several studies have focused on patient-provider communication, but less is known about patients' attitudes and beliefs about other sources of medical information.[10-13] Because the amount of information, the number of channels employed to disseminate information, and the skills necessary to access information are increasing, enhanced understanding of

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patients' perceptions of information sources is critical.[14-16]

The source of a message and the medium used to deliver the message are key elements of effective communication.[17-19] Furthermore, previous work has suggested there may be race/ethnicity-specific preferences for sources of medical information.[20-26] These studies have suggested that higher proportions of racial/ethnic minorities use medical personnel and electronic media (ie, television and radio) as information sources whereas higher proportions of white persons use print media (ie, newspapers, magazines, and books). Previous studies, however, have some limitations. First, previous studies have investigated the frequency of use of medical information sources but not the usefulness of those sources. Although frequency of use may reflect usefulness, frequency may also be influenced heavily by exposure to information sources. Second, previous studies have evaluated a narrow set of traditional sources of medical information. Given the rapidly increasing use of the Internet as a source of medical information as well as the variety of other information sources such as churches, family, and friends, it is important to analyze responses to these sources. Third, previous studies typically focused on persons with specific medical conditions (usually acquired immunodeficiency syndrome or cancer) and compared only 2 racial/ethnic groups.

If efforts to educate and empower patients are to succeed in helping to eliminate disparities, providers and public health practitioners must consider patients' use and perceptions of various sources of medical information. Minorities' perceptions of information sources are important because they are related to trust. Previous studies have shown connections between race/ethnicity, trust, and interactions in medicine and medical research.[22,27-28] Given new sources of information and recent demographic and health care trends in North Carolina, health practitioners would benefit from studies of medical and nonmedical information sources in a wider spectrum of racial/ethnic groups and asymptomatic individuals. The objective of this study was to investigate independent associations between race/ethnicity and perceptions of the usefulness of various sources of medical information.

Methods

Data for this study are from a cross-sectional, community-based survey designed to assess attitudes, perceptions, and beliefs about access to and quality of health care among black, Latino, and white persons residing in Durham County, North Carolina. The survey contained 40 items addressing a range of issues including personal health, perceptions of various sources of medical information, personal experiences in the health care system, knowledge of racial/ethnic differences in health and health care, and demographic characteristics. Many of the items were adapted from a national survey by the Kaiser Family Foundation.[29] Additional survey items were drawn from the California Health Interview Survey, El Centro Hispano Survey–Proyecto Life, and a literature review.[30-31] We made further modifications after conducting a provider survey (administered through a local independent practice association) and interviewing community leaders. Finally, we conducted interviews with Latino and black community members to assess content validity and to ensure that an exhaustive list of precoded responses was included in the survey. The survey was translated into Spanish and back-translated into English to ensure that the English and Spanish versions were consistent. Due to the survey's length, we split the survey into 3 components (a core survey, a set of questions for split-half sample 1, and a set of questions for split-half sample 2) and asked all participants to complete the core survey and 1 of the split-half set of questions.

Sample

Eligible participants were adults aged 18 years and older residing in Durham County, North Carolina, in households with telephones. The sample was designed to generalize to the Durham County adult population and to allow for analyses stratified by race/ethnicity. Two separate samples were used for all interviews. The first sample was obtained using a standard, list-assisted, random-digit dialing procedure. Active blocks of telephone numbers (area code + exchange + 2-digit block number) that contained 3 or more residential directory listings were selected with probabilities in proportion to the number of listed phone numbers. After selection, 2 more digits were added randomly to complete the number. The resulting numbers were compared with business directories, and matching numbers were removed. Telephone exchanges with greater than average density of black households were oversampled to increase the overall sample of black respondents. For the second sample, to achieve an oversampling of Latino respondents, participants were recruited by random-digit dialing from a list of households with Latino surnames. We selected this approach because Durham has few Latino households.

We used survey weights to adjust for the sample design (ie, oversampling of black and Latino populations) and for any nonresponse bias. Specifically, the survey weights helped to ensure that the study sample resembled the population of Durham County with respect to age, sex, and education level. Additional details of the survey weighting process are available from the authors upon request.

Survey Administration

The telephone interviews were conducted between October 14 and December 16, 2002, in either English or Spanish based on participant preference. A minimum of 15 attempts were made to contact a potential respondent at each sampled telephone number. The interviewers used a standard screening technique used by major policy research organizations and designed to obtain the best distribution of male and female respondents. Interviewers asked to speak to the youngest male at home. If a male was not available, interviewers asked to speak with the oldest female at home. Interviewers contacted 2615 people by phone, and 1415 (54%) agreed to participate. Of the 1415 consenting households, 1175 (83%) met eligibility criteria. Ninety-six percent (1131/1175) of consenting and eligible households completed the survey, either split-half sample 1 or split-half sample 2. The analysis presented here focuses on the

515 participants who responded to split-half sample 1 and identified themselves as black, Latino, or white. The institutional review board of the Duke University Health System approved the study.

Dependent and Independent Measures

The primary outcome of interest was the perception of the usefulness of 12 sources of medical information. Participants were asked, "How useful do you think the following sources are for medical information for yourself?" Possible responses were "very useful," "somewhat useful," "not too useful," "not useful at all." If participants did not use a particular source, they could also choose the responses "don't know" or "refuse to respond." The sources of medical information were medical personnel sources (ie, doctors, nurses, pharmacists, health department personnel), nonmedical sources (ie, ministers and churches, community centers, friends and relatives, libraries), and media (ie, Internet, newspapers and magazines, radio, television).

Self-reported race/ethnicity was the primary independent variable. Participants were asked if they were of Latino descent and then asked to indicate their race (Asian, black, white, or other). Because of small cell sizes, we excluded participants who indicated that their race was Asian or other. In the remaining sample, we coded participants of Latino descent as Latino, and we coded all others as black or white. In addition to race/ethnicity, we collected data on demographic characteristics, socioeconomic characteristics, health status, and health care experience.

Demographic and socioeconomic variables included sex, age, education level, marital status, employment status, financial status, facility with English, and country of origin. Financial status was assessed by asking about participants' current financial situation. Possible responses included "having difficulty paying the bills, no matter what," "enough money to pay the bills, but have to cut back," "enough money to pay bills, but little to spare for extras," "bills are paid and still have enough for extras," and "don't know" or "refused to answer." All participants who were interviewed in Spanish were asked, "If you have to speak in English on the telephone, would you say you can speak in English very well, somewhat well, or not too well?" Country of origin was coded as United States or other.

Health status and health care experiences were assessed by self-reported health (excellent, very good, good, fair, poor), diagnosis of 5 chronic diseases (diabetes mellitus, hypertension, lung disease, heart disease, cancer), type of health insurance, possession of a usual source of care, and time since last physician visit (within the past year, more than 1 year and up to 2 years, more than 2 years and up to 5 years, and more than 5 years).

Statistical Analysis

Weighting was used to adjust for features of the sample design (oversampling of black and Latino populations) and for bias that may have resulted from nonresponse. To determine whether an information source was perceived as useful, the outcome variable was dichotomized. Responses of "very useful" and "somewhat useful" were collapsed into "useful," and responses of "not too useful" and "not useful at all" were collapsed into "not useful." Responses of "don't know" and "refused" were excluded from further analysis due to small cell sizes. We dichotomized age (less than 40 years, 40 years or older), education level (less than high school degree, high school degree or more), marital status (married, other), and employment status (employed, unemployed). We dichotomized financial status as less wealthy (participants reporting difficulty paying bills or those able to pay the bills with cutbacks) and more wealthy (those with "enough for extras" or "little to spare for extras"). We dichotomized health status as more healthy (excellent or very good) and less healthy (good, fair, poor), insurance status as insured (private and Medicare/Medicaid) and uninsured, and time since last physician visit as more recent (within 1 year) and less recent (all responses greater than 1 year).

We then performed univariate analyses to assess differences by race/ethnicity in perceptions of medical information sources. Chi-square tests were used to compare the groups. Next, we performed bivariate analyses to test associations between respondents' race/ethnicity and the perceived usefulness of information sources, calculating unadjusted odds ratios. We also tested for associations between covariates and perceptions of medical information sources.

We then developed multiple logistic regression models to assess the independent association between race/ethnicity and the perceived usefulness of medical information sources. Before conducting multivariate analyses, we assessed collinearity of variables and developed groups of meaningful predictors. We used a sequential modeling approach and arrived at 2 models. The first model included the variables for age, sex, education, marital status, employment status, and financial situation. The second model included the factors above along with perceived health status, insurance status, possession of a usual source of care, and time since last physician visit. Data analysis was performed in STATA (StataCorp, College Station, TX).

Results

Table 1 gives the demographic, socioeconomic, and health characteristics of the survey respondents by race/ethnicity. The sample included roughly equal proportions of black, Latino, and white respondents. The Latino subgroup was younger, had a higher proportion of men, and had less formal education than the black and white subgroups. Most respondents were employed at the time of the interview. The proportion of respondents who reported excellent or very good health was highest for white respondents. The prevalence of chronic conditions was similar among the subgroups. Black and white respondents were more likely than Latinos to have health insurance and a usual source of care.

As shown in Table 2, all subgroups perceived doctors and nurses as useful sources of information. Perceptions of other sources of information varied. For example, black and Latino respondents more often perceived ministers and churches, community centers, and television as useful sources of medical

Table 1.
Characteristics of Survey Respondents by Race/Ethnicity[*]

Characteristic	Race/Ethnicity			*P*
	White (n = 197)	Black (n = 155)	Latino (n = 163)	
Age, mean (SD), year	45.7 (1.4)	43.3 (1.7)	34.9 (1.4)	< .001
Female	54.2	59.7	42.4	.16
Education				< .001
Less than high school diploma	6.0	25.0	68.9	
High school diploma	19.1	26.4	17.1	
Some college	23.2	27.9	5.9	
College degree	51.7	20.8	7.6	
Married	52.1	29.9	49.0	< .001
Employed	62.8	62.5	71.2	.56
Financial status				< .001
Bills paid, extras	50.0	34.7	9.4	
Bills paid, little extras	34.5	33.8	39.3	
Bills paid, cutbacks	10.2	10.1	24.7	
Difficulty paying bills	3.5	19.3	20.3	
No answer	1.8	2.1	6.3	
Facility with English language[‡]				
Very well			4.3	
Somewhat well			16.4	
Not too well			79.3	
Born in United States	94.9	97.0	4.8	< .001
Self-reported health				< .001
Excellent	26.7	14.8	11.7	
Very good	41.7	30.4	13.5	
Good	22.8	30.4	37.6	
Fair	4.1	21.5	34.1	
Poor	4.7	2.9	3.2	
Diagnosis				
Diabetes mellitus	4.8	13.2	9.0	.03
Hypertension	24.6	30.7	20.7	.31
Lung disease	13.0	16.6	3.3	.10
Heart disease	6.9	6.7	3.5	.59
Cancer	5.7	5.6	0.6	.38
Health insurance status				< .001
Private	75.7	53.6	28.3	
Medicare/Medicaid	15.8	21.0	1.7	
Uninsured	7.7	22.2	69.8	
Uncertain/no answer	0.7	3.2	0.2	
Has usual source of care	90.5	90.9	73.3	.01
Time since last doctor visit				.09
Less than 1 year	82.0	86.1	62.0	
1 to 2 years	8.7	7.8	17.2	
2 to 5 years	4.2	3.5	10.7	
More than 5 years	5.1	2.6	10.1	

[*] Values are expressed as weighted percentages unless otherwise indicated.

[†] For some variables, sample size varies due to nonresponse. Total sample size ranged from 511 to 515.

[‡] Facility with English was assessed in the 138 respondents who chose to complete the interview in Spanish.

Table 2.
Proportion of Respondents Perceiving Medical Information Sources as "Very Useful" or "Somewhat Useful" by Race/Ethnicity*

Information Source	Race/Ethnicity			*P*
	White (n = 197)	Black (n = 155)	Latino (n = 162)	
Medical Source				
Doctors	95.9	98.8	96.7	.25
Nurses	87.9	95.5	84.9	.04
Pharmacy	88.5	94.8	73.9	.002
Health department	43.6	68.0	88.8	< .001
Nonmedical source				
Minister or church	23.2	63.4	70.1	< .001
Community center	26.8	60.5	86.4	< .001
Friends or relatives	69.9	74.7	77.9	.43
Library	65.8	72.5	76.4	.23
Media				
Internet	66.1	63.8	59.5	.68
Newspapers/magazines	69.1	80.4	68.1	.05
Radio	34.9	62.7	74.8	< .001
Television	52.3	81.4	81.5	< .001

* Values are expressed as weighted percentage unless otherwise indicated.

information, compared to white respondents. Perceptions of print media and the Internet did not vary substantially.

Unadjusted associations between respondent characteristics and perceived usefulness of information sources were also examined. The pharmacy was perceived as useful by respondents who had more education, and the health department was cited as useful by respondents who were younger, less educated, less healthy, and uninsured. The odds of perceiving a minister, church, or community center as a useful source of information were higher for respondents without a high school diploma and those who were less wealthy, less healthy, and uninsured. Radio and television were seen as more useful by respondents who had less education and poorer health and those who were uninsured. Interestingly, respondents with less education and wealth, poorer health, and without insurance found most of these sources (excluding the pharmacy) to be useful as compared to their better educated, wealthier, healthier, and insured counterparts.

As shown in Table 3, controlling for demographic and socioeconomic characteristics and health status, significant differences persisted in the ways Latinos and black respondents perceived the health department, the pharmacy (for Latinos only), ministers and churches, community centers, television, and radio, as compared to white respondents. In most cases, the model controlling for demographic and socioeconomic variables accounted for part of the racial/ethnic difference (data not shown). The model controlling for both demographic and socioeconomic characteristics and health status also did not fully explain the racial/ethnic differences observed in univariate analyses.

Discussion

Although there have been suggestions that we can reduce health disparities by educating and empowering persons from racial/ethnic minority groups, there is little information on the effect of perceptions of the tools used to educate and empower. This study found persistent racial/ethnic variation in perceptions of several sources of medical information. Compared to white respondents, Latinos and black respondents were more likely to rate health departments, ministers, churches, community centers, television, and radio as useful sources. In addition, Latinos were less likely to report pharmacies as useful sources. These differences remained after controlling for demographic, socioeconomic, and health-related factors.

In the literature on race/ethnicity and sources of medical information, most studies have surveyed respondents with specific health conditions and have examined the actual use of information sources rather than perceptions of those sources. Still, these reports have been somewhat consistent with our findings in that they also detected racial/ethnic variations for certain sources of information. Cunningham et al[24] found that black respondents were more likely than white respondents to

Table 3.
Proportion of Respondents Perceiving Medical Information Sources as "Very Useful" or "Somewhat Useful" by Race/Ethnicity[*]

Information Source	Black Respondents			Latino Respondents		
	Unadjusted OR (95% CI)	Model 1†	Model 2‡	Unadjusted OR (95% CI)	Model 1†	Model 2‡
Medical source						
Doctors	3.4 (0.5-23.3)	2.3 (0.2-23.3)	2.1 (0.2-23.7)	1.2 (0.4-4.3)	0.7 (0.2-2.5)	0.4 (0.0-5.4)
Nurses	2.9 (1.0-8.7)	2.6 (0.8-8.7)	2.4 (0.6-8.8)	0.8 (0.4-1.7)	0.5 (0.1-1.5)	0.3 (0.1-1.1)
Pharmacy	2.4 (0.9-6.4)	2.2 (0.8-6.4)	1.9 (0.6-5.6)	0.4 (0.2-0.8)§	0.2 (0.1-0.4)§	0.1 (0.0-0.3)§
Health department	2.8 (1.6-4.7)§	2.3 (1.3-4.0)§	2.0 (1.1-3.5)§	10.3 (5.7-18.4)§	5.9 (2.6-13.3)§	3.7 (1.4-9.4)§
Nonmedical source						
Ministers/churches	5.7 (3.3-9.9)§	5.4 (3.0-9.6)§	5.0 (2.8-9.1)§	7.8 (4.3-14.0)§	6.6 (2.8-15.6)§	4.7 (1.7-12.6)§
Community center	4.2 (2.5-7.1)§	3.6 (2.1-6.3)§	3.2 (1.8-5.6)§	17.4 (9.0-33.3)§	9.3 (4.0-21.8)§	6.4 (2.4-16.9)§
Friends/relatives	1.3 (0.7-2.2)	1.4 (0.8-2.4)	1.3 (0.7-2.3)	1.5 (0.8-3.0)	2.4 (0.8-6.8)	1.7 (0.6-4.8)
Library	1.4 (0.8-2.4)	1.6 (0.9-2.9)	1.4 (0.8-2.8)	1.7 (1.0-3.0)	1.5 (0.7-3.3)	1.1 (0.4-2.7)
Media						
Internet	0.9 (0.5-1.5)	1.1 (0.6-1.9)	1.1 (0.6-2.1)	0.8 (0.4-1.3)	0.7 (0.3-1.7)	0.9 (0.3-2.4)
Newspaper/ magazines	1.8 (1.0-3.3)§	2.0 (1.0-4.0)§	1.7 (0.9-3.4)	1.0 (0.5-1.7)	1.2 (0.5-2.9)	0.8 (0.3-2.1)
Radio	3.1 (1.9-5.2)§	3.4 (2.0-5.9)§	3.2 (1.8-5.5)§	5.5 (3.2-9.6)§	6.4 (3.0-13.7)§	4.6 (2.0-10.5)§
TV	4.0 (2.3-7.0)§	4.1 (2.3-7.3)§	3.9 (2.1-7.2)§	4.0 (2.3-7.1)§	4.7 (2.0-11.1)§	4.0 (1.6-10.7)§

* Values are expressed as odds ratio (95% confidence interval). White respondents served as the reference group for both sets of comparisons.

† Model 1 included the variables for age, sex, education, marital status, employment status, and financial situation.

‡ Model 2 included the variables for age, sex, education, marital status, employment status, financial situation, perceived health status, insurance status, possession of a usual source of care, and time since last physician visit.

§ P < .05.

OR indicates odds ratio; and CI, confidence interval.

report using religious organizations, public health agencies, government sources, family, and friends for information about acquired immunodeficiency syndrome. Surveying black and Hispanic respondents, O'Malley et al[21] found variation in the use of health providers and radio as sources of information. Nicholson et al[25] found differences between white and black women in the use of print news media, computer-based resources, and health policy organizations. Other studies dealing with individuals' perceptions of sources of medication information for human immunodeficiency virus, cigarette smoking messages, and cancer treatment have also found racial/ethnic differences.[20,22,26]

Although some of our findings are similar to those of previous studies, the present study offers a number of contributions in this area. First, instead of using frequency of use as a measure of usefulness, we asked about the usefulness of the information sources directly. This allowed us to measure individuals' attitudes toward the sources. Second, we were able to measure an independent effect of race/ethnicity by controlling for demographic, socioeconomic, and health-related factors. Third, our study examined a broader spectrum of individuals and types of information than have other studies. We compared individuals from 3 racial/ethnic groups with different health status and asked about medical information in general rather than about information on one particular disease or health issue. Fourth, we included a wide range of information sources including some newer sources of medical information.

This study has some limitations that may affect the generalizability of the results. First, the study design sought to create a sample that was representative of one county's population rather than of the United States. Thus, some response patterns may be particular to Durham County. Conclusions based on the Latino subgroup are particularly vulnerable to this limitation. The arrival of large numbers of Latinos to Durham County is a relatively recent trend.[32] Ninety-five percent of Latinos in this study were born outside of the United States, compared to 49% in the national study by the Kaiser Family Foundation.[29] Due to recent "hypergrowth" in the Latino population in Durham County, there may not be an adequate supply of culturally and linguistically appropriate resources. In addition, Durham's

Latinos may be less acculturated than Latinos in other areas. Second, we tried to reduce confounding by controlling for demographic, socioeconomic, and health-related factors, but these factors are complex and some residual confounding certainly remained. For example, previous research has suggested that the correlation between self-reported health status and health indicators is less valid in Latino populations.[33] Third, although the response rate in this study was within the range of similar surveys of this type, the response rate increases the likelihood of some degree of bias in the results.[34] We attempted to correct for nonresponse bias by assigning weights to key demographic variables to arrive at a sample that more closely resembled Durham County's population. Finally, perceived usefulness may affect one's intention to act on information but may not always be correlated with the actual benefit gained from a particular source.

Using cross-sectional survey data, we found racial/ethnic differences in perceptions of the usefulness of various sources of medical information. Health professionals have struggled to construct high-quality informational messages that reach minorities, augment their health knowledge base, and alter their behaviors. When constructing messages designed for minorities, health professionals have begun to realize they should consider race/ethnicity when creating the format and content of the message. The present study suggests that race/ethnicity should also be considered when selecting the source that will be used to disseminate the message. Sources deemed useful by minorities should be used to spread messages that are particularly relevant to these groups. As an example, health practitioners seeking to reach minorities might consider forming new or stronger partnerships with churches and ministers because both black and Latino respondents seem receptive to health messages from these nontraditional sources of medical information. Health practitioners might also consider increasing the use of media to deliver health messages because these also seem to be trusted sources in some minority communities.

The subject of race/ethnicity and the transmission of medical information is a fertile area for further investigation that has received little previous attention. In our study we found racial/ethnic differences in perceptions of sources of medical information. Future studies should investigate the types of messages received and how these messages are integrated into health behaviors and beliefs about health care services. **NCMJ**

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ARTICLE

Emergency Contraception for Sexual Assault Victims in North Carolina Emergency Departments

Amy Tucker Woodell, MPH; James Michael Bowling, PhD, MA; Kathryn E. Moracco, PhD, MPH; Melissa L. Reed, MA

Abstract

Introduction: *One in 5 women is a victim of sexual assault. This study examines the administration of emergency contraception to victims of sexual assault in North Carolina hospital emergency departments.*

Methods: *One hundred seventeen surveys were mailed to hospital emergency departments across the state to determine their emergency contraception practices for victims of sexual assault. The survey contained 11 questions about emergency contraception practices for victims.*

Results: *Of the 117 surveys, 103 were returned revealing that just over 50% of the hospitals in North Carolina treated victims with emergency contraception without exception. Both dispensing emergency contraception and providing information about emergency contraception were significantly associated with having a sexual assault nurse examiner program.*

Conclusion: *Results from this study demonstrate inconsistent provision of emergency contraception to victims of sexual assault; however, there is greater consistency of emergency contraception use by emergency departments using sexual assault nurse examiners.*

Grants: *None*

Keywords: *Contraception, postcoital; emergency nursing; rape*

Pregnancy resulting from sexual assault is a traumatic experience, but it is preventable with emergency contraception, a high dose oral contraceptive that prevents pregnancy if taken within 120 hours after intercourse, often referred to as the "morning-after pill." Emergency contraception cannot harm or terminate an established pregnancy.

Previous research has shown that hospitals do not consistently provide emergency contraception to victims of sexual assault.[1-5] One study of emergency physicians found 8.4% would not prescribe emergency contraception to sexual assault victims.[1] A 2002 national study of Catholic and non-Catholic hospitals by Harrison found that emergency contraception was not available at 55% of Catholic hospitals and 42% of non-Catholic hospitals.[6] A report by Patel et al[7] found that 55% of Pennsylvania hospitals had emergency contraception available onsite, and 37% offered both counseling for and provision of emergency contraception. Eighty-five percent of the 201 responding hospitals in a NY survey said it is their standard policy to dispense emergency contraception immediately, onsite, to all rape victims who choose it after having been counseled.[8]

Nationally, 1 in 5 women reports being sexually assaulted at some point in her life.[9] Timely provision of emergency contraception prevents the additional psychological and physical trauma an unwanted pregnancy may cause a victim of sexual assault. Five percent of rapes result in pregnancy.[10] This translates to 25 000 rape-related pregnancies each year in the United States, 22 000 of which could be prevented with emergency contraception.[11]

Accordingly, several medical professional organizations, including the American College of Obstetricians and

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Gynecologists,[12] the American College of Emergency Physicians,[13] and the American Medical Association,[14] have recommended that pregnancy prophylaxis, such as emergency contraception, be provided to victims of sexual assault.

Across the state, there are hospitals with sexual assault nurse examiners who are specially trained to provide care to patients who have been sexually assaulted including offering emergency contraception and collecting forensic evidence. Fifty-one percent of North Carolina hospitals have a sexual assault nurse examiner program.

In 2004, the North Carolina Coalition Against Sexual Assault, Planned Parenthood of Central North Carolina, and NARAL Pro-Choice North Carolina, under the umbrella organization of North Carolina Women United, investigated whether emergency contraception was available to sexual assault victims in emergency departments. The purpose of this exploratory study was to present point estimates of emergency contraception use across North Carolina hospitals and then to examine variation in use of emergency contraception by hospital characteristics.

METHODS

Study Design

Self-administered questionnaires were mailed to North Carolina hospitals with emergency departments. The 11-question self-administered questionnaire addressed emergency department policies for dispensing emergency contraception to sexual assault victims and giving referrals to sexual assault victims. Further, hospital representatives were asked, "Is it standard policy for the hospital to dispense emergency contraception onsite to sexual assault survivors?" Participants who responded affirmatively were classified as having an emergency contraception policy.

We also assessed the presence or absence of a refusal clause, or "conscience clause," in the questionnaire. Responders that dispensed emergency contraception were asked, "Are there any exceptions to your policy based on the refusal of the provider on duty to dispense medication?" If hospitals did not provide emergency contraception or there were exceptions to their policy, they were asked if they provide prescriptions for emergency contraception or referrals to other providers.

Hospitals were also asked if they had a sexual assault nurse examiner program. Sexual Assault Nurse Examiners are defined by the North Carolina Coalition Against Sexual Assault as "specially trained Registered Nurses who perform a comprehensive evaluation and assessment, collect high quality evidence, and provide expert testimony in cases of sexual assault." Developing a sexual assault nurse examiner program was not considered as having a program because there is not automatic intervention. In addition, emergency departments were asked if these nurses are available 24 hours a day, seven days a week.

Other data collected included the title of the staff person who completed the questionnaire, hospital name, number of sexual assault victims treated per year in the emergency department, and other questions regarding emergency department practices for the treatment of sexual assault victims.

Hospital size was dichotomized according to bed number based on the median of 143 beds. Hospitals were classified as being located in a metropolitan area, micropolitan area, or neither according to the US Office of Management and Budget definitions of 2003. A metropolitan area has at least one urbanized area of at least 50 000 people, a micropolitan has an urban center of 10 000-49 999 people, and unclassified counties have towns with fewer than 10 000 people.[15] Metropolitan area is referred to as a large population and the micropolitan and "neither" areas were collapsed into one category for statistical analysis and referred to as a small population. Open-ended answers, such as title of hospital responder, were grouped and coded. Answers for "check all that apply" questions were each coded individually as checked or not checked.

Setting and Selection of Participants

Sample and setting were drawn from The North Carolina Hospital Association membership directory excluding hospitals without an emergency department, specialty hospitals, or psychiatric hospitals. Military hospitals (n=4), which are not NC Hospital Association members, were also included in the survey due to a particular interest in the policies of North Carolina military facilities by the survey sponsors. Hospitals were also excluded from the sample if they reported that they routinely transferred sexual assault victims to another emergency department (n=2).

Fifteen nonmember hospitals were not surveyed due to a lack of identifying information for these hospitals. Five of these nonsurveyed hospitals were specialty hospitals, and two others did not have emergency departments, leaving a possible 8 missed hospitals (2 with emergency departments, 6 unknown). Two questionnaires received from emergency departments belonging to hospital systems with one shared policy for the treatment of sexual assault victims were duplicated as representative responses for each of those emergency departments within those hospital systems. In all, we collected data from 117 eligible North Carolina hospital emergency departments. The NC Hospital Association directory data contained the names of hospital administrators, bed numbers, hospital ownership, and county location.

Methods of Measurement

We used data from the Emergency Care for Sexual Assault Survivors Survey collected in late 2004 and early 2005 by North Carolina Women United and the North Carolina Coalition Against Sexual Assault as well as supplemental information retrieved from the 2004 North Carolina Hospital Association Membership Directory.[16] The University of North Carolina at Chapel Hill's Office of Human Research Ethics Public Health Institutional Review Board (IRB) reviewed the application to complete a secondary analysis and determined that it was exempt from IRB governance.

The above mentioned questionnaire, Emergency Care for Sexual Assault Survivors Survey, was developed by the survey sponsors in consultation with Family Planning Advocates of New York state and pretested with 2 hospital individuals

Table 1.
Hospital Policies and Services for Victims of Sexual Assault (n=103)

Hospital	N	%
Standard policy to dispense emergency contraception onsite without exception	55	53
Standard policy to dispense emergency contraception with exceptions	9	9
Standard policy to dispense with unknown exceptions*	12	12
Not standard policy to dispense emergency contraception	27	26
Hospital Services	**N**	**%**
Have sexual assault nurse examiner coordinator**	52	51
Have sexual assault nurse examiner coordinator available at all times***	28	56

* Due to missing responses to exception question
** Sample size of 102 for this question due to 1 missing response
*** Sample size of 50 for this question due to 2 missing responses

familiar with emergency department policies for sexual assault victims and 2 researchers with survey expertise. A questionnaire with a cover letter from the survey sponsors was mailed to each hospital's chief executive officer, director of nursing, hospital attorney, and medical director of the emergency department. These 4 positions were sent questionnaires to replicate the protocol from the New York survey of emergency departments.[7] Up to 3 calls were made to nonresponders and questionnaires were faxed to nonresponding hospital emergency departments. At the end of the questionnaire, participants could request that a listing of local rape crisis centers and sexual assault nurse examiners, a sexual assault and health care fact sheet, and a fact sheet about emergency contraception in the emergency department be sent to them.

After the data were collected and compiled, data entry was crosschecked with the original questionnaires for accuracy. When more than one questionnaire was received from a hospital (n=12), the questionnaire completed by the higher-ranking staff member (n=6) or the questionnaire filled out more completely was included in the sample (n=6). Comments written in the margins of each questionnaire were used for clarification of responses. Follow-up phone calls were made to allow hospitals to confirm their answers when inconsistencies were found for specific questions of interest. When these attempts to contact hospitals were successful, this resulted in modifications to original questionnaire responses to reflect the most accurate information.

Data Analysis

Data were analyzed using SAS System for Windows Version 8 (SAS Institute Inc, Cary, NC), and frequencies and chi-square analyses were performed.

RESULTS

One hundred three hospitals responded to the survey for a response rate of 88%. More than half of these hospitals are privately owned. The number of beds in each hospital ranged from 6 to 989 with a median of 143 beds. Various staff from hospital emergency departments completed the questionnaires including directors of emergency departments, nurse managers and directors of nursing, registered nurses, sexual assault nurse examiner coordinators, sexual assault nurse examiners, clinical directors, medical directors of the emergency department, and emergency department managers.

The majority of hospitals reported treating 50 or fewer sexual assault patients each year; one hospital reported treating more than 200. Eighty-three percent of hospitals report that it is standard policy to provide information about emergency contraception to sexual assault victims. Seventy-four percent of hospitals dispense emergency contraception onsite to sexual assault victims as standard policy, but 9 of these allow exceptions based on the refusal of the physician on duty and 12 did not answer the exception question. This leaves 53% of hospitals dispensing emergency contraception onsite without exception. (See Table 1.) Seventy percent of hospitals report that emergency contraception is available 24 hours a day. Of the 27 hospitals for which it is not standard policy to dispense emergency contraception, 63% provide prescriptions and 60% refer to another provider. Eighty-nine percent of hospitals refer all sexual assault victims for follow-up counseling, and 88% reported referring specifically to a rape crisis center. Sexual assault nurse examiner programs are established at half of the hospitals, and more than half of these are available 24 hours a day, seven days a week. (See Table 1.) Hospitals with a sexual assault nurse examiner program are significantly more likely to provide information about emergency contraception (92% vs 72%; $p<0.05$) and to dispense emergency contraception (77% vs 46%; $p<0.05$) (see Table 2).

A significant association was also found between a hospital dispensing emergency contraception and its location in an area with a small population versus a large population. Hospitals in areas with small populations are less likely to have a standard policy to dispense emergency contraception compared with hospitals located in large population areas (45% small vs 74% large population hospitals; $p<0.05$). (See Table 2.) Hospitals located in small population areas were less likely than those in large population areas to have a standard policy to provide information about emergency contraception (78.6% vs 86.3%). This association, however, was not significant ($p>0.05$).

Hospitals in large population areas were more likely to have sexual assault nurse examiner programs. In areas with large

Table 2.
Relationship Between Hospital Emergency Contraception Policy and Presence of Sexual Assault Nurse Examiner Program and Population Size (n=91)

Hospital Characteristic	Hospitals with a policy to dispense emergency contraception	Hospitals that allow exceptions	Hospitals that do not dispense
Sexual assault nurse examiner program*			
Yes, No. (%), n=43	33 (77)	4 (9)	6 (14)
No, No. (%), n=48	22 (46)	5 (10)	21 (44)
Population Size*			
Small, No. (%), n=44	20 (45)	5 (11)	19 (43)
Large, No. (%), n=47	35 (74)	4 (9)	8 (17)

* p-value < 0.05 based upon chi-square test of association between emergency contraceptive policy and hospital characteristic

populations, 60.8% of hospitals have sexual assault nurse examiners, and in areas with small populations, 41% have sexual assault nurse examiners (p=0.05).

Limitations

There were several limitations to this study. One potential limitation is that not all hospitals with emergency departments were included; 19 hospitals were not NC Hospital Association members at the time of this survey. However, at most, only 8 of these could have been eligible for this study, which would have resulted in a response rate of 82%. Of the hospitals that did respond, there were several cases in which data were missing due to incomplete data. Item nonresponse occurred on questions regarding how many sexual assault survivors were served (n=1), whether or not the hospital allows exception to their policy to provide emergency contraception based upon the provider on duty (n=12), the availability of emergency contraception 24 hours a day (n=11), the presence/absence of a sexual assault nurse examiner program (n=1), and availability of a sexual assault nurse examiner program 24 hours a day (n=2). However, the strength of the survey was the overall high response rate.

Questionnaires were not anonymous; therefore, responders may have been influenced to answer questions in ways they deemed to be more socially acceptable to the survey sponsors, particularly the North Carolina Coalition Against Sexual Assault. However, survey questions focused on hospital policies and services, not on personal attitudes or behaviors; therefore, the level of social acceptability bias influencing survey responses should be minimal. Personal bias or interpretation poses another question about reliability and validity of the instrument as well as the study.

Different hospital staff members responded to the survey, which may affect the comparability of responses. However, because the information requested was on hospital policy, respondents' differing positions should not have greatly influenced variability in responses. The method of follow-up phone calls introduces the possibility of a mixed-mode effect to responses, as the original survey was a written questionnaire.[17]

CONCLUSION

In North Carolina, a little more than half of hospitals dispense emergency contraception without exception. Both dispensing emergency contraception and providing information about emergency contraception were significantly associated with having a sexual assault nurse examiner. Almost all hospitals that operate emergency rooms offer information on emergency contraception to victims of sexual assault, and most refer victims to some form of counseling. In addition, hospitals in metropolitan areas were also more likely to dispense emergency contraception.

Our findings indicate that timely access to emergency contraception may be limited by hospital policy and practices. For example, it is of concern that in the one-quarter of hospitals that did not dispense emergency contraception onsite, one-half provided either a referral to another provider or a prescription, measures that are not considered adequate alternatives to dispensing onsite, particularly for a time-sensitive treatment such as emergency contraception. Previous research by Harrison[6] found most referrals provided by hospitals that did not provide emergency contraception were ineffective. Furthermore, in this study, 14% of the hospitals that dispense emergency contraception had exceptions based on the preference of the physician on duty, which could also limit timely access to emergency contraception.

This study's results indicate that emergency departments should (a) change hospital policies to meet the needs of the victim rather than the preference of the provider by creating standing orders so that emergency contraception can be provided regardless of the physician on duty and (b) institute sexual assault nurse examiner program affiliation or training to ensure that treatment for sexual assault includes pregnancy prevention prophylaxis. Hospitals, particularly those in rural areas, would benefit from having sexual assault nurse examiners, preferably available 24 hours a day, to ensure that sexual assault victims receive the optimal complement of services.

Several states have taken legislative action to ensure the provision of emergency contraception for sexual assault victims. As of October 2006 11 states[a] required emergency departments to provide emergency contraception-related services or information to sexual assault survivors. Two bills introduced during the 2007-2008 NC General Assembly session (House Bill 961 and NC Senate Bill 968) would require North Carolina hospitals to provide emergency contraception onsite to sexual assault victims in emergency departments. However, measures must be taken to guarantee that any policies and legislation put into place are adhered to and fully implemented. **NCMJ**

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[a] States requiring emergency departments to provide emergency contraception-related services or information to sexual assault survivors as of October 2006 include California, Illinois, Massachusetts, New Jersey, New Mexico, New York, Ohio, Oregon, South Carolina, Texas, and Washington.

ARTICLE

Perceived Barriers to Physical Activity Among North Carolinians With Arthritis:

Findings From a Mixed-Methodology Approach

Kathryn Remmes Martin, MPH; Britta Schoster, MPH; Jack H. Shreffler, PhD; Andrea Meier, PhD; Leigh F. Callahan, PhD

Abstract

Background: *A goal of the North Carolina Arthritis Plan is to reduce arthritis burden through regular physical activity. We identified community and personal factors that influence physical activity in individuals with arthritis.*

Methods: *In 2004 and 2005, 2479 individuals (53% self-reported arthritis) from 22 North Carolina communities completed a telephone survey (59.5% response rate) assessing health status, neighborhood characteristics, health attitudes, and demographic variables. Qualitative discussions (N=32) were conducted to further examine understanding of community and health and were enhanced with photographs.*

Analysis: *Descriptive analyses were conducted. A 2-sided binomial test (for each reason given for not being physically active) was used to test for significance between individuals with arthritis and the general population, using a Bonferroni test for multiple comparisons. Interviews and photographs were analyzed using qualitative software ATLAS.ti Version 5.0.*

Results: *Quantitative results show similar community-level reasons for physical inactivity (rural environment, heavy traffic, and lack of sidewalks) despite arthritis status. Yet personal reasons differed as individuals with arthritis more often cited physical inability and illness. In qualitative discussions, walking surfaces emerged as a primary barrier for those with arthritis.*

Limitations: *Findings from this exploratory study may have limited generalization and warrant further study.*

Conclusions: *The built environment and personal barriers should be considered when examining physical activity in individuals with arthritis.*

Key words: *Physical activity, community, neighborhood, perceived barriers, mixed-methodology, focus groups.*

Currently 27% or 1.75 million North Carolinians report some form of arthritis.[1,2] Estimates suggest that over 46.4 million adults in the United States (21.6%) report doctor-diagnosed arthritis,[3] with an estimated financial burden of $128 billon in 2003.[4] Additionally, about 19 million Americans (8.8%) have activity limitations caused by their arthritis,[3] and in 2005 activity limitations due to arthritis affected approximately 11% of adults in North Carolina.[2] Arthritis is the most frequently cited chronic condition for limiting activity among working-age and older adults.[5]

Both Healthy People 2010 and the North Carolina Arthritis Plan 2007-2010 set goals of increasing the amount of physical activity for the general population and for individuals with arthritis so as to decrease risk of chronic disease and increase both mental and physical benefits.[2,6] People with arthritis are encouraged to engage in regular physical activity to gain benefits of prolonged and increased function, increased mobility, flexibility, and decreased pain.[7-10] Yet recent studies have found that physical inactivity levels range from 24% to 39% in adults with arthritis.[11-15] These high rates of physical inactivity may

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demonstrate the complexity of a behavior that is influenced not only by individual beliefs and perceptions of personal barriers but also by the built and social environments.

Public health researchers linked the environment to health and health outcomes long ago.[16-21] Recent research has focused on identifying and measuring characteristics of the built environment that influence physical activity levels using both subjective[22-26] and objective[27-29] methods. One review focused on the built environment found that access to facilities, availability of physical activity options, crime and safety, weather, and aesthetics were most often associated with physical activity in adults.[30] Few studies have examined the role of the built environment on physical activity in individuals with arthritis. However, known barriers to physical activity in individuals with arthritis are financial cost and lack of access to exercise facilities,[15] no transportation, lack of programs, and poor environmental conditions (eg, weather, congested parking, concrete surfaces, presence of dogs, lack of sidewalks).[31]

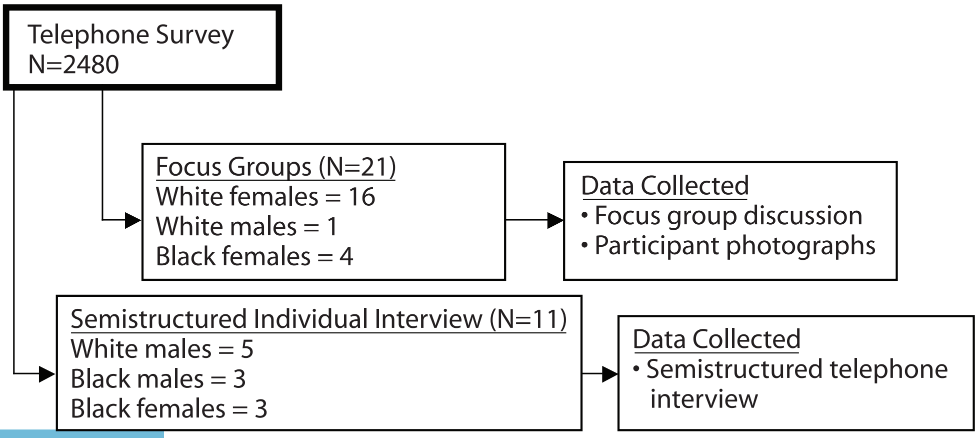
The aims of this study are twofold: (1) to understand the difference between people with and without arthritis when examining the perception of community built environment's influence upon physical activity; and (2) to identify the issues related to the built environment that are influential to the physical activity levels of individuals with arthritis. This study uses mixed methodology to evaluate both quantitative and qualitative data related to physical activity. Data were obtained through telephone surveys about general health and well-being and qualitative discussions.

METHODS

Participants and Data Collection

A cohort of 6700 participants were recruited from the NC Family Medicine Research Network.[32] The NC Family Medicine Research Network is a practice-based patient cohort for primary care research that was established in 2001 and enriched in 2004 and 2005. It currently consists of 25 practice sites. All consecutive patients (for 20 working days) seeking care at a North Carolina Family Medicine Research Network site were informed of the North Carolina Health Project. Eligible participants were those aged 18 years and older who spoke English or Spanish fluently. All study components were approved by the Medical Institutional Review Board of the University of North Carolina at Chapel Hill and all participants gave oral consent. Data sources are depicted in Figure 1.

Figure 1.
Data Collection Framework, North Carolina, 2004-2005.



Telephone Survey

Recruitment. Of the 6700 NC Family Medicine Research Network participants enrolled in 2001 and 2004, 4442 gave consent for follow-up. Participants meeting eligibility criteria (current address, telephone number, and the ability to speak English fluently) were initially mailed an introductory letter and later telephoned. A total of 277 individuals were ineligible because they lived outside the US, had no telephone, had a language barrier, were medically unable, were active military, were incarcerated, or had died. The telephone survey was completed by 2479 individuals, 59.5% of eligible participants. The 30-minute survey contained open- and close-ended questions assessing health status, chronic health conditions, community and neighborhood characteristics, health attitudes and beliefs, and demographics.

Measures. For this study, demographic measures, comorbid conditions, body mass index (BMI), community characteristics, and reasons for physical inactivity were analyzed. We calculated age using date of birth and date of the telephone interview. Education was recorded as highest grade of school completed and converted to 5 categories: less than high school, high school degree, some college, college degree, and postgraduate. Race and ethnicity data were categorized as non-Hispanic white, non-Hispanic black, and other. Participants were asked if they had ever seen a health professional for 18 different chronic conditions. The number of comorbid conditions is a sum of all self-reported comorbid conditions including arthritis. Arthritis status was determined according to the Behavioral Risk Factor Surveillance System definition of self-reported doctor diagnosis of arthritis.[33,34] For the purpose of this study, anyone self-reporting any type of doctor-diagnosed arthritis (eg, osteoarthritis, gout, rheumatoid arthritis, fibromyalgia) was included as having arthritis. Body mass index (BMI) was calculated from self-reported height and weight using the US Customary System to Metric (BMI=kg/m^2).

Questions regarding community and personal reasons for physical inactivity came from the 2000 Behavioral Risk Factor Surveillance System Questionnaire. Participants were asked in an open-ended question to list up to 3 things in their community or neighborhood that kept them from being more physically active. Participants were then asked, "Do you have access to places to be physically active?" with 4 response options.[35] Several questions assessed their perception of safety from crime and the presence of neighborhood characteristics such as sidewalks, walking/jogging/biking trails, heavy traffic, street lights, and unattended dogs.[36]

Focus Groups

Focus groups were conducted to enrich the quantitative telephone survey data by further examining community influences on health.

Recruitment. We recruited participants who had completed a telephone survey from 6 of the 25 sites specifically chosen for geographic and demographic diversity. They were contacted first by letter and then followed up with telephone invitations.

Photograph Component. To prepare for the focus groups, we asked participants to take pictures of objects and scenes in their communities that—on a typical day—either helped or hindered their health. The pictures were used to stimulate discussions of different aspects of community and health. We mailed participants a package containing a disposable camera and camera use instructions. Taking photographs was encouraged but not required for participation.

Conducting the Focus Group. Seven focus groups were held in the southeast, central, and western parts of North Carolina in urban and rural communities with 21 total participants (Range: 2-5 participants per group; average 3). Focus groups lasting 1.5 hours met at well-known community buildings (eg, senior centers, libraries) and were cofacilitated by 2 trained leaders with digital audio-recordings and hand transcription conducted at each session.

Participants were asked to describe their community and neighborhood and then discuss those community factors that they believed influenced their health. They were specifically probed on 7 topics: community connectedness, crime/safety, eating habits, environment, occupation, physical activity, and services/resources available in their community.

Focus group leaders invited participants to share their photographs if the participants believed the picture represented the topic being discussed. Participants received $20 for their participation.

Semistructured Individual Interviews

Recruitment. Because our focus groups were small and composed mostly of white women, we purposefully recruited an additional 11 individuals who were demographically underrepresented (3 black men, 3 black women, and 5 white men) in order to incorporate their perceptions into our qualitative findings. Semistructured interview participants were recruited from the same contact list we used for recruiting focus group members. Prospective interviewees were contacted consecutively by telephone and invited to participate in a semistructured individual (telephone) interview. Study staff described the interview process, discussion topic, and the $20 incentive. Interviews lasted an average of 30 minutes. As with the focus groups, participants were queried on 7 community factors and their relation to health.

Data Analyses

Telephone Survey. Demographic variables for participants with and without arthritis were examined for differences using Pearson chi-square and t-statistics for dichotomous and continuous variables, respectively. (See Table 1.) Descriptive analyses were conducted on community resource variables and key community and personal reasons for not being more physically active. Frequencies were used to numerically rank the community and personal reasons listed by respondents for not being physically active and Bonferroni tests for multiple comparisons were conducted. For a particular reason for not being physically active, a binomial test was used to see if a significant difference existed between the proportions reporting the reason in the general population and those reporting the reason in the arthritis subgroup.

Qualitative Interviews. The focus groups and semistructured individual interviews were transcribed verbatim, and transcripts were uploaded into ATLAS.ti Version 5.0. The questions asked at both the focus groups and semistructured individual interviews served as a basis for the development and definition of codes representative of converging themes. Calibration coding was conducted by independently coding 2 transcripts and comparing results to ensure interrater reliability. Any discrepancies were discussed by 2 coders with a third party brought in for resolution when needed. Transcripts from the focus groups and the semistructured individual interviews were first read independent of each other, and it was determined that there were no major thematic differences in content. Therefore, focus group and semistructured individual interviews were analyzed together and were examined for common themes within and across interviews. The constant comparison method[37] was used to identify other emerging themes, with all transcripts being reread to ensure consistent coding of the emerging themes. In addition, subanalyses were conducted by theme to examine whether differences existed by arthritis status.

RESULTS

The characteristics of the telephone survey sample and the qualitative participants are presented in Table 1 by arthritis status. Telephone survey participants with arthritis significantly differed from participants without arthritis in that they were generally older, had more chronic comorbid diseases, and had a higher body mass index. (See Table 1.) Those with arthritis also had significantly less education and lower income levels. Among the qualitative participants, only the number of chronic comorbid conditions significantly differed by arthritis status.

Telephone Survey. The response frequencies of both community and personal reasons for not being more physically active are ranked for the total group as well as for those with and without arthritis. (See Table 2.) Many participants (n=1749) responded that there was no community reason that

Table 1.
Demographic Characteristics of Study Participants, North Carolina, 2004-2005

	Telephone Survey Participants (N=2479)				Qualitative Participants (N=32)		
	Total Mean (SD, N)	Arthritis Mean (SD, N)	Nonarthritis Mean (SD, N)	p-value	Arthritis Mean (SD, N)	Nonarthritis Mean (SD, N)	p-value
Age (years)	52.8 (15.3, 2454)	57.0 (13.9, 1292)	48.1 (15.4, 1145)	p<0.001	58.8 (11.6, 19)	51.8 (16.0, 13)	p=0.162
Body Mass Index (BMI)	29.4 (7.1, 2349)	30.4 (7.4, 1246)	28.3 (6.6, 1086)	p<0.001	31.2 (8.1, 19)	31.3 (7.7, 13)	p=0.969
Mean # of Comorbid Conditions	3 (2.2, 2479)	4 (2.1, 1307)	2 (1.6, 1154)	p<0.001	4 (1.6, 19)	2 (1.2, 13)	p=0.004
	% (N)	% Arthritis (N)	% Nonarthritis (N)	p-value	% Arthritis (N)	% Nonarthritis (N)	p-value
Female	52.8 (15.3, 2454)	57.0 (13.9, 1292)	48.1 (15.4, 1145)	p<0.001	58.8 (11.6, 19)	51.8 (16.0, 13)	p=0.162
Non-Hispanic White	75.4 (1838)	75.0 (967)	75.7 (858)	p=0.346	68.4 (13)	61.5 (8)	p=0.937
High School Degree and Above	86.7 (2127)	82.1 (1058)	92.1 (1055)	p<0.001	84.2 (19)	92.3 (13)	p=0.512
<$45 000 Annual Household Income	60.5 (1359)	66.9 (796)	53.2 (554)	p<0.001	83.3 (15)	66.7 (8)	p=0.306
Currently Married	62.6 (1538)	61.2 (791)	64.3 (737)	p=0.117	68.4 (13)	53.9 (7)	p=0.419

* N varies due to missing data

kept them from being more physically active. These participants more often cited personal reasons such as being ill, not having enough time, being too tired or being lazy as reasons for not being more physically active. The top 4 most frequently listed community reasons for participants with and without arthritis were not enough sidewalks, a rural environment, not enough recreational facilities, and unattended dogs. Two community reasons for inactivity reached statistical significance for those reporting versus those not reporting arthritis: heavy traffic ($p=0.004$) and high crime ($p=0.008$).

In contrast, ranking of personal reasons greatly differed by arthritis status. Those with arthritis reported that they were ill or otherwise physically unable to be physically active as the most common reason for not being more physically active ($p<0.001$) far more often than those without arthritis. Not enough time ($p<0.001$), already getting enough physical activity ($p<0.001$), and being a caretaker ($p=0.018$) were more often reported by those without arthritis as primary reasons for not being more physically active.

Although many of the pairwise comparisons were significant at the $\alpha=0.05$ level, we adjusted for multiple comparisons. For the 20 community reasons, Bonferroni adjustment would indicate no significant differences for the arthritis group. Similar adjustment for the 13 personal reasons shows "caretaker" losing significance while the other 3 reasons retain significance. Therefore, while the findings for community reasons may be of general interest, the findings for personal reasons are far more compelling.

Focus Group and Semistructured Individual Interview Results. Main themes that emerged from the qualitative interviews were related to accessibility of community resources, community and personal barriers to physical activity, and quality of walking surfaces. Subanalyses by arthritis status revealed that quality of walking surfaces was the only theme unique to individuals with arthritis. Embedded throughout the 7 themes was a discussion of walking for physical activity. Quotations from qualitative discussions that illustrate the primary barriers to physical activity are presented in Table 3.

Availability of Community Resources. There was consensus among members in all focus groups that there were a variety of physical activity options available in their communities. Participants listed community resources such as gyms, pools, exercise classes, and malls, and offered photographs of these resources. In each focus group, members discussed the wide range of outdoor options that were available to them (eg, walking tracks and community areas). The opinions expressed in the focus groups are reinforced by the telephone survey findings. The majority of participants, 67.6% (1647 of 2436), reported having places to be physically active both indoors and out. Few stated that they had access to indoor places only (6.2%), access to outdoors only (14.0%), or did not have access to any places to be physically active (12.2%).

Accessibility. While participants were in general agreement over the availability of community places to be physically active (especially those at little or no cost), opinions were mixed

Table 2.
Community and Personal Reasons Given in Telephone Survey Interviews for Not Being More Physically Active, North Carolina, 2004-2005

Reasons Given for not Being More Physically Active	Total Group Rank (N**)	Arthritis Rank (N)	Nonarthritis Rank (N)
Community Reasons			
No community reason	1 (1749)	1 (894)	1 (855)
Not enough sidewalks	2 (212)	2 (123)	2 (89)
Rural environment	3 (154)	3 (84)	3 (70)
Not enough recreation facilities	4 (153)	4 (83)	4 (70)
Unattended dogs	5 (126)	5 (74)	5 (52)
Heavy traffic	6 (84)	6 (58)*	8 (26)
Not enough physical activity programs	7 (83)	8 (48)	7 (35)
Bad weather	8 (75)	9 (38)	6 (37)
High crime	9 (71)	7 (49)*	10 (22)
Too many hills	10 (50)	10 (33)	11 (17)
No street lights	11 (47)	11 (24)	9 (23)
Not enough bike lanes	12 (25)	14 (12)	12 (13)
Fearful for safety	13 (18)	13 (13)	14 (5)
Wild animals or pests	14 (13)	15 (8)	15 (5)
Distance to facilities	15 (11)	17 (6)	16 (5)
Roadway issues	16 (8)	18 (2)	13 (6)
Not enough outdoor options	17 (8)	16 (7)	18 (1)
Foul air from cars	18 (3)	19 (2)	19 (1)
Environmental concerns	19 (3)	20 (1)	17 (2)
Poor scenery	20 (1)	21 (1)	20 (0)
Personal Reasons			
Ill or otherwise physically unable	1 (528)	1 (424)*	4 (104)
Don't have enough time	2 (519)	2 (193)*	1 (326)
Already get enough physical activity	3 (455)	3 (192)*	2 (263)
Too tired, no energy	4 (342)	4 (190)	3 (152)
Laziness	5 (190)	5 (89)	5 (101)
No personal reason	6 (140)	6 (76)	6 (64)
Caretaker	7 (41)	10 (14)*	7 (27)
No one to be active with	8 (36)	8 (17)	8 (19)
Don't enjoy being active	9 (33)	7 (18)	9 (15)
Too expensive	10 (22)	9 (15)	11 (7)
Enjoy indoor activities more	11 (21)	11 (9)	10 (12)
Weight	12 (11)	13 (4)	12 (7)
Afraid of injury	13 (10)	12 (8)	13 (2)

* Proportion of those with arthritis that are statistically different from the total population at $\alpha=0.05$

** Telephone survey participants were able to give up to 3 answers for this question, therefore sum of N>2479. Total group N=2479, arthritis group N=1307, and nonarthritis group N=1154.

regarding the accessibility of places for physical activity. Several participants mentioned that while there were private gyms in their community, they were expensive and memberships were prohibitive. In addition, these exercise gyms did not provide childcare for parents who used these facilities. Several participants discussed other places for physical activity (eg, YMCA) that were difficult to access due to their physical disabilities.

Quality of Walking Surfaces. We did not specifically probe participants for differences in community reasons for physical inactivity by arthritis status. However, content analyses revealed that among participants with arthritis, a theme related to quality of walking surfaces emerged as a barrier to physical activity. Many described problems they had walking for long periods on cement, uneven sidewalks (eg, cracks), and gravel and pebbles.

Community Barriers to Physical Activity. Lack of sidewalks, heavy traffic, and living in a rural area were found to be the 3 main community characteristics that acted as barriers to physical activity. While participants discussed walking as a major source

Table 3.
Barriers to Physical Activity Identified by Focus Group and Semistructured Interviewees, North Carolina, 2004-2005

	Age	Arthritis Status	Sex	Quote
Accessiblity				
High Cost	55	Yes	F	There's one gym in town but I checked out those prices and they are out of my price range any way.
	35	No	F	But if you're not employed, if you're a stay at home mom or if you're retired or whatever, you don't get the benefit of an employer subsidy. I don't know how much Curves® is, but it tends to be expensive.
Lack of access for those with disabilities	58	Yes	F	My problem with the Y was they didn't want me to take my chair in there because they said they couldn't protect it. So they wanted me to walk from the parking lot through the lobby, down the hallway, into the dressing room, through the dressing room and out to the pool. Before I got to the front door I'd have to stop and take a sit down break. Five breaks to get to the pool. By the time I got there I was so tired I didn't care about working out in the pool.
Lack of childcare	35	No	F	There are two places in town to exercise as far as gym type things. We have a Curves® and it does not have child care, which is a problem. I like it because it's all female and I like the concept, but whenever you have kids, which is another issue with physical activity, you have to either have somebody to watch them or be able to take them with you.
Community Barriers to Physical Activity				
Rural area, lack of sidewalks and heavy traffic	50	No	F	Actually, to tell you the truth I don't walk in my neighborhood, because the area where I live is not a safe place to walk. It's rural, we don't have sidewalks or it's not wide enough streetwise to be able to do that because most of the time it's two lanes cars are coming up and down, so it's just really not safe to walk.
	48	Yes	F	Well actually there are no local parks nearby, and there's constant traffic, you don't get out on the roads. Actually this road could use some speed knots, it's near an old school, but they don't pay any attention.
Personal Barriers to Physical Activity				
Personal health and comorbid conditions	58	Yes	F	...And it's a very quiet little community. It goes in a circle and it will go for almost completely a mile around if you take the circle around and come back out on the street. Up until a few years ago, my husband and I used to walk that mile every day, but then it got to where it was difficult for both of us.
	56	Yes	F	I used to walk quite a bit and since my knees and my hips are really deteriorating, it's harder to walk long distances. But I still make myself walk as much as possible. I park farther from the building at the office and things like that. And make myself get more steps in, try to get as many steps in in a day as I possibly can. But I can't go out and walk a mile any more.
	63	Yes	F	Well, I can't do too much walking on account of my knees. I had a knee replacement and all, but I get out there and clean out my flowers, I work in my flower yard. I used to have a garden, but I don't have that any more because I can't bend over and pick my stuff.
Family obligations/ care-giving	56	Yes	F	And I need to be home to cook dinner. My husband has severe diabetes and I have to have dinner on time, his insulin and things like that. So, it was a barrier getting to the Y at 7:00 in the evening, and I can't do the morning class.
Walking Surfaces				
Quality of cement surfaces	58	Yes	F	I do my walking at home because concrete and asphalt are really hard on me. I cannot go very far, I can't get from the first handicapped spot to the door at Walmart. That's too much distance. At home, on the sand and soft grass, I can probably walk that far, especially with my canes...So, when I can I walk at home.
	58	Yes	F	I have but not lately because see it's better walking outside than down yonder at the mall because it's cement. But it's cement out there too. It makes a difference whether you're on ground or on cement.
Uneven surfaces	86	Yes	M	Yeah we have sidewalks on one side. So it depends on which side you want to walk on. The sidewalk really is not all that level, so sometimes you get out on the street. And it's a wide street. It's not bad to walk on.
	64	Yes	F	I have a rough uneven, rocky walkway to my doorway. It makes walking hard.

of physical activity, a lack of sidewalks in the neighborhood emerged in all qualitative discussions as a major barrier for getting outside and feeling safe while walking for exercise. When asked in the telephone survey, 76% (1854 of 2452) stated they did not have sidewalks in their neighborhood and 65% (1580 of 2442) did not have walking/jogging/or biking trails in their neighborhood. Further, 36% (874 of 2448) of those surveyed reported heavy traffic in their neighborhood.

Personal Barriers to Physical Activity. While qualitative participants were specifically probed on the environmental factors in the community that made it hard to be physically active, many participants offered unsolicited examples of personal barriers to being physically active. They told us that poor personal health and chronic illnesses such as arthritis, diabetes, obesity, and mental illness kept them from being physically active. Nearly all participants discussed their current physical activity level in relation to their current physical health. Most mentioned that they had been more active in the past, but their health problems now limited what they could do. Participants also mentioned that family obligations often prevented them from being physically active.

Lifestyle Physical Activity. Participants told us that they were often physically active as part of daily activities and interactions with people. Several participants gave examples of gardening and mowing the yard as well as completing household chores and walking their dogs. Several other participants mentioned they considered physically demanding activities on the job as part of their daily physical activity. Some mentioned that children or grandchildren kept them active and showed pictures to illustrate this point.

Strategies to Overcome Barriers. Qualitative participants often discussed what they did to overcome barriers so they could be more physically active. They described how they worked within their physical limitations to maintain and/or increase their physical activity level by keeping active with various lifestyle activities. Some participants mentioned parking further away at shopping centers to increase their daily number of steps and also mentioned driving to places where they could walk safely.

DISCUSSION

Using quantitative and qualitative methodology, this study set out to examine community factors that North Carolinians perceive to influence their physical activity. Overall, participants reported that they had affordable and accessible community places available to them for physical activity. Participants also described community barriers to activity including no easy access for those with disabilities, lack of childcare, and cost of membership to recreational facilities. In fact, cost has been previously found to be a common reason given among adults with arthritis reporting lack of access to a fitness facility.[15] Qualitative discussions confirmed telephone survey results that a lack of sidewalks, rural environment, heavy traffic, and accessibility were community barriers to physical activity. Quality of walking surfaces emerged as a major built environment barrier for those with arthritis. Overall, a major theme that emerged was the importance of illness and physical limitations as a reason for physical inactivity, specifically in participants with arthritis. This supports previous research finding that functional and social limitations, anxiety/depression, and pain act as barriers to physical activity in people with arthritis.[15]

While this exploratory study is unique in using multiple methodologies, a few limitations should be noted. Attendance at focus groups was lower than expected despite our best recruitment efforts. Recruitment of men and minorities was particularly difficult. Adding semistructured individual telephone interviews to our methodologies allowed us to incorporate the perspectives of these underrepresented groups into our study and reach a total qualitative sample size of 32. Researchers have indicated that with adequate representation, regardless of qualitative methodologies used, a sample of 30 individuals is enough to uncover the perceptions of the majority of individuals in a population.[38,39]

Because this study lacked a measure of physical activity level for all participants we could not examine how community resources and characteristics influence physical activity level by arthritis status. Arthritis status was not validated by health care professionals but determined by self-reported doctor diagnosis. This has previously been shown to be a reliable method.[33,34] And, while we recognize that reasons for inactivity might vary due to arthritis type or location of affected joint, subanalyses were not conducted by arthritis type because the majority of participants self-reporting arthritis (60%) had osteoarthritis/degenerative arthritis and arthritis site was not collected.

CONCLUSION

In conclusion, our study suggests that while individuals living with arthritis encounter similar community and personal challenges to being physically active as those without arthritis, they navigate their environment with additional physical limitations. Goals of Healthy People 2010 and the North Carolina Arthritis Plan 2007-2010 are to prevent and reduce the burden of arthritis so as to improve quality of life.[2,6] It is imperative that the complex interactions between personal and community barriers, social networks, and built environments be better understood and discussed as part of health maintenance for individuals with arthritis. **NCMJ**

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POLICY FORUM

Arthritis in North Carolina

> *"North Carolina has a higher rate of arthritis than the US national average and is one of the states with the highest projected increase in arthritis prevalence by the year 2030."*

INTRODUCTION

Policy Forum:
Arthritis in North Carolina

The aches and pains we feel when we are younger are just a hint of the kind of serious pain and disability that can accompany arthritis at a later age. Arthritis is a term that describes more than 100 different specific diseases, the most common of which are osteoarthritis, fibromyalgia, and rheumatoid arthritis. In North Carolina alone there will soon be more than 2 million adults with doctor-diagnosed arthritis. The Centers for Disease Control and Prevention predicts our state will experience a 40% increase in the number of adults with arthritis by 2030. Nationally, arthritis is now the leading cause of disability in the United States.

The impacts of pain and activity limitations on the lives of people with arthritis can extend well beyond the direct effects to include psychological distress, pressure on family and work life, and diminished ability to cope with adverse events. Fortunately, there are many new interventions and treatments for arthritis patients. Several articles in this issue of the *North Carolina Medical Journal* highlight therapeutic approaches to arthritis including physical activity, surgery, and pharmaceutical options. For some types of arthritis, effective treatments are limited, but there is promising research underway identifying new mechanisms to treat and prevent the disease. With this new information, North Carolina must address its rheumatology workforce shortages, and as the need for care grows, so must the capacity to use new interventions and treatment methods.

Population-based prevention programs have the potential to help alleviate future problems with arthritis. Obesity and arthritis are closely linked, thus obesity interventions and prevention programs could play a critical role in reducing the risk of arthritic diseases while concurrently addressing other serious chronic diseases aggravated by excess weight. North Carolina also has an invaluable source of research and information in the Thurston Arthritis Research Center at the University of North Carolina at Chapel Hill. This issue of the *Journal* is an avenue for disseminating some of the good work being done there.

The National Arthritis Action Plan provides overall guidance for public policy on arthritis prevention and control. The United States Bone and Joint Decade is part of a global plan to set guidelines and measurable objectives in the treatment and prevention of musculoskeletal conditions. These two initiatives outline strategies to reduce the burden of arthritis and to improve future outcomes. We know the direction in which to go, and this issue of the *Journal* is part of an overall effort to spread the word about what we have to do to conquer arthritis and how we need to do it.

Thomas C. Ricketts, III, PhD, MPH
Editor-in-Chief

Kristen L. Dubay, MPP
Managing Editor

ISSUE BRIEF

Arthritis and Its Impact:
Challenges and Opportunities for Treatment, Public Health, and Public Policy

Leigh F. Callahan, PhD; Joanne M. Jordan, MD, MPH

Although literally meaning "inflammation in a joint," the term arthritis is commonly used to describe more than 100 rheumatic diseases and conditions that affect joints, the tissues surrounding joints, and other connective tissue.[1] Conditions such as osteoarthritis, rheumatoid arthritis, fibromyalgia, systemic lupus erythematosus, gout, and bursitis are characterized by musculoskeletal pain and, in some cases, progressive physical impairment of joints and soft tissues.[2] Arthritis is one of the most prevalent chronic conditions in the United States, and the economic, social, and psychological impact associated with it is enormous.[3-6] It has been cited as one of the most pressing public health problems in the US.[3] Some of the effects of arthritis are easily translated into economic terms (eg, lost wages, medical care costs), but many other effects are not easily quantified (eg, pain, reductions in housekeeping activities, inability to enjoy leisure activities).

Although its impact is primarily on quality of life rather than mortality, arthritis significantly affects not only the individuals who have the disease but their families and society as well. Fortunately, over the past several decades there have been dramatic advances in the understanding of risk factors for arthritis and in its treatment. It is important for clinicians and other health care providers, public health officials, and policymakers to understand the burden of arthritis and recent advances in the field so that they can respond to the challenges of arthritis in terms of services and interventions to minimize its impact. In this issue brief, we will review the prevalence and impact of arthritis in terms of pain, activity and role limitations, work disability, and economic, social, and psychological consequences. We will discuss public health strategies and examine what can be done to target arthritis in terms of primary, secondary, and tertiary prevention. Finally, we conclude with some policy implications for North Carolina.

> *"It will take dedicated financial investment from the public, nonprofit, and private sectors to minimize and prevent arthritis-related disabilities from affecting the state's workforce as well as keeping people living with arthritis active and living independently."*

Prevalence

Arthritis affects an estimated 46 million Americans,[4] approximately 1 in 5 US adults. This number is expected to increase to an estimated 67 million individuals by the year 2030.[7] Approximately 21 million people have osteoarthritis,

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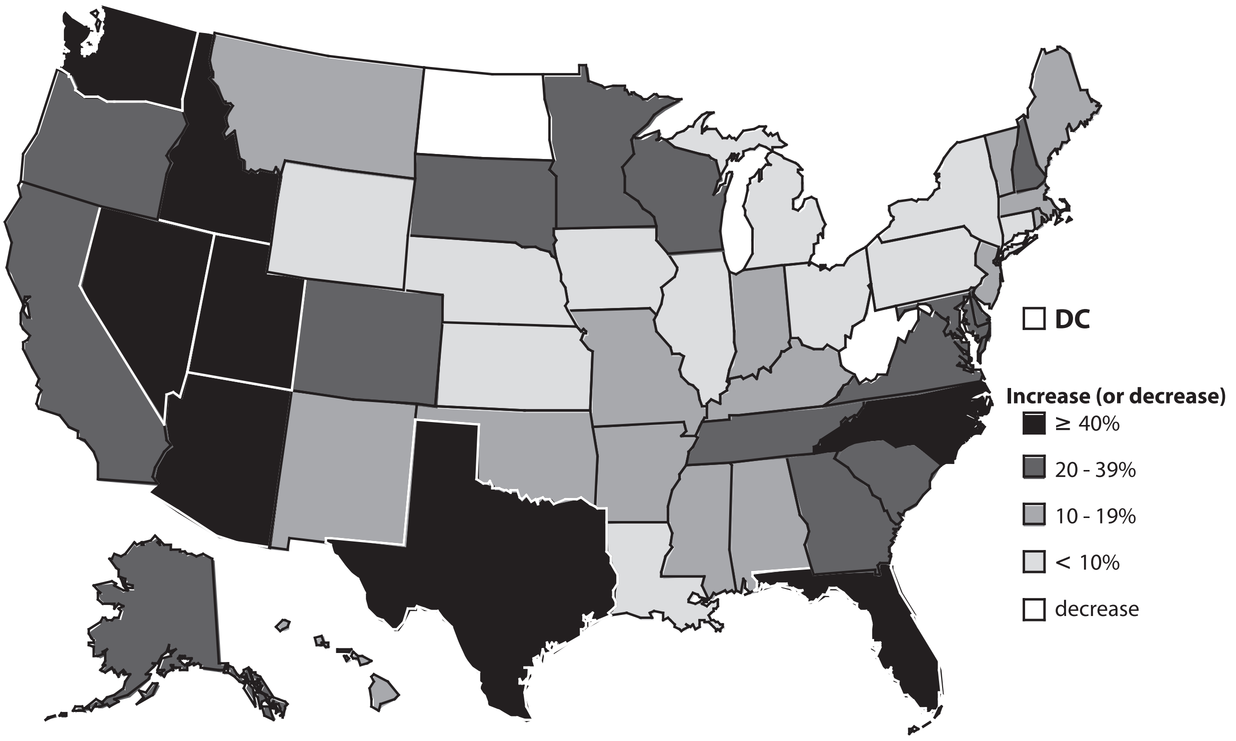
3.7 million have fibromyalgia, and another 2.1 million have rheumatoid arthritis.[2] North Carolina has a higher rate of arthritis than the US national average and is one of the states with the highest projected increase in arthritis prevalence by the year 2030.[8] (See Figure 1.) For this issue of the *North Carolina Medical Journal*, the North Carolina State Center for Health Statistics has provided recent data on the prevalence of self-reported doctor-diagnosed arthritis in North Carolina along with a breakdown by selected demographics and risk factors. (See Running the Numbers.) More than 1.7 million North Carolinians reported having arthritis in 2005, and this number is projected to increase to more than 2.7 million by 2030. Individuals who report arthritis also are more likely to report their health as fair or poor than are individuals without arthritis.

Estimates of the prevalence of knee symptoms and radiographic knee osteoarthritis in African American and Caucasian adults aged 45 years or older were recently reported by our research group at the Thurston Arthritis Research Center at the University of North Carolina at Chapel Hill. Data were collected from the Johnston County Osteoarthritis Project, a population-based study of osteoarthritis in North Carolina.[9] Knee symptoms were present in 43% of participants. Twenty-eight percent had radiographic knee osteoarthritis, and 16% had symptomatic knee osteoarthritis. African Americans had slightly higher prevalence of knee symptoms and both radiographic knee and symptomatic knee osteoarthritis, but significantly higher prevalence of severe radiographic knee osteoarthritis compared to Caucasians. The Johnston County Osteoarthritis Project has been a unique resource for the nation as a population-based laboratory for the study of risk factors for, and racial and gender disparities in, osteoarthritis. This long-standing community-based project is discussed in the commentary by Edwin Hartman and colleagues.

Although some risk factors associated with various forms of arthritis are nonmodifiable (eg, female sex, older age, genetic predisposition), identification of modifiable risk factors is critical to improve the lives of individuals with arthritis or to prevent its occurrence or progression.[10-13] (See Table 1.) Modifiable risk factors include obesity, joint injuries, infections, and certain occupations (eg, shipyard work, farming, heavy industry, any occupation with repetitive knee bending). Several commentaries in this issue discuss arthritis risk factors. Stephen Marshall and Yvonne Golightly discuss the link between sports injuries and osteoarthritis and note the biological basis for such a relationship. Stephen Messier and colleagues describe dietary and physical activity interventions. Individuals with lower levels of formal education and lower income have long been known to be at higher risk for arthritis and poor outcomes. Our commentary on the relationship between arthritis and the environment discusses sociodemographic issues and introduces a novel approach to evaluating potential factors behind these observations.

Figure 1.
Percent Increase From 2005-2006 in the Projected Number of Adults With Self-Reported Doctor-Diagnosed Arthritis, by State.



Source: Centers for Disease Control and Prevention. *MMWR Morbidity and Mortality Weekly Report*. May 4, 2007/56(17);423-425.

Table 1.
Risk Factors for Arthritis

Nonmodifiable	Female sex Older age Genetic predisposition
Modifiable	Obesity Joint injuries Infections Certain occupations Lower levels of formal education Lower income

Impact of Arthritis

Activity and Role Limitations

In addition to its high prevalence, arthritis is the nation's leading cause of disability. Activity limitations due to arthritis were reported by nearly 19 million US adults each year during the period 2003 to 2005.[7] Individuals who are disabled from arthritis have problems in more areas of daily life than do individuals with disability from other conditions.[14,15] Arthritis has negative effects on family role functioning as well.[16] Role limitations associated with rheumatic disease include significant reductions in the amount of time individuals spend engaging in activities such as shopping, visiting the bank and supermarket, homemaking, interacting with friends and family, or participating in hobbies.[6,16,17]

Economic Impact and Work Disability

In comprehensive studies of the economic cost of musculoskeletal disease, Rice and colleagues estimated that the total cost of these conditions is equivalent to 2.5% of the Gross National Product.[6] Total costs for arthritis rose from $65 billion in 1992 dollars to $82.5 billion in 1995 dollars.[6,18] In 1995, the estimated economic impact of musculoskeletal conditions on the US economy was $214.9 billion. (See Table 2.) Of this amount, direct costs accounted for 41% and indirect costs accounted for 59%. For all types of arthritis, the total cost was $82.5 billion or 38% of the cost of all musculoskeletal conditions.[18] (See Table 2.)

Table 2.
Total, Direct, and Indirect Costs of All Musculoskeletal Conditions and All Forms of Arthritis in Billions of 1995 Dollars.*

Condition	Direct Costs	Indirect Costs	Total Costs
All musculoskeletal conditions	88.7 (41%)	126.3 (59%)	215
All forms of arthritis	21.7 (26%)	60.8 (74%)	82.5

* Adapted from Praemer, Furner and Rice, Musculoskeletal Conditions in the United States, American Academy of Orthopaedic Surgeons, 1999.

The estimated direct costs of medical care for all forms of arthritis totaled $21.7 billion. (See Table 2.) Expenditures for nursing home care were $12.7 billion and accounted for 59% of direct costs. Hospital inpatient care totaled $3.1 billion or 14% of direct costs. According to the National Hospital Discharge Survey, patients hospitalized for arthritis account for approximately 2.6 million days of care. Administration and physician outpatient costs were $1.2 billion and $1.1 billion, respectively, with each approximately 5% of direct costs.[18]

The magnitude of the estimated indirect costs due to arthritis in 1995 dollars was $60 billion[8] or 74% of total cost.[18] (See Table 2.) As noted in previous arthritis cost studies, indirect costs are almost 3 times greater than direct costs.[6] This estimate would be even larger if the costs attributed to loss of homemaking functions could be more easily determined. Also, older women have lower labor force participation rates, resulting in lower estimates of economic impact for the current cohort of women.

As reflected in the indirect costs, the capacity of individuals with arthritis to work is significantly affected.[19-24] In fact, arthritis is a leading cause of work loss and work disability payments.[22,25] In two of the most prevalent rheumatic conditions, osteoarthritis and rheumatoid arthritis, many studies have documented significant work disability.[26] Determinants of work disability in individuals with rheumatic disease exist at both the societal and individual levels. Societal level risk factors include economic conditions, attitudinal and architectural barriers, types of jobs available, employer practices, and the characteristics of disability pension plans.[25] Individual level determinants include work autonomy, social factors, and disease factors.[21,25]

The costs of arthritis extend far beyond the direct medical care costs and the indirect costs associated with work loss. The intangible costs include pain, psychological distress, changes in family structure, limitations in instrumental and nurturing activities, and changes in appearance resulting from deformity.[6,26]

Pain and Psychological Consequences

As noted in the commentary by John Winfield, pain is a major determinant of physician visits for patients with arthritis. It is a significant predictor of patient and physician assessment of general health status as well as an indicator of future level of disability. Pain also has been found to be more important than physical or psychological disability in explaining medication use among patients with rheumatoid arthritis.[27,28] Pain presents challenges to health care providers, and some important suggestions for addressing this problem in arthritis are noted in Winfield's commentary on pain and arthritis.

In addition to the significant economic costs, activity and role limitations, and pain and disability associated with arthritis, the psychological impact of arthritis has been documented in a number of clinical studies.[6] The impact of arthritis on psychological status has been measured in terms of depression, anxiety, learned helplessness, coping strategies, cognitive changes, and self-efficacy. Higher levels of psychological distress have been noted in individuals with arthritis than in members of the general population in most studies. The levels of distress reported in arthritis patients were comparable to levels noted in clinical samples of individuals with other chronic conditions.[29] Higher levels of psychological distress in individuals with arthritis have also been associated with poorer status on clinical outcome variables as well as with increased health services utilization.[30]

Research efforts in depressive symptoms and disorders have focused on osteoarthritis, rheumatoid arthritis, fibromyalgia, and systemic lupus erythematosus.[29] Although depressive symptoms and disorders are more common among clinical samples of individuals with arthritis than in samples of the general population, the majority of individuals with arthritis do not report increased depression. Among persons with rheumatoid arthritis, the loss of valued activities and the self-perception of the ability to do activities are strongly correlated with psychological status.[17] Robert DeVellis and Brenda DeVellis discuss the links between depression and arthritis in their commentary.

Public Health Strategies

Although there is presently no cure for arthritis, there are interventions targeting primary, secondary, and tertiary prevention. (See Table 3.) The aim of primary prevention is to reduce the incidence of symptomatic disease (impairment). In order for primary prevention to be successful or even feasible, the risk factors for the disease must be known. While the risk factors for some types of arthritis and many rheumatic conditions are not known, data from cross-sectional and longitudinal studies reveal that obesity and occupational and sports-related injuries are risk factors for osteoarthritis.[13,31,32] The Framingham Osteoarthritis Study demonstrated that weight change significantly affected the risk for development of osteoarthritis of the knee in women; a weight reduction of 5.1 kilograms (11.2 lb) over a 10-year period reduced the risk of symptomatic knee osteoarthritis by over 50%.[32] Greg Griggs and Marie Shelton highlight the role North Carolina's *Eat Smart, Move More...NC* program can have in reducing obesity in our state and possibly attenuating some of the arthritis epidemic.

The physical demands of an occupation as a risk factor for osteoarthritis of the knee has been observed in several studies.[13,31,33] Data from Framingham and the first National Health and Nutrition Examination Survey indicate that jobs that require knee bending and which have at least medium physical demands are associated with increased rates of radiographic and clinical osteoarthritis of the knee.[13,33] Risk factor modification such as weight reduction and avoidance of occupational and other injuries may prevent the development of osteoarthritis of the knee. Another known target for primary prevention is exposure to ticks that carry the spirochete *Borrelia burgdorferi*, a known risk factor for Lyme disease. Lyme disease is an infectious arthritis which may have chronic manifestations. Avoiding tick-infested areas, checking oneself and one's pets for ticks, and using antitick pesticides are primary preventive measures for Lyme disease.

Secondary prevention is aimed toward early detection and treatment of a disease so that its course may be controlled or favorably altered. (See Table 3.) Secondary prevention is targeted toward reducing disability and generally involves screening for disease. Currently the most appropriate screening test for arthritis is a complete history and physical examination.[34] Arthritis may have a wide variety of clinical presentations which may or may not involve the musculoskeletal system. A complete history and physical examination allow the clinician to develop a differential diagnosis, order the appropriate laboratory studies, and formulate a diagnosis and treatment plan. Since early, aggressive therapy may be associated with improved outcomes in arthritis, it is imperative that the clinician consider these diagnoses when evaluating individuals with musculoskeletal or ill-defined systemic complaints. In order for secondary prevention to be successful in improving the outcomes of persons with arthritis, it will be necessary to increase efforts to educate health

Table 3.
Examples of Prevention Strategies for Persons With Arthritis

	Primary Prevention	Secondary Prevention	Tertiary Prevention
Goal	Reduce incidence of disease	Detect disease at early, treatable stage	Reduce disease complications
Target Population	Susceptible	Asymptomatic	Symptomatic
Examples	■ Weight reduction ■ Avoiding sports & occupational associated injuries ■ Avoiding tick exposure ■ Checking self and pets for ticks (Lyme)	■ History and physical ■ Improved education of health professionals ■ Public education to encourage early diagnosis and treatment ■ HLA/genetic testing (potential)	■ Improved education of health professionals ■ Medication ■ Physical therapy ■ Exercise ■ Occupational therapy ■ Assistive devices ■ Education ■ Use of effective coping strategies ■ Joint replacement surgery

professionals about arthritis. It is also imperative to increase public awareness about the value of early treatment and diagnosis of arthritis, and it is imperative to have sufficient health care professionals to treat people with arthritis. The manpower shortage in rheumatology is reviewed by Gregory Schimizzi, and Kate Queen gives her perspective on the role of nurse practitioners and physician extenders in meeting the manpower shortage challenge.

Tertiary prevention is aimed at reducing the complications and handicaps resulting from the impairment or disease in symptomatic persons. (See Table 3.) Most research efforts in arthritis have focused on tertiary prevention. Treatment of individuals with arthritis is often a multidisciplinary effort that includes medications to reduce pain and inflammation; complementary and alternative medicines; physical exercise and occupational therapy to maintain functional status and prevent disability; and education to develop coping and health management skills. Recent therapeutic advances in the treatment of rheumatoid arthritis, including the biologic therapies, are discussed by Beth Jonas. Esi Morgan DeWitt examines medication safety in children with arthritis, Jayalakshmi Rao reviews the use of complementary and alternative medicine in arthritis treatment, and Victor Goldberg discusses joint replacement therapy later in this issue of the *Journal*.

Despite its importance in reducing disability, exercise is a frequently neglected part of the treatment plan. Arthritis is now being incorporated into public health messages regarding the benefits of exercise. In contrast to the traditional belief that those with arthritis should avoid vigorous physical activity, recent studies have demonstrated that people with arthritis can benefit from appropriate aerobic exercise without exacerbating their disease.[35,36] Compared to their peers without arthritis, people with arthritis are often deconditioned and this may worsen their disability. Prolonged inactivity can produce muscle weakness, decreased flexibility, poor endurance, osteoporosis, cardiovascular deficit, fatigue, depression, low pain threshold, and other problems which historically have been accepted as either the natural progression of arthritis or the consequences of therapy.[37]

In a trial of supervised fitness walking, people with osteoarthritis of the knee who were randomized to the walking group had significant improvement in walking distance and functional status and a decrease in pain and medication usage compared to the control group.[36] Similarly, in a trial of people with rheumatoid arthritis and osteoarthritis of weight-bearing joints, those randomized to aerobic exercises had a significant improvement over controls in aerobic capacity, 50-foot walking time, depression, anxiety, and physical activity.[37] In a 5-year follow-up study of a conditioning program for people with rheumatoid arthritis, study participants who reported more than 5 hours of exercise per week showed less radiographic progression of joint damage, less hospitalization, and less work disability than those who exercised less than that amount.[38] The Arthritis, Diet, and Activity Promotion Trial found that the combination of modest weight loss plus moderate exercise provides better overall improvements in self-reported measures of function and pain and in performance of mobility in older overweight and obese adults with knee osteoarthritis compared with either intervention alone.[39]

Studies of community-based exercise programs sponsored by the Arthritis Foundation (eg, Aquatics Program) have shown significant positive changes in participants' pain levels and their ability to perform activities of daily living. This indicates the benefits of regular aerobic exercise in persons with arthritis may extend beyond improved physical functioning. These benefits are discussed in-depth in the commentary by Stephen Messier.

Patient education programs such as the Arthritis Self-Help Course are another adjunct in the treatment of people with arthritis. A meta-analysis of 15 controlled evaluations of psychoeducational interventions for people with rheumatoid arthritis or osteoarthritis showed beneficial improvements in pain, depression, and disability.[40] There is an emphasis on educational processes which increase self-efficacy and empower the participants to make appropriate health decisions. In a 4-year follow-up study, participants in the Arthritis Self Management Course retained improvements in pain level and self-efficacy and had a 43% decrease in physician visits compared to nonparticipants.[41] Based on a reach of just 1% of the population with rheumatoid arthritis and osteoarthritis, the projected cost savings to society that would result from a broader implementation of the program would be $33 000 000. Effective self-management programs with similar content and self-efficacy enhancing processes are also available for people with systemic lupus erythematosus and fibromyalgia.

Conclusions and Policy Implications

In 1998 a consortium of national organizations produced "The National Arthritis Action Plan: A Public Health Strategy," which is a comprehensive and ambitious plan for addressing the looming epidemic of arthritis.[42] This inspiring plan was developed under the leadership of the Centers for Disease Control and Prevention, the Arthritis Foundation, and the Association of State and Territorial Health Officials. These 3 organizations were joined by nearly 90 other organizations including academic institutions, professional societies, governmental agencies, voluntary health agencies, and others with an interest in arthritis prevention.

The National Arthritis Action Plan is based on the principles that the disability and chronic pain associated with arthritis reduce quality of life and that arthritis can be prevented. The plan is based on a growing recognition that public health must shift its emphasis to include diseases that destroy quality of life and not just those that kill.

The National Arthritis Action Plan outlines a public health strategy with emphasis in 3 areas: (1) surveillance, epidemiology, and prevention research; (2) communication and education; and (3) programs, policies, and systems. Activities in the surveillance and epidemiology area address the need to establish a solid scientific base of knowledge about the prevention of arthritis. The communication and education activities are designed to raise awareness of arthritis as a public health problem and to stimulate creative responses to this problem. The emphasis in the area of program, policies, and systems is on developing approaches for systematic change based on recognition that arthritis affects individuals in a social context and that this context can be changed in ways that promote health and prevent disease.

The National Arthritis Action Plan followed 2 historic national efforts to address arthritis. The first was the National Arthritis Act of 1975 which led to the development of Multipurpose Arthritis and Musculoskeletal Disease Centers. The second was the establishment of a separate arthritis institute at the National Institutes of Health in 1986, the National Institute of Arthritis, Musculoskeletal, and Skin Diseases. The National Arthritis Action Plan, a third milestone, provided a framework for new partnerships and collaborations to address the important issues and challenges of arthritis. These partnerships helped ensure that Healthy People 2010, the nation's blueprint for improving population health, contained a chapter on Arthritis, Osteoporosis, and Chronic Back Conditions.[43] This chapter has specific objectives related to pain reduction, activity limitations, and racial disparities in the rate of knee replacements. The North Carolina Arthritis Program, discussed in the commentary by Denise Brewster and Mary Altpeter, uses these Healthy People 2010 objectives to guide much of its work.

In addition to the incorporation of arthritis-specific objectives in Healthy People 2010, the launch of the Decade of Bone and Joint Disease in the year 2000 has further enhanced society's understanding of the burden of arthritis.[44] The Bone and Joint Decade is a global, multidisciplinary initiative targeting the care of people with musculoskeletal conditions and bone and joint disorders. Its focus is on improving quality of life as well as advancing the understanding and treatment of those conditions through research, prevention, and education. Worldwide more than 750 organizations have endorsed the Bone and Joint Decade initiative. More than 50 countries, including the US, have established multidisciplinary National Action Networks to plan activities in their respective countries. All 50 states have endorsed the Bone and Joint Decade, and over 85 health care organizations have pledged their support to the US Bone and Joint Decade Network. This network supports the current efforts of the Arthritis Foundation to pass the Arthritis Prevention, Control, and Cure Act of 2007 (S.626, H.R. 1283).[45] This Act proposes to strengthen arthritis public health initiatives, which would ensure that more people are diagnosed early and avoid pain and permanent disability. It also proposes to ensure that limited federal funding for arthritis research is used in the most strategic manner possible through the formation of a federal interagency coordinating committee. Additionally, it authorizes a remedy to help address the shortage of pediatric rheumatologists as well as a prevalence study of arthritis in children and a patient registry. Neither North Carolina senator was a cosponsor of the Senate bill in the fall of 2007, but Representatives Butterfield, Etheridge, Price, and Hughes are all cosponsors of HR 1283.

Given its high prevalence and significant economic, functional, social, and psychological consequences, arthritis should receive considerable attention from a societal perspective. The burdens of arthritis will increase dramatically in the near future due to the aging of the population, and this underscores the need for a public health approach. As highlighted in this issue of the *North Carolina Medical Journal*, what we know about the prevention and treatment of arthritis has advanced considerably over the past few decades. There is much that can be done on an individual and societal level to reduce the burden of arthritis, and our challenge is to deliver that message broadly. **NCMJ**

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COMMENTARY

Arthritis:
The Public Health Partnerships for Improving Health

Denise G. Brewster, MEd, CHES; Mary Altpeter, PhD, MPA, MSW

For many North Carolinians, dealing with the aches and pains and limited mobility of arthritis and joint conditions often takes a back seat to health issues such as diabetes and heart disease which may be seen as more life threatening. Many people with arthritis believe they cannot or should not be physically active with their aching joints, making management of other chronic diseases even harder. North Carolina public health professionals, the Centers for Disease Control and Prevention, and the National Arthritis Foundation recommend that people with arthritis can and should be physically active—the correct and safe way. There are proven methods for how they can successfully manage their condition, decrease pain, stay productive, improve quality of life, and reduce health care costs. To that end a collaborative public health approach to preventing and treating arthritis has been developed in the state, the North Carolina Arthritis Program.

The North Carolina Arthritis Program was revitalized in 1999 with a vision and a shoestring budget of only $70 000 from the Centers for Disease Control and Prevention to build state infrastructure and capacity to reduce the burden of arthritis across the state. Given this daunting challenge, it was clear that the Arthritis Program needed to reach out to build interdisciplinary and interorganizational community partnerships to strategically pool resources, build infrastructure capacity, and help carry out programs and advocacy efforts. An Arthritis Program Advisory Board was created with membership of key stakeholders in aging services, public health, medical care, community-based services, advocacy groups, and academia. Aging services representatives include key staff and leaders from Senior Games, AARP, Area Agencies on Aging, NC Division of Aging and Adult Services, and the Cary Senior Center. Medical community members include representatives from Vocational Rehabilitation, Sprain Strain Treatment Center, Rex Senior Health Center, WakeMed, Wilson Medical, Blue Cross Blue Shield of NC, and NC Division of Medical Assistance. Community-based organizations include the Arthritis Foundation, Pitt County Community Schools and Recreation, NC Citizens for Public Health, City of Raleigh Parks and Recreation, Mid-Carolina Council of Government, and local health departments. Academic partners include the University of North Carolina (UNC) at Chapel Hill (Schools of Public Health and Nursing, Institute on Aging, Department of Health Policy and Administration, and Thurston Arthritis Research Center), NC Office on Disability and Health, East Carolina University Brody School of Medicine, Duke University Divisions of Community Health and Rheumatology, UNC Charlotte School of Nursing, and Wake Forest University School of Medicine.

> *"Many people with arthritis believe they cannot or should not be physically active with their aching joints, making management of other chronic diseases even harder."*

This broad-based advisory board serves as the driving force of the Arthritis Program. The board has reviewed the statistics and services available in our state (documented in the North Carolina Arthritis Report 2002) and crafted the North

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Carolina Arthritis Plan,[1] a 3-goal, 3-year road map for decreasing the burden of arthritis. The NC Arthritis Plan is consistent with NC General Statute 130A-222 which mandates a state arthritis program and the Healthy Aging People 2010 national health objectives.

The first goal is to increase the number and accessibility of evidence-based arthritis programs and to increase the number of people participating in them. There are 5 programs nationally recognized as effective in helping manage arthritis. Three programs are oriented to physical activity: the Arthritis Foundation Exercise Program, the Arthritis Foundation Aquatics Program, and the EnhanceFitness exercise program. Two programs focus on self-management skills and patient-physician communication strategies: the Arthritis Foundation Self-Help Program and the Stanford University Chronic Disease Self-Management Program. These evidence-based programs have proven to provide benefits in symptom management, improved mobility, and reduction in depression among participants in study groups.[2,3]

To achieve the goal of reducing the arthritis burden, the North Carolina Arthritis Program and its lead partner agency, the Arthritis Foundation Carolinas Chapter, work together to identify organizational networks in areas where evidence-based programs are currently unavailable or underutilized. Most of the evidence-based programs in the state are clustered around the largest metropolitan areas and about half of the counties have no evidence-based arthritis programs at all. Community members and participants of the regional senior centers in rural communities can, however, be trained to lead Arthritis Foundation exercise, aquatics, and self-help programs.

Leading a key partnership effort, the NC Division of Aging and Adult Services has embarked on a 3-year project to train volunteers in Stanford University's Chronic Disease Self-Management Program and deliver the program in 46 counties. The program has been shown to provide the same benefits (managing their disease, continuing activities of daily living, and coping with emotions) to people with arthritis as arthritis only self-help programs.[4] The Division of Aging and Adult Services project will reach over 3000 North Carolinians living with chronic diseases such as arthritis. This effort is crucial—nationally, less than 1% of people with doctor-diagnosed arthritis participate in self-help programs.[5]

The second goal in the Arthritis Plan is to conduct community campaigns to raise public awareness that physical activity is an effective way to manage arthritis symptoms. To begin to address this statewide goal, the Arthritis Program has conducted 3 regional communication campaigns in North Carolina saturating 15 counties with media messages. The key message of the campaigns has been "Physical Activity. The Arthritis Pain Reliever." The communication campaigns have been pivotal opportunities for identifying community interest and commitment to establishing local exercise, aquatics, and self-help programs. For example, during the 6-week communication campaign in Pitt County, a special one day "Move More with Arthritis" event was held along with Arthritis Foundation aquatic program leader training. The two components, educating community members about the benefits of physical activity and building community capacity to meet the demands of an informed citizenry, depend upon community-based partnerships like Pitt County Community Schools and Recreation who hosted the event and the aquatic leader training.

Since arthritis affects people of all ages and is also a leading cause of disability and work-related disability,[6] senior communities are not the only focus of the Arthritis Program's efforts. Key arthritis messages are shared with participants of all wellness programs to encourage them to see their doctor, stay active, watch their weight, and protect their joints. Information about the evidence-based Arthritis Foundation Exercise Program will be included in the web-based menu of activities available in the "Worksites Eating Smart and Moving More" materials available to every workplace with a wellness program. The Arthritis Program is also working to make evidence-based program information available to all NC State Health Plan enrollees through the more than 150 state wellness committees currently established. The exercise program is an ideal fit for employees who have permanent disabilities that prevent participation in more vigorous physical activities or who have been sedentary and need a graduated approach to becoming more physically active. Families also benefit from learning to protect the joints of their children to reduce the possibility of future arthritis.

The third goal of the Arthritis Plan is directed toward creating policies and environments supportive of arthritis management in North Carolina by working with state legislators and local elected officials and organizations. Although some health savings accounts recognize the value for enrollees participating in evidence-based programs to maintain health and reduce medical costs, not all employers and insurance policies recognize this. Other types of plans and actions for supportive policies and environments are multi-faceted and long term in scope. For example the Arthritis Program hopes to increase the use of prescriptive physical activity recommendations from health care providers, but such prescriptions demand the availability of community resources for safe and effective physical activity opportunities.

What does the future hold for citizens living with arthritis in North Carolina? There are 3 major challenges. First, with the continuing momentum toward a dedicated plan to reduce the burden of arthritis, more evidence-based programs need to be available throughout communities. Citizens should have the opportunity to engage in physical activity that is safe, effective, and close to home. Persons living with arthritis will gain greater control over their lives and condition from participating in chronic disease self-management programs. Our challenges are to increase the number of master trainers, identify organizational sites for programs, and train program leaders. Currently there are only 8 Arthritis Foundation master trainers in North Carolina. The number of Arthritis Foundation exercise, aquatic, and self-help program leaders varies from year to year (currently around 100) due to attrition. There are only 8 Chronic Disease Self-Management Program trainers in the state who have completed Stanford University's intensive training preparation.

Second, employers need to recognize that supporting physical activity for employees with arthritis keeps them on the job and performing better. A major challenge will be to create and implement strategies to address people with arthritis who may experience periodic or increasing functional impairment. We need to work with employers to examine how the work environment, employee tasks, and schedules may be adapted to offer flexibility for workers with arthritis while at the same time maintaining expected performance levels and overall productivity.

Third, these challenges cannot be met without cooperative efforts and dedicated funding. Strong collaborative partnerships are the biggest asset in accomplishing the goals of the Arthritis Plan. The biggest challenge is the cost of building infrastructure with severely limited dollars. Currently the Arthritis Program budget for fiscal year 2007-2008 is supported by a grant of $135 000 from Centers for Disease Control and Prevention, an increase of only $65 000 from its initial funding 9 years ago. With a 2005 estimate of 1 754 000 North Carolina citizens diagnosed with arthritis,[7] that means less than 8¢ per person is available for evidence-based programming, raising community awareness, and creating supportive policies and environments. It will take dedicated financial investment from the public, nonprofit, and private sectors to minimize and prevent arthritis-related disabilities from affecting the state's workforce as well as keeping people living with arthritis active and living independently. Basic funding and partner agencies working together through the comprehensive, multi-faceted public health response to arthritis can build a state in which all citizens enjoy the high level of wellness and quality of life that all tarheel citizens deserve. **NCMJ**

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COMMENTARY

Recent Therapeutic Advances in the Treatment of Rheumatoid Arthritis

Beth L. Jonas, MD

Rheumatoid arthritis is a systemic disease which targets the joints as well as other organ systems. It is the most prevalent of the inflammatory arthropathies and is estimated to affect about 1% of the world's population. The clinical presentation is varied, but most patients have a progressive disease that leads to joint destruction and the associated disability if left untreated. There is significant morbidity associated with some of the extra-articular manifestations of the disease including pulmonary disease, osteoporosis, inflammatory eye disease, and in rare cases a systemic vasculitis. Recent studies have highlighted the role of chronic inflammation in the development of cardiovascular disease which leads to excess mortality in patients with rheumatoid arthritis.

Rheumatoid arthritis is thought to occur in a genetically susceptible host in response to some antigenic trigger. While the factors that initiate this process are poorly understood, the pathogenesis of the disease is beginning to be understood. Pathologic changes in the joint begin in the synovial lining of the diarthroidal joints. Early pathologic changes include neovascularization and thickening of the normally thin and delicate synovial membrane. There is infiltration of the tissues with leukocytes, increased expression of adhesion molecules, proteolytic enzymes, and cytokines and other inflammatory mediators. Together, these factors lead to the development of a pannus, a localized tissue that invades articular cartilage, bone, and the supporting structures of the joint.

It has been known for some time that joint damage can occur early in the course of the disease, and a majority of rheumatoid arthritis patients have erosion of bone within the first 2 years of disease onset.[1] It has also been established that treatment with disease modifying antirheumatic drugs during this early phase of rheumatoid arthritis can result in improved outcomes.[2] An appreciation of the importance of early intervention prior to the development of erosive disease has led to an algorithm of early detection and aggressive intervention. However, until recently the therapeutic options were limited to single or combination therapies with only modest benefits in most patients. Medications such as intramuscular gold, cyclosporine, azathioprine, sulfasalazine, hydroxychloroquine, and methotrexate comprise the majority of oral agents used to treat rheumatoid arthritis, yet only hydroxychloroquine, sulfasalazine, and methotrexate are currently in wide use. Combinations of oral therapies may be beneficial in some patients, and the addition of a newer oral agent, leflunomide, has added to the armamentarium of therapeutic options. Despite this, oral therapies are clearly inadequate for the majority of patients with rheumatoid arthritis.

> *"Although the precise etiology of rheumatoid arthritis is not known for certain, significant advances in understanding the pathogenesis of the disease have led to new and more effective therapies."*

Although the precise etiology of rheumatoid arthritis is not known for certain, significant advances in understanding the pathogenesis of the disease have led to new and more effective therapies. The most significant breakthrough over the last 10 to 15 years has been the development of the tumor necrosis factors (TNF) - inhibitors Etanercept, Infliximab, and Adalimumab. Each drug has a unique mechanism of action, but they all inhibit the biologic action of TNF, a cytokine known to play a role in the pathogenesis of joint inflammation in rheumatoid arthritis. Tumor necrosis factors has myriad effects that may

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initiate or perpetuate inflammation in rheumatoid arthritis including regulation of other proinflammatory cytokines, growth of new blood vessels, activation of endothelial cells and osteoclasts, and induction of metalloproteinases. Etanercept is a fusion protein of a TNF receptor linked to the Fc portion of IgG1. Its action prevents TNF from interacting with cell surface receptors. Infliximab is a chimeric mouse/human monoclonal antibody which binds TNF, thus inhibiting its biologic activity. Adalimumab is a fully humanized monoclonal antibody which has a similar mechanism of action to Infliximab. These drugs have had a profound impact on the ability to treat patients who had previously shown little or no response to traditional disease modifying antirheumatic drugs. Numerous studies of these agents have confirmed their ability to control signs and symptoms of disease, improve quality of life, and retard, or in some cases halt, the progression of erosive disease. Clinical studies also indicate that the combination of TNF inhibitors with Methotrexate yields better outcomes than either drug alone.[3]

Despite the therapeutic advances demonstrated by the TNF inhibitors, there remains a subset of patients who have an inadequate response to available therapies. These patients may continue to have evidence of disease activity with tender and swollen joints or may have progressive radiographic changes despite a good clinical response. Two newer agents approved by the FDA, Abatacept and Rituximab, may be effective with these patients. Abatacept is a T cell inhibitor which acts by blocking the second signal necessary for effective T cell stimulation. Rituximab is an anti-CD20 chimeric monoclonal antibody which selectively depletes pre-B, naïve, mature, and memory B cells, leaving stem cells and mature plasma cells unaffected. Both drugs, given by intravenous infusion, have been shown in well-controlled clinical trials to decrease signs and symptoms of rheumatoid arthritis as well as retard the structural progression of the disease.[4]

Research and investigation of the next generation of biologic therapy continues with agents aimed at new targets. Anticytokine therapies targeting IL-1, Il-6, Il-15, and IL-17 are currently under development. Tocilizumab, an anti-IL-6 monoclonal antibody, is currently in phase III clinical trials for rheumatoid arthritis, and preliminary results suggest that it has good efficacy. In addition, second generation drugs targeting TNF and B cells are also in clinical trials. Some investigators believe that gene therapy may someday play a role in the treatment of the most aggressive disease, but there are many hurdles to overcome.

Primary care physicians are often the first point of care for patients with early rheumatoid arthritis. With the recent advances in understanding the importance of early diagnosis and aggressive management of the disease, primary care physicians are in a position to take that knowledge and apply it to clinical practice. It is critical to consider the diagnosis and pursue the workup since intervening early can make a significant impact on the long-term outcome. Working closely with their rheumatology colleagues and remaining vigilant for signs of early inflammatory joint disease, the primary care provider plays a most important role for patients with rheumatoid arthritis. **NCMJ**

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COMMENTARY

Medication Safety in Children with Arthritis

Esi Morgan DeWitt, MD, MSCE

Chronic arthritis affects approximately 1 out of 1000 children, many of whom will be affected into their adulthood.[1] Over the past decade the advent of potent biological therapies such as tumor necrosis factor-alpha (TNF-alpha) antagonists has altered our expectations for the outcomes of polyarticular arthritis for the better. It is now rare to see arthritis leave a child wheelchair-bound, and measures such as serial casting and bracing to treat fixed joint flexion contractures are now infrequently needed. These advances are due in part to maturation of the field of pediatric rheumatology but also due in large part to available therapeutic options that are more effective than were the agents used in the past. However, by virtue of their novelty, these biologic medications lack much data on long-term safety. The safety data are limited in adults, and they are even sparser in children given smaller numbers of patients, less data collection, and fewer studies performed. When we consider that individuals affected with chronic arthritis from childhood will be exposed to various immunomodulatory and other medications (eg, nonsteroidal anti-inflammatory drugs, nonbiologic disease-modifying antirheumatic drugs) over the course of many years, it is important to be systematic in our study of the possible long-term side effects in children. Extrapolating from adult studies is inadequate because there are unique safety considerations in children.

> *"Treating children with arthritis on the basis of studies in adults is not sufficient and arguably not ethical."*

Lack of safety data for medications in children is not confined to novel biologic therapeutics. In the past the lack of systematic drug testing in pediatric therapeutics has resulted in widespread off-label use—across primary and specialty care—of an estimated 75% of medications and well-publicized examples of resultant harm done to children.[2] Despite the knowledge that children are not little adults in terms of therapeutic regimens, it has long been practice to treat children with medications studied only in adults by adjusting dosage for weight. Due to differences in pharmacokinetics and the added complexity of metabolism changes with age, growth, and development, treatment of children based on studies in adults could result in harm from underdosing and exposing patients to potential side effects without therapeutic benefit, from potentially overdosing, or from unknown pediatric-specific adverse effects.[3]

Recent legislation has stimulated and mandated more widespread testing in children. The Best Pharmaceuticals for Children Act of 2002 and the Pediatric Research Equity Act of 2003 were recently reauthorized for another 5 years as Public Law 110-85.[4] The first act creates an incentive for pharmaceutical companies to study existing medications in children by granting an additional 6 months of marketing exclusivity (ie, pediatric exclusivity).[5] The Pediatric Research and Equity Act requires drug manufacturers applying for a new product or new product indication to submit data on testing the product in children. These acts served to expand the knowledge of appropriate medication use in children with subsequent pediatric label changes for over 130 medications resulting from the Best Pharmaceuticals for Children Act[6] and more than 60 new listings resulting from the Pediatric Research and Equity Act.[7] The Best Pharmaceuticals for Children Act also has resulted in mandatory study of adverse events specific to children for 12 months postexclusivity which has provided some new information on pediatric-specific adverse events.[8]

The resultant increase in clinical trials for pediatric patients spurred by these legislative acts has implications for the practice of rheumatology. They have expanded the evidence base with which to prescribe and set expectations of therapeutic effectiveness. The successful pursuit of clinical trials in pediatric patients also has practical implications from the standpoint of being able to seek

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insurance coverage for therapeutics that have a pediatric indication. Even so, the challenge to conduct pediatric rheumatology clinical trials remains daunting. The relative rarity of these conditions in children generally requires a multisite, multinational effort over a lengthy enrollment period to reach sample sizes necessary to adequately power a study. Despite the best of planning, this may still result in a negative study. For example, a recent clinical trial of the TNF-alpha antagonist infliximab in juvenile rheumatoid arthritis failed to reach the primary endpoint despite the apparent benefit observed in the clinical practice setting.[9] Such a frustration does not mean that similar studies should not be performed, but rather that the pediatric rheumatology research community needs to redouble its efforts in the conduct of randomized clinical trials of novel therapeutics with improved study design and identification of more effective trial endpoints.

Treating children with arthritis on the basis of studies in adults is not sufficient and arguably not ethical. Just as children are not small adults, rheumatoid arthritis is a distinct entity from the various forms of childhood arthritis.[10] In addition to studying results of drug manufacturers' 12-month safety extension of clinical trials under pediatric exclusivity, it behooves pediatric rheumatologists to pursue independent means of better assessing medication safety through the development of safety registries to capture larger numbers of treated patients, to promote more systematic adverse event reporting through the Food and Drug Administration Med Watch system (www.fda.gov/medwatch), and to conduct studies of administrative claims data for evidence of adverse events as has been done in several studies of TNF-alpha antagonists safety in treatment of adult rheumatoid arthritis.[11-13]

When information was released on the adverse cardiovascular risk profile of the selective Cox-2 inhibitor VIOXX in adults and it was withdrawn from the market (ironically just 6 weeks after its approval for treatment of juvenile rheumatoid arthritis), there were few data to provide parents about long-term cardiovascular risk in children. The reply in response to questions about possible ill effects of these medications with long term use, "There have been no such reports in children," while true to the best of our knowledge is not a rigorously studied answer. For this reason, once childhood arthritis is under control, it is often a goal of the pediatric rheumatologist to try and taper off systemic medications in order to limit cumulative exposure.

From the standpoints of the individual primary care provider, parent, and pediatric rheumatologist, there are practical steps to advance safe medication use in children with arthritis. One of the key steps to promoting patient safety in children with arthritis is a strong partnership between the prescribing rheumatologist and the child's primary care provider. There are 3 primary threads to this relationship. First, collaboration to ensure patient compliance with routine laboratory testing (often performed locally every 4-8 weeks) to monitor for medication toxicity[14] and communicating these results to the rheumatologists for review; second, maintenance of up-to-date immunization status including yearly influenza vaccination with inactivated virus vaccine (live vaccines are currently contraindicated in children on immunosuppressive medications);[15] and third, prompt evaluation and treatment of patients on immunosuppressant medications who present with suspected bacterial infection due to the decreased ability to contain the infection.

The partnership between primary care providers and rheumatologists extends in other ways. For example, in some cases the primary care provider's office administers subcutaneous injection arthritis medications for the patients where the parent or guardian is unable. This partnership in care is particularly important in our state because many patients travel long distances across North Carolina to see a pediatric rheumatology specialist located at an academic medical center. The local medical provider will be the first responder to these children in case of infection or disease flare. Good communication between the local treating physician and the pediatric rheumatologist in the care of children with arthritis is invaluable.

The partnership extends to patient education, acceptance of the diagnosis, and comfort with the treatment plan. Pediatric rheumatologists face hurdles with new patients. They begin with overturning the misconception that the child will simply outgrow the arthritis. When parents arrive with this notion, it takes some convincing to explain that medication is indicated and that the known benefits of averting disability and pain from untreated arthritis outweigh the potential risks, some of

Information on Arthritis in Children:

Readers interested in more information on arthritis in children or specific therapeutics are encouraged to consult the Web resources listed below. The Pediatric Education Drug Safety (PEDS) project underway at the University of North Carolina at Chapel Hill (UNC) is developing online continuing medical education for primary care providers along with downloadable provider resources. One of 3 PEDS modules is devoted to medication use and safety in childhood arthritis. The resource will be free to all and available in 2008 (http://harryguess.unc.edu/index.htm).

Web Resources:

UNC PEDS:
http://harryguess.unc.edu/index.htm

American College of Rheumatology:
http://www.rheumatology.org/

Arthritis Foundation:
http://www.arthritis.org/index.php

Childhood Arthritis & Rheumatology Research Alliance:
http://www.carragroup.info/

Food and Drug Administration Pediatric Drug Development:
http://www.fda.gov/cder/pediatric/index.htm

MedWatch:
http://www.fda.gov/medwatch/index.htm

which are unknown. The primary care provider may use the trust resultant from a long-term relationship with the family to help cope with the diagnosis and facilitate care.

The family may be preoccupied by the child's pain, worried by his or her present functional limitations, and concerned that the child is standing on the sidelines instead of participating with peers. Although they may be eager for their child to get better, many parents are anxious about giving their child any medications because they fear side effects, although not infrequently these same individuals may administer a host of natural supplements that are not regulated or scientifically tested. Time and care are necessary for patient education. It is important to review the medications, indications, the administration process, known and potential side effects, and toxicity monitoring. This helps make the family more comfortable with the treatment plan and enhances compliance. In rare instances parents have reported that the pediatrician told them the medications prescribed by the rheumatologist for arthritis are too strong for a child and advised against taking them. On occasion even some pharmacists have told parents their child should not have been prescribed a medication recommended by the rheumatologist. As a pediatric rheumatologist, I would rather discuss the rationale for prescribing a medication with the pharmacist or local care provider than have a child return to the office for his or her follow-up appointment with untreated ongoing inflammation, risking permanent joint damage. Partnership along the chain of medical care will result in more effective treatment.

The future is bright in arthritis care. Increasing numbers of new therapeutics will be available, particularly new biologic therapeutics currently under development. Indeed, a number of emerging biologic treatments studied in arthritic adults remain to be studied in children. It is imperative that clinical trials proceed in children to ultimately allow for evidence-based rather than experimental medication use in children. Until we routinely and systematically collect safety data on children using medications for arthritis, we will be left with anecdotal reports, the lowest level of scientific evidence. **NCMJ**

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COMMENTARY

Sports Injury and Arthritis

Stephen W. Marshall, PhD; Yvonne M. Golightly, MS, PT

> *"…Then come home my children, the sun is gone down*
> *And the dews of the night arise…"*
> William Blake, 1757–1827

A major theme in William Blake's poetry is the transformation of youth's innocence and simplicity into disfigurement, pain, and bitterness in old age. The "dews of the night" that arise in today's society are largely chronic diseases such as arthritis. In this commentary, we explore the connection between acute sports injury, which occurs during the playful period of early life, and arthritis, a widely prevalent later-life chronic condition with high impact on quality of life.

Relationship Between Sports Injury and Arthritis

It is helpful to begin by comparing the basic descriptive epidemiology of these two apparently divergent conditions. Nationally, the incidence of sports injury rises dramatically through the middle and high school years and then subsides throughout adult life.[1] (See Figure 1.) This is largely a reflection of the fact that children and youth play a greater amount of high-intensity sports than adults. Likewise, the incidence is higher in males than females in large part because boys have greater participation in full-contact sports (eg, football, wrestling, and some martial arts) and these sports have a higher risk of injury.

Trauma from sports injury is most closely linked with osteoarthritis. Reliable national data for osteoarthritis is not readily available, but national prevalence data for overall arthritis is available. Osteoarthritis comprises over 50% of the more than 100 types of arthritis in the United States, and thus arthritis prevalence is a reasonable proxy for osteoarthritis prevalence. The prevalence of arthritis is essentially zero for adolescents and young adults (when sports injury incidence is at its peak), but steadily rises with increasing age. (See Figure 2.) Arthritis is more prevalent in women than in men.

How are the curves in Figures 1 and 2 related? It is widely believed that if we could drive down the spike in sports injury incidence during adolescence (eg, through prevention programs), the arthritis curve would be shifted further to the right—that is, pushed further into later life—because there would be less early-onset osteoarthritis.

Is this belief correct? A strong association between injury and osteoarthritis is widely acknowledged in the biomedical community, but the epidemiologic evidence for this relationship is surprisingly sparse. For the knee, several epidemiologic studies have suggested that a history of injury is positively associated with an increased occurrence of knee osteoarthritis.[2-4] However, the few studies published on injury and osteoarthritis of the

"… based on the available evidence, it appears that programs addressing the prevention and care of sports injury will pay dividends in terms of preventing early onset of osteoarthritis."

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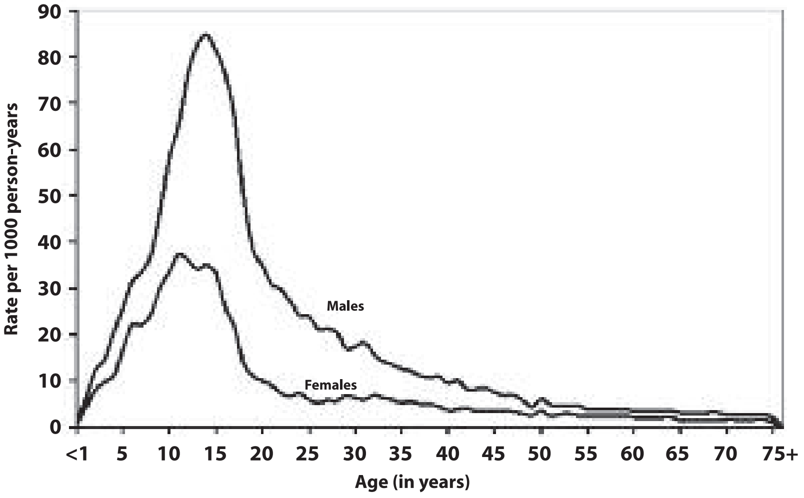
hip[5,6] and the hand[2,7] present conflicting results. There is no research on the association between injury and osteoarthritis at body sites other than the knee, hand, and hip.

Despite the limited epidemiologic data, there is a strong biological basis for linking injury to early onset of osteoarthritis, at least at load-bearing joints. Trauma to the soft tissues (eg, tendons, ligaments, cartilage, and muscles) that surround and support a load-bearing joint such as the knee erodes their ability to absorb and dissipate impact forces. Thus, the cumulative force transmitted to the joint surfaces from simple everyday activities such as walking, running, and jumping is increased. Breakdown of cartilage could result in narrowing of the joint space or fragments of cartilage or other tissues in the joint, common radiographic features of osteoarthritis. Further loss of cartilage may lead to greater contact between the joint surfaces, and bone may respond to this stress by developing osteophytes, another radiographic feature of osteoarthritis. Animal models of meniscus damage[8] and human studies of surgical removal of the meniscus after knee injury[9] support the biological rationale of load-bearing tissue defects contributing to knee osteoarthritis.

Youth Sports Injury in North Carolina

Despite the fact that the epidemiologic data is underdeveloped, it is reasonable to assume a causal relationship between sports injury and osteoarthritis based on the available biological information. Thus, from a public health standpoint, we need to ask, *What do we know about sports injury in North Carolina?* There is no surveillance system that adequately captures the extent of the youth sports injury problem in our state. However, by combining data from various sources some portions of the picture come into focus. Some key statistics are presented in the accompanying sidebar.

Figure 1.
Incidence of Injury from Sports and Recreational Physical Activity, by Age and Sex



Source: Emergency Department Records (National Electronic Injury Surveillance System All Injury Program), United States, July 2000-June 2001 (reproduced from *MMWR* 2002;51:736-740).

The problem of sports injury is concentrated in youth and in males. Important facts to note are:

- For boys ages 10 to 14 years, sports injuries account for over 50% of all emergency department visits for treatment of an unintentional injury.[1]
- For girls ages 10 to 14 years, sports injuries account for nearly 40% of all emergency department visits for treatment of an unintentional injury.[1]
- Boys account for 60% of high school athletes in North Carolina but sustain nearly 75% of high school athletic injuries.
- Football accounts for 16% of high school athletes in North Carolina but over 40% of high school athletic injuries.

Statistics such as these have stark implications for the burden of osteoarthritis in later life and underscore the need for prevention programs aimed at youth sport injury. Recommendations for preventing youth sports injury include correct preparation and care of playing surfaces, improved physical fitness and conditioning of athletes, care and maintenance of playing equipment, and a requirement for the provision of qualified health care professionals (preferably certified athletic trainers) in all schools. The American Academy of Pediatrics' Committee on Sports Medicine has an extensive set of recommendations on preventing injury in specific youth sports including soccer, hockey, baseball/softball, and horseback riding.[10] The National Athletic Trainer's Association also has an extensive set of online resources addressing youth sports injury prevention.[11]

Sports medicine professionals are very concerned about the increasingly competitive nature of youth sports. Over the past few decades, youth sport has evolved from informal neighborhood pick-up games into highly-structured and financially-lucrative competitive leagues that, in the case of at least one sport, are nationally televised. Parents are progressively more focused on collegiate scholarships and the high salaries earned in some professional sports, although only a tiny fraction of youth athletes ever compete at the collegiate or professional level.[12]

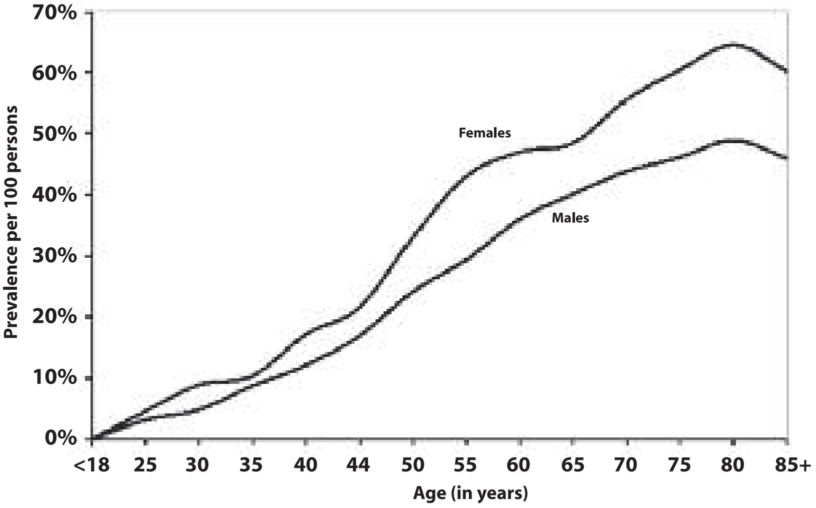
As an example of this trend, it is worrisome that weight gain is now being emphasized at the junior levels of football. The combination of more weight being placed on weight-bearing joints (such as the knee) and a higher risk of joint trauma (due to increased competitiveness) is likely to be a "double whammy" for developing osteoarthritis in later life.

Parents and coaches need to remember that winning and excelling should be secondary goals in youth sport. Personal development, increased physical fitness, skills development, and simply having fun are the primary goals.

Obesity Prevention Through Youth Sports

Aside from trauma due to sports injury, another major factor that increases joint loading is body weight. North Carolina, like the rest of United States, has experienced an alarming increase in prevalence of obesity and overweight over the past few decades.[13,14] The rapid increase in sedentary recreational activities, such as home computers and electronic games, has fueled an equally spectacular growth in our children's body mass index.[14,15] Increasing academic pressures from schools further limit leisure time for children and youth. Obese/overweight children grow into obese/overweight adults who are more likely than the rest of the population to develop osteoarthritis of the hip and knee in addition to diabetes, cardiovascular disease, and other chronic conditions.[16,17]

Figure 2.
Prevalence of Self-Reported Arthritis, by Age and Sex



Source: National Health Interview Survey, United States, 2001.

One obvious solution to the obesity epidemic is to encourage kids to participate in youth sports. In addition to obesity prevention, youth sports are widely surmised to have beneficial effects in terms of personal development and team skills. But not all youth sports are created equal; some carry a high risk of injury. The expected reductions in arthritis from increased promotion of youth physical activity could be negated if we do not also devote resources to preventing and caring for youth sports injuries. Even when sports injuries cannot be prevented completely, proper treatment and rehabilitation of these injuries is important to restore optimal movement patterns, likely reducing the risk of both reinjury and developing osteoarthritis. Thus, the public health equation is not:

More sports in early life = Fewer adults with
lower extremity osteoarthritis

but rather:

More sports in early life + fewer sports injuries
+ maintenance of healthy body weight
+ good rehabilitation after sports injuries
= Fewer adults with lower extremity osteoarthritis

Additionally, injury often forces participants into reducing their level of activity. Uninjured participants, on the other hand, are more likely to maintain their activity program.[18,19] Thus, programs addressing the prevention of sports injury will increase the public health benefit of physical activity promotion campaigns. Sports injury prevention advice should always be incorporated into physical activity health promotion campaigns.[20]

Future Directions for Research and Policy

Epidemiologically, the relationship between injury and osteoarthritis needs to be further clarified through additional research. However, based on the available evidence, it appears that programs addressing the prevention and care of sports injury will pay dividends in terms of preventing early onset of osteoarthritis. Reductions in osteoarthritis prevalence can also accrue from obesity prevention through increased sports participation. However, increasing participation in youth sports without addressing the potential for a resultant increase in injury incidence may fail to attain the overall goal of arthritis prevention. One sport of particular concern in this regard is football, not only for its high incidence of injury, but because the sport is increasingly associated with weight gain during the high school years. **NCMJ**

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Sports Injury in North Carolina Youth—Key Statistics

- Total number of North Carolina high school athletes … 175 582
  - Girls: 67 774 (39%)
  - Boys: 107 807 (61%)
  - Football: 28 074 (16% of total)

- Annual number of North Carolina high school sports injuries …10 531
  - Girls: 2864 (27%)
  - Boys: 7667 (73%)
  - Football: 4381 (42% of total)

- Annual number of emergency department visits for sports injury in North Carolina…123 000

- Proportion of all emergency department visits for treatment of unintentional injury that is due to sport:*
  - Across all age groups: 16%
  - Girls ages 10 to 14 years: 38%
  - Boys ages 10 to 14 years: 52%

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Depression and Arthritis

Brenda M. DeVellis, PhD; Robert F. DeVellis, PhD

The onset of symptoms and eventual diagnosis of chronic disease typically cause emotional distress. In most cases this distress subsides over time as psychological adaptation to the condition occurs.[1] A significant minority of people, however, develop less transient, more severe psychological distress that can result in significant additional disability and suffering. The comorbidity of depression and arthritis is a major problem compromising the health of a significant number of Americans. This type of comorbidity is far more prevalent than previously thought and can have a negative impact greater than the sum of the 2 illnesses separately.[2] Thus, failure to appreciate the presence of depression in patients with arthritis can significantly compromise not only diagnosis and treatment of the affected patient but the impact of both illnesses and the health of the public overall.

Depression: Prevalence and Impact

In a lead editorial in the *American Journal of Public Health* in 1999, Neugebauer called for increased attention by the medical and public health communities to the devastating personal and economic impact of mental illness.[3] He cited findings from the 1994 National Comorbidity Survey showing that 17% of a national probability sample of US noninstitutionalized adults aged 15 years to 54 years had experienced one or more episodes of major depressive disorder in their lifetime.[4] Of equal concern were the 12-month prevalence findings; in the previous year, 10% of adults had experienced one or more depressive disorders. In a replication study of the 1994 survey, Kessler found that the prevalence numbers from 2001-2002 for a new population sample of 9282 were similar for lifetime prevalence (16.6% of people with one or more episodes of major depression in their lifetime) and somewhat lower (6.6%) for those experiencing an episode in the past year.[5,6] These findings are important because of the intense suffering and the significant morbidity and mortality associated with depression. One of the most tragic consequences of depression is suicide. In 2004, 32 439 people died by suicide in the US making it the 11th most frequent cause of death. In contrast, the number of homicides in 2004 was almost half this number at 17 357.[7] Further, more than 90% of people who commit suicide have a diagnosable mental disorder, most commonly a depressive disorder or a substance abuse disorder.

When Schulz et al examined mortality in adults over 65 years of age, they found that depressive symptoms at baseline were an independent risk factor for all cause mortality 6 years later even after controlling for multiple sociodemographic, disease, and health risk factors.[8] Pennix et al also studied the relationship of earlier self-reported depressive symptoms to later morbidity in older adults (age greater than 64 years) who were initially free of disability. Of these 6247 disability free people, 496 had scores greater than 20 out of 60 on the Center for Epidemiologic Symptoms Depression Scale, scores suggestive of depression.[9] At follow-up, instances of new heart attacks and new hip fractures occurred more frequently among those with more initial depressive symptoms but no initial disability. In addition, incident activities of daily living and mobility disability were higher in the initially-depressed group which, by 6 years of follow-up, had an activities of living disability rate of 36% and a mobility disability rate of 67% compared to those with fewer or no initial depressive symptoms (24% and 48% for activities of daily living and mobility disability, respectively). This significant difference in activities of daily living scores between those with more versus fewer depressive symptoms emerged after the first year of the study and steadily increased over the following 5 years. Almost half of this increased disability risk was explained by sociodemographic (gender, education, and income) factors, and a smaller part of the increase was explained by physical activity and having close contacts with relatives. However, after controlling for all of these factors, arthritis and angina were the 2 health conditions that contributed the most to the increased risk for disability in depression.

Depression and Arthritis

Increasing recognition of the importance of studying psychiatric and medical comorbidity has emerged over the past 15 years due to several large scale and pivotal studies in the areas of health services research and psychiatric epidemiology.

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The Medical Outcomes Study involved over 22 000 patients who visited 523 different medical providers during a specified period of time in 1986.[2] The major focus of this 4-year prospective study was on the consequences (outcomes) of chronic illness; it was the first large scale study "to include a psychiatric condition (depression) on equal footing with chronic medical conditions." Of the many important findings that have emerged from the Medical Outcomes Study, 4 are particularly relevant. First, Wells et al found that depression was associated with the same level or more of disability than 6 of the major medical chronic conditions studied and that only myocardial infarction in the previous year or current congestive heart failure and arthritis were associated with greater morbidity in any domain of functioning when compared with the functioning of people with depression.[2] Moreover, this finding was maintained over time in the longitudinal analyses. Second, Wells et al concluded that when arthritis was comorbid with depression, the resulting disability exceeded the disability level one would expect from simply combining disability due to depression with disability due to arthritis. That is, the negative effects of depression and arthritis are multiplicative rather than additive. Third, the negative consequences of subthreshold depression (ie, having some depressive symptoms without reaching the threshold for a depressive disorder diagnosis) were similar to consequences for people whose symptoms did reach diagnostic criteria. And, fourth, people's subthreshold depressive symptoms "remained unchanged in functioning and well-being over two years," which suggests that subthreshold depressive symptoms are not transient.

Other studies underscore the negative impact of comorbid depression and arthritis. Ang et al followed 1290 consecutive outpatients with rheumatoid arthritis over an 18-year period and found that depressive symptoms at baseline increased the risk of mortality many years later.[10] Stang et al used National Comorbidity Survey Replication data to examine the relationship between major depressive disorder and self-reported arthritis.[11] When controlling for age and other sociodemographic factors, they found that arthritis and major depressive disorder were significantly associated. Finally, Lin et al did the first, and to our knowledge only, major intervention study aimed at decreasing depression in patients with arthritis.[12] Their randomized controlled trial included 1801 depressed older adults (aged 60 years or older) from 18 primary care clinics in 5 states. The intervention consisted of antidepressant medications and/or 6 to 8 sessions of psychotherapy (Problem Solving Treatment in Primary Care). At 12 months they found a significant decrease of depressive symptoms in the intervention group compared to the usual care treatment control group as well as lower mean pain scores. In addition, they found improved activities of daily living and improved quality of life.

Overall, the pattern of findings from research indicates a substantial impact of depression on the trajectory of comorbid arthritis. In addition, the pain and loss of function associated with arthritis can contribute to depression. Both arthritis and depression have substantial prevalence rates. Thus, patients presenting with comorbid arthritis and depression are fairly common. It is important that health care providers recognize the presence and effects of depression as they treat patients with arthritis. Better control of depressive symptoms should be an integral component of treating people with arthritis who also experience depression. Helping arthritis patients obtain relief from their depression promises both to mitigate the added risk associated with depression and to enable the patient and physician to manage the arthritis itself more effectively. A first step to optimal treatment may simply be an awareness of the role that depression can play in the course of arthritis and its treatment. A second achievable step is screening for depression using one of several brief instruments developed for use in primary medical care settings. Finally, physicians should assist patients who have depression in finding appropriate care. Doing so will not only reduce unnecessary suffering arising from the depression itself but will also improve arthritis outcomes. **NCMJ**

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Physical Activity and Weight Loss Interventions in Older Adults With Knee Osteoarthritis

Stephen P. Messier, PhD

Osteoarthritis is a degenerative disease that affects articular cartilage and the underlying subchondral bone. The cartilaginous surfaces become pitted resulting in hypertrophic changes along the joint margins and reactive changes in the subchondral bone. Severe osteoarthritis is characterized by joint space narrowing, absence of articular cartilage, increased density and stiffness of the subchondral bone, and osteophyte formation along the joint margins.[1,2]

The knee is the most commonly affected weight-bearing joint. The major symptoms of knee osteoarthritis are pain and stiffness. Decreased mobility leading to muscle atrophy, an accelerated decline in physical function, and the inability to engage in activities of daily living such as walking and climbing stairs are clinical consequences that often lead to a loss of independence and a poor quality of life.[2-6]

The etiology of primary (idiopathic) osteoarthritis is unknown, although biomechanical and inflammatory mechanisms have been proposed as causative factors. Biomechanically, either structural abnormalities such as obesity or neuromuscular dysfunction may cause increased joint loads during walking. Failure to absorb these loads properly may cause microcracks in the subchondral tissue leading to increased stresses and cartilage degradation.[7]

Recent studies demonstrate that low-grade inflammation plays a pathophysiological role in osteoarthritis. The inflammatory cytokine interleukin-1 beta (IL-1ß) is present in the joint fluids of osteoarthritis patients.[8] Interleukin-1 beta is believed to play a role in mediating joint inflammation and cartilage degradation in osteoarthritis.[9] Likewise, an inflammatory component associated with osteoarthritis can be detected in the circulation since serum concentrations of inflammatory markers such as cytokines (interleukin-6, IL-6; tumor necrosis factor alpha, TNFα) and the acute-phase reactant C-reactive protein are higher in persons with knee or hip osteoarthritis compared to those without osteoarthritis.[10-13] Longitudinal studies demonstrate that high serum levels of C-reactive protein and TNFα predict increased radiographic progression of knee osteoarthritis as much as 5 years later.[11,14,15] Moreover, a few studies associate osteoarthritis severity and physical function with higher inflammatory markers in the blood.[10,16,17] Thus, severity, mobility, pain, stiffness, and radiographic progression are at least partly mediated by the level of chronic inflammation in osteoarthritis patients. Diffusion of cytokines from the synovial fluid into the cartilage could contribute to the cartilage matrix loss observed in osteoarthritis by stimulating chondrocyte catabolic activity and inhibiting anabolic activity.

Obesity is a major risk factor for knee osteoarthritis.[18] Weight change and the risk of developing knee osteoarthritis are significantly associated. Felson et al showed that a 5.1 kg loss in body mass over a 10-year period reduced the odds of developing osteoarthritis by more than 50%.[19] Obese individuals have higher concentrations of inflammatory markers than lean people, and a large percentage of people with knee osteoarthritis are overweight or obese. Hence, obese individuals with knee osteoarthritis may have an even greater contribution of inflammation to functional limitation and disease progression.[20] Besides direct effects on the joint, inflammatory mediators can also affect muscle function and lower the pain threshold.

> *"Several studies have shown that pain and disability improve with short-term (3 to 6 months) exercise."*

Unfortunately, treatments that affect the underlying biomechanical and inflammatory disease pathways are limited. The primary aim of therapies currently available is pain relief.

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Antiinflammatory medications and orthopaedic procedures are primary methods of treatment. More recently, exercise and weight loss have been used as therapeutic modalities for knee osteoarthritis patients.

The difficulty patients with knee osteoarthritis have with activities of daily living often result in activity avoidance.[21] Physical exercise, however, is an effective nonpharmacologic treatment. Several studies have shown that pain and disability improve with short-term (3 to 6 months) exercise. Short-term walking programs improve aerobic capacity, walking time, and self-reported function.[22,23] Similarly, lower extremity resistance training increases strength, decreases pain, and improves function in patients with osteoarthritis.[24,25] More recently, long-term walking and resistance training programs have been effective in slowing the decline in physical function commonly seen in this disabled population. A randomized clinical trial of 18-month walking and resistance training programs in 439 community-dwelling older adults with knee osteoarthritis reduced disability and pain and improved balance and mobility relative to a health education control group.[26] In a similar population, greater adherence to a physical activity program was associated with better physical performance and self-reported physical function.[27] Exercise also has been shown to improve late-life minor depression.[28]

Short- and long-term aerobic and resistance training programs are safe and effective treatments for knee osteoarthritis.[21] Traditional 3 days per week, 1 hour per day programs have been the most common regimens studied. Unfortunately, little is known regarding the dose response to exercise in the older, mostly female, sedentary, and predominately overweight population. Continuous weight-bearing aerobic exercise such as walking can initially be difficult for patients with knee osteoarthritis who experience significant pain. Starting with short bouts of exercise and inserting several rest periods when the patient has progressed to 30 or 40 minutes of walking improves adherence. Adding several resistance training exercises between periods of walking has proven effective and popular with patients.[8,29] The intensity of the exercise intervention may differ depending on the desired outcomes. If the goal is making exercise a part of a healthy lifestyle, then continued participation is more important than intensity. The exercise prescription should be flexible enough to accommodate periods of greater pain.

An important component of treatment for knee osteoarthritis is the reduction of body weight in patients who are overweight or obese. Results of a randomized, controlled clinical trial have shown that a program of diet and exercise results in greater improvements in self-reported function, mobility, and pain than exercise only, diet only, or healthy lifestyle interventions.[29] A dose response to weight loss indicated that participants who lost between 7.5% and 11.0% of their body weight exhibited significantly better self-reported function than participants who exhibited more modest weight loss (2.5% to 7.5%) or no weight loss (gained to 2.5%).[2] Christensen et al[30] recently found that an 11% weight loss in an intensive diet group over an 8-week period produced a 3-fold improvement in function in older, obese adults with knee osteoarthritis relative to a control diet group that lost 4% of their body weight.

Studies have shown that weight loss decreases inflammation, reducing the cytokine activity that may be related to cartilage degradation. Nicklas et al[20] showed that a 5% weight loss over 18 months significantly reduced C-reactive protein, IL-6, and TNFα receptor 1 concentrations compared with a weight stable group. However, it is not yet known whether a specific amount of weight loss maximally reduces inflammation or whether improvements in physical function, pain, and osteoarthritis progression are related to a decline in chronic inflammation with weight loss.

Weight loss also has a beneficial effect on knee joint loads. Messier et al[31] found that every 1 lb in weight loss was related to a 4 lb decrease in knee compressive forces per step. These results imply that if an average weight knee osteoarthritis patient (about 200 lb) lost 10 lb, each knee would be subjected to 48 000 lb less in knee compressive forces per mile walked. Accumulated over thousands of steps per day, a reduction of this magnitude would appear to be clinically meaningful.

Both exercise and weight loss interventions improve pain and self-reported function, reduce inflammation, and enhance balance and mobility in older, obese adults with knee osteoarthritis. While effective, neither exercise nor weight loss interventions have attenuated disease progression. We suggest that a weight loss of 10% to 15% of baseline body weight, or 2 to 3 times greater weight loss than achieved in recent long-term studies, may provide the necessary stimulus to reduce inflammation and knee joint loads to levels that result in less cartilage degradation and a slowing of disease progression. **NCMJ**

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COMMENTARY

Community and Environmental Factors and Arthritis Outcomes

Joanne M. Jordan, MD, MPH; Leigh F. Callahan, PhD

Great strides have been made in the past century in preventing disease and reducing early mortality, but disparities in health between and within countries are still pervasive.[1-3] The National Institutes of Health defines disparities broadly as "differences in the incidence, prevalence, mortality, and burden of diseases and other adverse health conditions that exist among specific population groups in the United States."[4]

The national health care research agenda places high priority on reducing disparities in health outcomes among persons of different socioeconomic and racial/ethnic groups through examining the mechanisms for disparities and proposing prevention strategies.[5] There is now an increasing interest in more explicit investigations of the complex issues regarding disparities and health outcomes. The urgency of understanding the effects of external forces at multiple levels including individuals and their behaviors, communities and environments, and social policies was made vividly apparent in the wake of Hurricane Katrina. The same could be illustrated in how we reacted to the fall 2007 California wildfires. We cannot deny that place can have a significant impact on outcomes regardless of an individual's resources. We also cannot deny that there are racial and ethnic differences in communities in the US.

The association between lower levels of individual socioeconomic status and poorer health outcomes has been documented for centuries in various parts of the developed world.[6-9] Associations between lower socioeconomic status and increased prevalence of disease, morbidity, and mortality in persons with arthritis and rheumatic conditions have been demonstrated in a number of population-based and clinical studies.[10-13] The role of individual socioeconomic status has been studied examining variables such as formal education level, income, occupation, and home ownership. Health outcomes have been shown to be associated with the socioeconomic environment of an individual's neighborhood,[14-16] independent of the individual's socioeconomic status.[15-17] Although there is a long tradition of public health research relating community factors to patterns of health and disease,[18,19] this has traditionally been in the context of hygiene, clean water, and the presence/eradication of infectious disease-bearing vectors. Increasingly, research findings are beginning to focus on the upstream determinants related to the community in the context of chronic diseases. These include place of residence, work environment, or wider social and economic policies. These community variables often are described as "social context," a catch-all phrase referring to the spectrum of societal factors that may not be directly measured at the individual level. The socioeconomic context of communities may affect characteristics of the social, service, and physical environments to which all residents are exposed regardless of their own socioeconomic position[20,21] and may have a greater negative impact on those with fewer individual resources.[22,23]

> *"In preliminary data from the Johnston County Osteoarthritis Project, we observed higher blood lead levels were associated with knee osteoarthritis severity in men and women..."*

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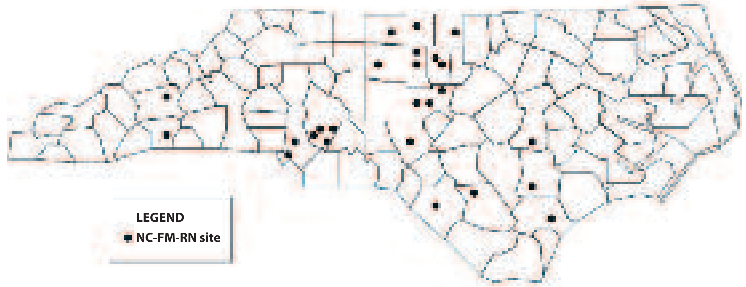
Figure 1.
Map of the 25 North Carolina Family Medicine Research Network (NC-FM-RN) Sites



We at the Thurston Arthritis Research Center at the University of North Carolina also have been very interested in the role of individuals' community and socioeconomic environments on health outcomes in people with arthritis throughout the state of North Carolina. We have examined the associations of community poverty level with arthritis prevalence and health status.[24,25] (L. F. Callahan, T. Mielenz, B. Schoster, et al, unpublished data, 2007; L. F. Callahan, J. Schreffler, T. Mielenz, et al, unpublished data, 2007) We have also embarked on a novel research agenda that examines one particular aspect of the environment—chronic environmental metal exposures—in relationship to osteoarthritis in Johnston County, the site of a longitudinal community-based research study of racial/ethnic disparities in osteoarthritis and disability outcomes between African Americans and whites.[26]

Community Poverty Level and Health Outcomes in North Carolina

In one study using patients from the North Carolina Family Medicine Research Network, a research consortium of 25 family medicine sites in rural, urban, and suburban practices across the state[27] (see Figure 1), we observed that white patients with low educational attainment (defined as less than a high school degree) and who lived in high poverty areas (defined for the block group using the 2000 Census as the percentage of the population in households with income below the poverty level) had 1.56 times the odds of reporting arthritis compared to white patients with higher educational attainment who lived in low poverty areas. African-American patients with low education living in an area with high poverty levels were more than twice as likely to report arthritis compared to African-American patients with high education levels living in low poverty areas. (L. F. Callahan, T. Mielenz, B. Schoster, et al, unpublished data, 2007)

We have also examined associations between education and census-based community-level measures of socioeconomic status in 4565 whites and African Americans in the Research Network. We used health-related quality of life assessed by the SF-12v2 Physical Component Summary and Mental Component Summary and 3 Centers for Disease Control and Prevention health-related quality of life measures to summarize the impacts of the environments.[28,29] Analyses also were conducted on subgroups of arthritis and cardiovascular disease patients. In whites, all 5 health-related quality of life outcomes had significant and meaningful associations for those with the lowest education and poorer outcomes; and 4 outcomes associated high community poverty level with poorer status. Four outcomes had associations with poorer status for the lowest education and high community poverty levels in the African-American group. Arthritis and cardiovascular disease subgroup analyses showed parallel findings. (L. F. Callahan, J. Schreffler, T. Mielenz, et al, unpublished data, 2007) These findings indicate that even using crude environmental measures, community level variables are important.

Environmental Exposures as Potential Explanations of Community and Social Determinants of Outcome

What could explain geographic, socioeconomic, and community variation in arthritis outcomes? One potential explanation is environmental exposures to harmful substances in areas that are economically depressed. Many of the rheumatic illnesses such as systemic sclerosis, systemic lupus erythematosus, and rheumatoid arthritis are autoimmune in nature with both genetic and environmental components. Environmental exposures in relationship to autoimmune conditions have usually been examined in response to report of a cluster of affected persons surrounding an environmental pollution source or a common occupational exposure.[30-34] Such exposures have included organic solvents, petroleum products, mercury, and silica dust,[35-37] all of which can affect the immune system. However, interest in the role of *routine* environmental exposures, including those from childhood or throughout the lifecourse, is gaining traction. There is concern that routine environmental exposures could act as "triggers" to induce or maintain an autoimmune response or poor health outcome in individuals not exposed to overt environmental disasters. These include risk factors such as prior infections and tobacco and hormone use.[38,39] Since some of these hypotheses are preliminary, their penetration into clinical practice has not yet widely occurred; nonetheless, the impact of treating these exposures as potentially modifiable targets for primary and secondary prevention could be significant.

Examination of environmental causes of nonautoimmune musculoskeletal conditions such as osteoarthritis has been limited. Some occupations, particularly those requiring heavy physical labor or repetitive knee bending, are more likely to be associated with osteoarthritis presumably through their physical demands and the biomechanical loads they entail.[40] Dietary intake and use of hormones and tobacco have also been examined in relationship to osteoarthritis[41-45] but few other environmental exposures have been examined.

We have recently begun examination of metal exposures, many of which occurred throughout the lifetime, and osteoarthritis using data from the Johnston County Osteoarthritis Project, a longitudinal community-based research study of racial/ethnic disparities in osteoarthritis and disability outcomes between African Americans and whites.[26]

Environmental Metal Exposures as Potential Risk Factors for Osteoarthritis

Heavy metals are ubiquitous, and exposure through drinking water, contaminated food, pesticides, and other means is widespread in our society[46-51] and remains a significant public health problem particularly in high-risk sociodemographic groups and certain geographic locations.[46,51] The varied and sometimes subtle health effects of low-level, chronic exposures to multiple elements such as lead, mercury, arsenic, and cadmium have only recently been recognized.[52-61] Many metals are divalent or trivalent cations with a tropism for bone and the potential to bind to negatively charged components of proteoglycans in cartilage.[55,62-65] Yet little attention has been directed at the possible roles of these metals in relationship to osteoarthritis, a condition accompanied by profound disruption in both bone and cartilage.[66-69]

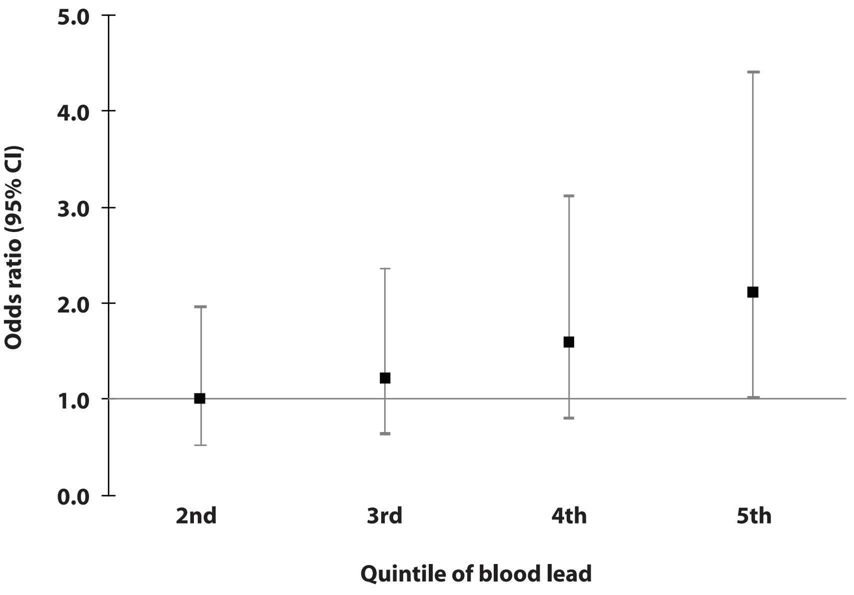
Lead and Osteoarthritis

Approximately 95% of total body lead burden in adults is stored in bone with accumulation occurring into the 7th decade. Bone lead is released into blood chronically, making bone a target tissue for lead toxicity and an endogenous source of persistent lead toxicity particularly after menopause.[70-73] Lead affects bone formation and resorption, and recent data suggest that lead affects cartilage as well.[74] In preliminary data from the Johnston County Osteoarthritis Project, we observed higher blood lead levels were associated with knee osteoarthritis severity in men and women (see Figure 2) and with serum and urine osteoarthritis biomarkers in women with possible racial differences in effect.[75,76]

Selenium and Osteoarthritis

One potentially protective environmental exposure is selenium. Selenium is an essential trace element and a required cofactor for glutathione peroxidase and antioxidant defense against free radicals and peroxide.[77,79] It has been evaluated for its protective role in cardiovascular disease, cancer, and other conditions of aging.[77,79] Animals with selenium deficiency have irregular bone formation, decreased bone strength, and abnormalities in types I and II collagen in cartilage.[80-82] In areas of China and eastern Asia where selenium levels in the soil are among the lowest in the world, low selenium, among other risk factors, has been associated with Kashin-Beck Disease, an endemic, early onset osteoarthropathy. Early intervention regarding deficiency in this environmental factor has decreased the incidence of this disease.[83,84] Selenium levels may be low in the southeastern United States as well,[85] leading us to investigate the role of selenium in osteoarthritis. Interestingly, preliminary data showed that those with low selenium levels, measured in toenails, were more likely to have knee osteoarthritis and more severe knee osteoarthritis,[86] and women with low selenium were more likely to have hip osteoarthritis. (J. M. Jordan, F. Fang, J. B. Renner, et al, unpublished data, 2007).

Figure 2.
Blood Lead Levels and Severity of Radiographic Knee Osteoarthritis



These results are compelling in that they suggest there may be modifiable environmental factors that could influence the onset and progression of osteoarthritis with the potential for intervention. We suspect these factors interact with genetic and other risk factor susceptibility, and future studies of these issues are planned.

Examination of the role of both individual and community social determinants of health outcomes in arthritis and rheumatic conditions is overdue. Future studies will be needed to verify cross-sectional associations longitudinally and to tease out explanatory factors behind observations. Arthritis and autoimmune conditions are areas in need of further research in the role of environmental exposures in etiology and maintenance of disease. The possibility that environmental exposures could contribute to these conditions and to ethnic disparities in these conditions would likely lead to changes in clinical practice and public policy. **NCMJ**

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Pain and Arthritis

John B. Winfield, MD

Arthritis is virtually synonymous with pain. Arthritis-associated pain is the number one reason patients visit a doctor. For the past 8 years, I have been practicing rheumatology in western North Carolina. Before that, my entire career had been in academic or medical research institutions, most notably at the University of North Carolina at Chapel Hill. The current foray into the "real world" of medicine has been enlightening, to say the least, and has allowed some insight into how arthritis pain is approached in North Carolina that could come only from being part of a local medical community. In this commentary, I will make some suggestions as to how we could do a better job. In addition to medical practice issues such as diagnosis, classification, and management, I will touch upon several less conventional topics such as physician attitude and behavior in the approach to pain.

Chronic pain is an extremely important aspect of illness, yet it is woefully neglected at all levels of training and practice starting with medical school curricula. The public health burden of chronic pain falls mostly on the primary care physician. It has been my experience in "the real world" that there is enormous variability in the willingness and effectiveness of the primary care physician to manage chronic pain in his or her patients. All too often there is a direct "punt" of the entire problem to the local anesthesia pain clinic where after a series of epidural blocks—which don't help—the patient is "punted" back to the primary care physician and then to me.

Suggestion 1

Address pain as a disease entity, not as a sensory entity.[1] Not infrequently in office-based practice, treatment of pain is secondary to diagnosis and treatment of the disease state. This is unfortunate because pain, especially chronic pain, is among the most disabling and costly medical problems in Western countries.[2] Patients suffering with chronic diffuse pain who lack objective clinical and laboratory findings (ie, fibromyalgia) are especially likely to be dismissed as not having "real" pain, which only perpetuates their illness. Presence of pain should be specifically sought and evaluated in all patients and, if present, relief of pain should be a primary focus of the physician's efforts.

"Presence of pain should be specifically sought and evaluated in all patients and, if present, relief of pain should be a primary focus of the physician's efforts."

Suggestion 2

Classify pain immediately after recognition. Pain classification is not difficult. Nociceptive pain is due to stimulation of peripheral pain receptors on thinly myelinated Ad and/or unmyelinated C afferents during inflammation or injury of tissues. The pain experienced generally matches the noxious stimulus. Both peripheral and central nervous system processes play a role in neuropathic pain, which may occur with direct nerve injury. There are 3 common types: (1) peripheral neuropathic pain (eg, postherpetic neuralgia, painful diabetic neuropathy, radiculopathic pain due to injury to spinal nerve roots); (2) central neuropathic pain (eg, central poststroke pain, spinal cord injury pain); and (3) cancer-associated neuropathic pain. Complex regional pain syndrome (reflex sympathetic dystrophy), while very rare, is another neuropathic pain syndrome. Neuropathic pain may be paroxysmal, with unusual characteristics such as electric shock-like shooting or burning, and may be

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associated with hyperpathia (persistence after the stimulus has ended, spreading or worsening in crescendo-fashion with repeated touching). Chronic pain of complex etiology occurs in fibromyalgia and a large number of substantially overlapping regional pain syndromes such as migraine headache, temporomandibular disorders, irritable bowel syndrome, and atypical chest pain, to name a few. Previously termed "functional pain syndromes" on the basis of absent structural pathology, these illnesses share very close relationships etiologically and pathophysiologically. Recent advances in the understanding of the psychophysiologic/neurophysiologic dysregulation in such illnesses is impelling a unifying reclassification as central sensitivity syndromes.[3] More purely psychogenic pain is seen in somatoform and somatization disorders and hysteria and is quite rare.

Suggestion 3

Invest some time catching up on recent developments in fibromyalgia. Forget the disparaging and dismissive comments of your professors and senior residents. These patients are not crocks or neurotic whiners. Rather, they have a complex neurosensory disorder manifest by multiple abnormalities in how the central nervous system processes and interprets sensory input. At least 5% of adult females have fibromyalgia. Approximately 25% of patients with rheumatoid arthritis and perhaps 50% of patients with lupus also have fibromyalgia, and both illnesses must be treated for optimum therapeutic response. In fibromyalgia, altered central nociceptive processing results in a decrease in the pain perception threshold and in the threshold for pain tolerance. Except for pain with palpation of tender points, the physical examination and all routine laboratory tests are normal yet the pain is very real, as can be demonstrated by sophisticated quantitative sensory testing methods and functional MRI studies. Multiple genes[4,5] that increase vulnerability to this and related disorders have been identified. These genes encode molecules involved in nociceptive processing, and their identification is proving to be invaluable in new drug discovery. Very effective management strategies have evolved,[6,7] and for the first time a drug, pregabalin (Lyrica), has been specifically approved by the Food and Drug Administration for treatment of pain in fibromyalgia. Several more (eg, duloxetine/Cymbalta and sodium oxybate/Xyrem) should receive Food and Drug Administration approval shortly.

Suggestion 4

Apply some simple approaches for measuring pain, fatigue, sleep, psychological well-being, and daily functioning in your patients. This sounds complicated and time-consuming, but it is not. Pain intensity can be measured with either a verbal or numerical rating scale or a visual analog scale. Observation of pain behaviors such as guarding, rubbing, grimacing, and sighing provides insight into self-efficacy for control of chronic pain—more prominent pain behavior equates to low self-efficacy—which in turn greatly compromises a patient's capacity to cope with chronic pain conditions. A number of measurement tools can be applied in just a few minutes while the patient is in the waiting room through use of a multidimensional health assessment questionnaire. This instrument combines simple self-report forms that incorporate validated scales for physical and psychological health status (modified health assessment questionnaire); visual analog scales for pain, fatigue, and patient global self-assessment; a checklist of current symptoms; and scales for helplessness and cognitive performance.[8] Easily adaptable to a busy practice, such information is invaluable for the psychosocial assessment of pain both diagnostically and in monitoring response to therapy.

Suggestion 5

Do not be afraid of opioids. It is my experience that certain primary care physicians or even entire practice groups have a policy of not prescribing narcotics, period! This is ridiculous, bad medicine, and perhaps even malpractice. Some chronic noncancer pain can be managed only with opioids including pain in occasional patients with fibromyalgia. Not every patient who requests hydrocodone is a drug-seeker. Low-dose opioids taken concurrently with nonsteroidal anti-inflammatory drugs or Cox-2 inhibitors for patients with osteoarthritis who fail acetaminophen are not only effective when used as part of a multimodal approach to pain control, but may have fewer potentially life-threatening complications.[9] Reasonable guidelines for use of opioids in more severe musculoskeletal pain include exclusion of substance abusers, concomitant attention to psychological and social perpetuators of pain, use of an opioid treatment contract, a one physician-one dispensing pharmacy policy, and close monitoring. It should be remembered that drug-seeking behavior (pseudoaddiction) may indicate that pain is not being controlled adequately.

Summary

Address arthritis-associated pain as a disease entity, not as a sensory entity. Attempt to classify chronic pain as nociceptive pain, neuropathic pain, fibromyalgia-type pain, or psychogenic pain (very uncommon); specific treatment approaches are required for these different types of pain. Overcome your negative bias against fibromyalgia and review recent discoveries that have led to classification of fibromyalgia as a biologically-based neurosensory disorder. Use the simple and convenient ways that are available to measure pain and its concomitants (fatigue, poor sleep, depression, anxiety, and impaired physical functioning) both at initial evaluation and in follow-up visits as a guide to therapy. Do not fear use of opioids; just be careful with this class of drug. **NCMJ**

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COMMENTARY

Contemporary Total Joint Arthroplasty

Victor M. Goldberg, MD

Total joint arthroplasty has become a successful and reproducible surgical treatment for significant arthritis. Both pain relief and functional outcomes have been excellent. In 2004 over 475 000 total knee replacements and more than 230 000 total hip replacements were performed in the United States, and this number is increasing at a rate of 11% for knee replacement and 2.5% for hip replacements each year. Although joint replacements have an excellent outcome, there still has been a small although disturbing incidence of mechanical and biological failures. The causes of these failures include implant surface wear, loosening, and instability. Infection remains a long-term concern.[1,2]

Early in the history of joint arthroplasty, younger, more active patients and very elderly patients were discouraged from having replacements because of the increased incidence of failures in these populations. Recent advances in implant design, materials, and surgical techniques have widened the indication for total joint arthroplasty in all patients with end stage arthritis. For example, alternative bearing surfaces such as metal-on-metal articulations have significantly reduced wear and its associated bone loss and implant loosening.[3-6] Minimally invasive surgical procedures have accelerated patient rehabilitation, and enhanced instrumentation has provided excellent restoration of joint anatomy.[7-9] An understanding of the present state of the art of joint arthroplasty is critical in order to provide physicians and patients with the basis of contemporary indications and expected realistic outcomes of the procedure.

Total Knee Arthroplasty

Enhanced designs and techniques have improved the long-term survival rates of total knee replacements so that 90% to 95% of active patients can expect a satisfactory result for 15 to 20 years. Implant fixation can be accomplished by either cementless or cemented methods. The success of cementless fixation depends upon a stable implant with a porous surface composed of either titanium or cobalt chromium alloys configured to support bone regrowth. Stability of the components can be achieved by using screw fixation and press-fit stems and/or pegs.[10-12] Precise surgical instruments provide close implant-bone interface. Studies indicate that component movement of less than 75 to 100 micrometers will support bone ingrowth, whereas motion of greater than 150 micrometers encourages fibrous tissue ingrowth.[4]

> *“Recent advances in implant design, materials, and surgical techniques have widened the indication for total joint arthroplasty in all patients with end stage arthritis.”*

Contemporary knee component designs have closely reproduced knee anatomy. Recently gender-specific implants have been introduced to better match the size and geometric dimensions of the female distal femur. (See Figure 1.) This should improve patellar tracking and ligament balancing. Knee flexion is important for functional activities. Newer designs are now available that allow as much as 140° to 150° of knee flexion.[12] This is especially important in patient populations that require kneeling activities.

Wear of contact surfaces is a significant cause of failure of total knee replacement. Improvement in the manufacturing technique of polyethylene has reduced wear debris from the articulating surface. These advances include processes to reduce oxygenation of polyethylene to improve fatigue wear of the material.[4] The use of thicker polyethylene tibial inserts and optimization of component designs has also reduced wear failures in total knee arthroplasty.[12] Another approach to reducing stress on polyethylene has been to increase conformity between

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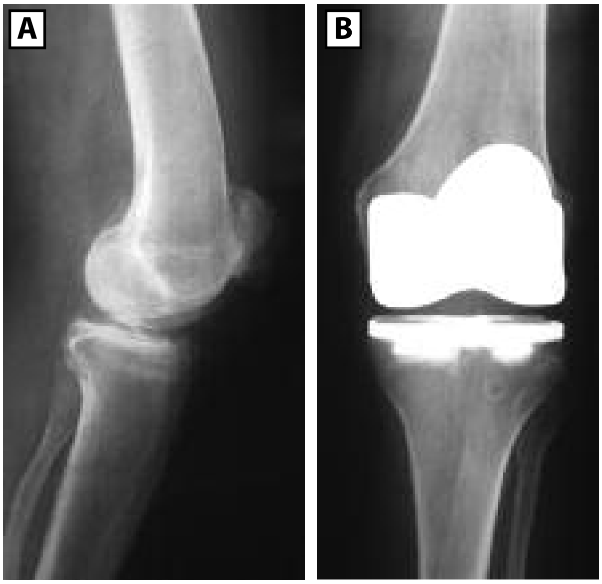
Figure 1.
(A) Lateral Radiograph of a Female Patient With Significant Osteoarthritis
(B) Arthroplasty Radiograph Demonstrating the Anatomical Relationship of the Component With the Femur Using an Implant Specifically Designed for Females



surfaces. Mobile bearing prostheses have been developed that provide conformity without sacrificing rotational movements of the knee.[13] Although the results are satisfactory with a follow-up of 9 to 12 years, there is still an incidence of periprosthetic bone loss as a result of wear-induced osteolysis.

Traditional total knee arthroplasty has been highly successful in pain relief and functional long-term survivorship. Patients, however, have expressed dissatisfaction with the postoperative pain and prolonged rehabilitation. These issues have encouraged surgeons to adopt minimally invasive surgical techniques which use smaller skin incisions and muscle-sparing approaches.[8] The early results of minimally invasive surgical techniques are encouraging, but usually by 6 months to 1 year after surgery there is no difference in results when compared to traditional approaches. Longer term data will be necessary to substantiate the early results of minimally invasive techniques which are inherently more difficult and have the potential for increased complications.

Optimizing surgical techniques in total knee arthroplasty has been reported to improve long-term survivorship of the procedure.[7] Adapting computer assisted navigation to the total knee arthroplasty surgical technique may improve knee alignment and component position. The early results indicate that these outcomes can be accomplished using this technique, but extensive exposure is necessary and the instrumentation is complex and difficult to master.[7] Ultimately this approach combined with a minimally invasive technique will assure anatomically aligned knees with the least intrusion on bone and soft tissues.

Total Hip Arthroplasty

Since total hip arthroplasty was introduced into the United States in 1969, there have been extensive changes in implant designs, materials, and surgical techniques. Using contemporary designs, hip implant survival rates have approached 90% to 95% at 15 to 20 years after surgery.[14] Early concerns focusing on perioperative infection have largely disappeared due to the use of perioperative antibiotics, ultraclean operating rooms using laminar flow methods, and exhaust exclusion hoods that isolate the surgeon from the patient. Implant breakage has virtually been eliminated by the use of high strength materials such as titanium and forged cobalt chromium stems. Newer hip stem designs use more flexible materials that match the stem's material characteristics with the surrounding bone to enhance implant integration with the patient's femur and also preserve native bone.[15] (See Figure 2.) Fixation methods have evolved so that either cemented or cementless modes of fixing the component to bone have been highly successful.[14,16,17] Major advances in this area have included methods of assuring excellent cementing techniques to provide optimum fixation of the implant to the host bone.[18] Porous surfaces have been redesigned to closely mimic the structure of the surrounding bone.[15] These newer surfaces provide the best geometric configuration to enhance bony ingrowth and long-term component fixation.

The major focus of research and development over the past decade has been directed towards reduction of bearing surface wear and the biologic reaction to this periprosthetic debris.[3]

Figure 2.
Arthroplasty Radiographs of a Hip Six Years After Replacement With a Component Stem Made of Flexible Materials Demonstrating Excellent Bone Preservation

The resulting bone loss or osteolysis may compromise implant fixation and ultimately result in component loosening. Alternative bearing surfaces have been developed which may reduce wear of the articulating surfaces and prolong the longevity of the total hip replacement.[4-6] Hard surfaces include metal-on-metal or ceramic-on-ceramic. Although wear is reduced significantly with these surfaces, there still are potential problems that could compromise the replacement. For example, metal-on-metal surface wear results in the release of metal ions which circulate systemically and could have long-term consequences.[5] Ceramic surfaces have the potential to fracture if any impingement results because of even minor implant malposition.[6] The recent introduction of highly cross-linked polyethylene as a counter surface to the femoral head also has significantly reduced the generation of wear particles.[4] However, the ultimate role of each of these bearing surfaces requires longer term follow-up, so that the choice of the best articulating surface can be adapted cost-effectively to the appropriate patient.

Computer assisted navigation and minimally invasive surgical techniques have also been used at selected centers to improve implant positioning and early rehabilitation. Initial experience with both of these approaches has been encouraging, but long-term follow-up is necessary to assess the real value of these approaches compared to established methods.[9]

The use of total hip replacement in young, active patients has always been controversial considering the reported increased failure rate in these patients.[16] Revision total hip replacement is significantly more complicated than the primary procedure because of the bone and soft tissue loss seen with the failed total hip replacement. Recently metal-on-metal surface replacement arthroplasty has been introduced to replace the hips of this younger, active patient population.[19] (See Figure 3.) This replacement preserves bone and resurfaces the acetabulum and femoral head. The larger ball size may enhance range of motion and hip function without the risks of hip dislocation. The early results have been good, however, an additional complication not seen in classical total hip replacement has been observed.[20] Femoral neck fractures have been reported which require an early revision, perhaps because the surgical procedure itself compromises the blood supply to the femoral head. The reported incidence of this complication varies from 1.5% to 3%. Prevention of this early failure requires surgeon education and improved sophisticated instrumentation. Longer follow-up is necessary to define the role of this replacement compared to a standard total hip replacement with large heads, now available with the new alternative bearing surfaces.

Total Ankle Arthroplasty

The reported results of the first generation total ankle arthroplasty were significantly poorer than total hip and total knee replacement. Loosening and mechanical failure were the primary reasons for failure of the total ankle replacement.[21,22] As a result, ankle arthrodesis, inducing ossification between bones, was the preferred treatment for end-stage ankle arthritis. Recently contemporary implants have been introduced with improved designs, surgical techniques, and materials, and early results have been encouraging.[21] Both mobile bearing designs and fixed bearing implants have reported satisfactory intermediate clinical results. One recent systematic review of the literature comparing ankle arthrodesis with total ankle replacement indicated that each procedure had about 25% poor results, and the revision rate was 9% for arthrodesis compared to 7% for total ankle replacement.[22] However, these results are predominantly retrospective and uncontrolled without direct comparison between the 2 procedures. The major difficulties in designing implants for total ankle replacement are a lack of complete understanding of the complex kinematics of this joint, material properties of the tibia compared to talus, and the very thin and poorly vascularized soft tissues. By contrast to total knee arthroplasty, the surgical techniques required to obtain anatomical alignment of the ankle and soft tissue balance are not well established. Indications for this procedure are still being refined. It appears that with the second generation total ankle replacement the optimal patient is older with lower demands. Patients who exhibit significant arthritis in the subtalar or midtarsal joints may be better functionally after an ankle replacement compared to arthrodesis. Absolute contraindications for the procedure include active infection and inadequate soft tissues or vascularity. Marked ankle instability, poor bone, or osteonecrosis of the talus are relative contraindications. Presently there are a number of ongoing clinical trials in the United States evaluating the different design philosophies.[21] Each of the 4 new total ankle replacements being studied do have some clinical concerns such as subsidence and/or dislocation of the components. Wear of the surfaces still remains a long-term worry. Current recommendations are for the procedure to be performed for low-demand patients by surgeons who have completed special training for the technique.

Figure 3.
Arthroplasty and Lateral Radiographs Demonstrating Surface Replacement

Summary

Total joint arthroplasty is a highly successful procedure for end-stage lower extremity arthritis. Excellent pain relief and significantly improved function is usual after surgery when used for appropriate indications by highly skilled surgeons using contemporary designed components. Future improvement in design and materials to reduce wear will further enhance clinical outcomes and long-term implant survival. **NCMJ**

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COMMENTARY

Eat Smart and Move More to Combat Arthritis

Greg Griggs, MPA, CAE; Marie Shelton, MPH, RD

The statistics are alarming. In the recent publication *F as in Fat: How Obesity Policies are Failing in America, 2007*, North Carolina was ranked 17th in the nation in adult obesity.[1] In fact, nearly 2 out of 3 older North Carolinians (aged 65 years and above) are either overweight or obese. This excess weight has enormous health implications for diabetes, cardiovascular disease, and, yes, arthritis.

Arthritis is often overshadowed by other conditions related to obesity, but the fact remains that 70.4% of obese North Carolinians over the age of 65 years have been diagnosed with arthritis. In comparison, only 49.8% of our state's older citizens who are considered normal weight or underweight have been diagnosed with this disease.[2] These numbers make it clear: we cannot address arthritis without addressing the issue of weight.

> *"Persons who are overweight or obese are also more likely to incur activity limitations due to arthritis."*

Obesity is considered a risk factor for arthritis and can exacerbate already existing conditions. According to the Centers for Disease Control and Prevention, the prevalence of arthritis increases as weight does. Maintaining a healthy weight can help prevent onset and help slow the progression of this condition. Persons who are overweight or obese are also more likely to incur activity limitations due to arthritis. In North Carolina, of those 65 years and older who have been diagnosed with arthritis and are also obese, 46.5% report that their activity is limited by joint pain. On the other hand, only 32.6% of normal and underweight persons report such limitations.[2] However, even a small weight loss can have a significant positive impact. Research has shown that losing only 11 pounds can reduce the incidence of knee arthritis.[3]

Ironically, one of the key behaviors to weight management also has positive outcomes for arthritis. Physical activity not only helps with weight loss and maintenance, but regular activity also has been shown to improve the health of muscles and bones, reduce pain, and increase flexibility of joints and ease of movement. Despite these health benefits, in North Carolina only 1 in 3 adults over the age of 65 years who have been diagnosed with arthritis achieve the recommended amounts of physical activity.[2]

Eat Smart, Move More…NC is a statewide movement to reduce the rising tide of obesity and related chronic disease among North Carolinians by helping them to eat smart, move more, and achieve a healthy weight. The *Eat Smart, Move More…NC* Leadership Team representing over 40 academic, government, nonprofit, health care, and private organizations helps to guide the movement and ensure that healthy eating and physical activity choices become easier to make in North Carolina.

The *Eat Smart, Move More…NC* Leadership Team executive committee provides guidance to the leadership team and includes chairs of the various committees. Greg Griggs, MPA, CAE, from the North Carolina Academy of Family Physicians, serves as chair of the leadership team. Carolyn Dunn, PhD, of North Carolina State University and the North Carolina Cooperative Extension Service, assists as vice chair. Dave Gardner, DA, of WakeMed Health and Hospitals, leads the advocacy committee in its efforts to recommend legislation, regulations, policies, and funding to enhance physical activity and healthy eating in North Carolina. The communications committee is headed by Patrick Gibbons of RTI International. This committee is responsible for communicating the need for physical activity and healthy eating opportunities particularly as they relate to policy and environmental change.

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Maggie Sauer, MS, MHA, is chair of the implementation committee which supports and promotes programs and efforts that enhance physical activity and healthy eating opportunities.

Through *Eat Smart, Move More…NC* citizens gain knowledge, resources, and support needed to achieve and maintain a healthy weight. A consumer Web site at *www.MyEatSmartMoveMore.com* provides tools and tips for incorporating good nutrition and physical activity into daily life. Advertisements on billboards, in print media, and on the radio and television encourage North Carolinians of all ages to spend less time in front of the television and computer, be active every day, drink fewer sugar-sweetened beverages, prepare more meals at home, decrease portion sizes, and eat more fruits and vegetables. These messages serve as a reminder of how simple changes in daily lifestyle can have a large impact on weight management.

Eat Smart, Move More…NC increases healthy eating and physical activity opportunities wherever North Carolinians live, learn, earn, play, and pray. In order to make healthy behaviors the norm, rather than the exception, appropriate policies and environmental changes must be put into place at both the state and local level to encourage eating smart and moving more. Examples of these polices and environmental changes include creating healthy worksites or faith communities that encourage and facilitate these behaviors as well as building walking trails and greenways that provide opportunity for moving more.

Helping our citizens reach a healthy weight and maintain healthy eating and physical activity behaviors will have a profound impact on the health of our state. Eating smart and moving more also may be key to addressing the incidence and severity of arthritis in North Carolina. **NCMJ**

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COMMENTARY

Complementary and Alternative Medicine for Arthritis

Jaya K. Rao, MD, MHS

Since the mid-1990s, the prevalence and costs associated with the use of complementary and alternative medicine have attracted the interest of health care organizations, policy makers, providers, and consumers. Complementary and alternative medicine is usually defined as medical interventions that are neither taught widely in US medical schools nor generally available in US hospitals[1] and includes modalities such as herbal medicine, spiritual healing, and aromatherapy. It is important to remember, however, that with data from efficacy studies complementary and alternative medicine treatments have the potential to become part of mainstream medicine. For example, digitalis and colchicine were once considered "alternative" but are now prescribed by mainstream practitioners. In this commentary, I will briefly review the epidemiology of complementary and alternative medicine use by patients with rheumatologic conditions and highlight recent data on selected complementary and alternative medicine treatments for arthritis.

"While most individuals use complementary and alternative medicine to supplement conventionally-prescribed treatment, many do so without informing their doctor, raising concerns about the potential for adverse interactions with prescribed treatments."

Epidemiology

It is well documented that people with chronic conditions use complementary and alternative medicine to treat their symptoms. Depending on the study population and how it is defined, the estimated prevalence of complementary and alternative medicine use by Americans ranges from 33% to 90%.[1-5] In a landmark study, Eisenberg and colleagues reported that 33% of Americans used an alternative therapy in 1990.[1] By 1997 the percentage of Americans reporting complementary and alternative medicine use increased to 42%, and 46% reported visiting a complementary and alternative medicine practitioner.[2] While most individuals use complementary and alternative medicine to supplement conventionally-prescribed treatment, many do so without informing their doctor,[1,2,6] raising concerns about the potential for adverse interactions with prescribed treatments.

Complementary and alternative medicine use is particularly common among people with musculoskeletal disorders.[1,3] Population- and clinic-based data indicate that 28% to 90% of people with arthritis and other rheumatologic conditions use complementary and alternative medicine.[4-8] Studies of patients with specific rheumatologic conditions (eg, fibromyalgia, osteoarthritis, systemic lupus erythematosus) demonstrate a similar degree of use. In general, people with a higher educational level, a longer duration of disease, poorer functional status, and higher levels of pain are more likely to use complementary and alternative medicine.[4,7] Data also indicate that use (and the specific types used) varies by race and ethnicity.[9,10]

Data From North Carolina

Population-based data document a geographic variation in complementary and alternative medicine use with higher rates

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reported by residents of the western United States.[1,3] While the variation in rates may relate to the definition of complementary and alternative medicine used in the survey, it is also important to note, however, that complementary and alternative medicine use is not uncommon in the South.[3]

Data from studies of North Carolina residents underscore this point. In a study of 1059 adult residents of western North Carolina, nearly one-half (45.8%) reported using complementary and alternative medicine to treat their chronic conditions.[11] Although its use was not associated with the number of chronic conditions or health care utilization, people with less education were more likely to use honey-lemon-vinegar-whiskey combinations while people with greater education were more likely to have visited a complementary and alternative medicine practitioner. In a study of 211 rural community-dwelling adults with arthritis, Arcury and colleagues reported that complementary and alternative medicine use was common and they found differences in the types used based on race and ethnicity. African Americans were more likely to rely on prayer and topical treatments (eg, liniments, turpentine) than European Americans.[9] Finally, in a study of 752 arthritis patients who were seen in 16 primary practices in rural and urban North Carolina, 89% reported using at least one complementary and alternative medicine.[5] Interestingly, 71% of those who used at least one treatment discussed this behavior with the physician.[5]

Given the widespread interest in complementary and alternative medicine, it is not surprising that medical universities have developed integrative medicine programs. Three medical universities in North Carolina (Duke University, the University of North Carolina at Chapel Hill, and Wake Forest University) have established such programs to provide selected forms of complementary and alternative medicine treatment to patients and to conduct research.

Recent Data on Selected Complementary and Alternative Medicine Treatments for Arthritis

Complementary and alternative medicine is big business in the United States. Since the passage of the Dietary Supplemental Health and Education Act of 1994, dietary supplements and herbal products have become widely available. In 1997 an estimated 165 million adults (18.4% of all prescription users) used herbal medicines along with conventionally prescribed medications, and they spent $5.1 billion dollars out-of-pocket on these remedies.[2] Furthermore, they made 629 million visits to alternative practitioners, far exceeding the total number of visits made to primary care providers in 1997.[2] An extensive review of complementary and alternative medicine therapies is beyond the scope of this commentary. Instead, I will highlight data on 2 treatments used for arthritis symptoms that have been the focus of recent investigation: glucosamine/chondroitin sulfate and acupuncture.

Since the 1980s glucosamine and chondroitin have been used to treat osteoarthritis, primarily in European countries.[12] Notably, in Europe and other countries, glucosamine sulfate is approved as a prescription treatment for osteoarthritis.[13] Glucosamine is a precursor to the glycosaminoglycan molecule, and chondroitin is the most abundant glycosaminoglycan found in cartilage.[13] Short-term (4 to 6 week) controlled trials indicate that patients treated with glucosamine experience modest improvements in pain and function compared to those receiving placebo[14] and experience treatment effects comparable to nonsteroidal anti-inflammatory drugs.[15]

Two recent meta-analyses that examined randomized trials of glucosamine and chondroitin report mixed conclusions regarding efficacy which may relate to the specific formulations of glucosamine used in the trials, methodologic concerns, and industry bias.[12,16] A large multicenter trial was designed to address some of these concerns: patients with symptomatic knee osteoarthritis were randomized to glucosamine, chondroitin, glucosamine plus chondroitin, celecoxib, or placebo treatment for 24 weeks.[17] Patients who were treated with glucosamine and chondroitin sulfate alone or in combination did not experience a significant improvement in pain compared to controls.[17] Unfortunately, this trial involved treatment with glucosamine hydrochloride, a formulation that other investigators have concluded is not effective compared to the glucosamine sulfate formulation.[16,18] At this time, patients who are considering using glucosamine for their osteoarthritis symptoms should be advised to take glucosamine sulfate rather than glucosamine hydrochloride, and those with severe pain might consider adding chondroitin sulfate to this regimen.[18]

Acupuncture is an important modality in traditional Chinese medicine that involves the transcutaneous placement of needles, sometimes with ancillary electrical current, heat, or moxibustion (ie, incense burning), to specific sites in order to restore the person's balance of vital energy (also known as qi or chi).[19] Acupuncture, which is often used for pain relief, has been the focus of several recent trials. These trials have highlighted the methodological dilemma of finding an appropriate comparison to acupuncture. Sham acupuncture may stimulate pain inhibitory fibers or endorphin release while positive comparisons to a wait list control may be due to treatment expectations or placebo effects.[20]

Witt and colleagues reported significant improvements in outcome among those who received acupuncture compared to a wait-list control group.[21] These investigators also performed a 3-arm randomized trial in which one group received sham acupuncture.[22] Compared to the sham acupuncture or wait-list control groups, the group who received acupuncture experienced significant improvements in pain and function immediately after receiving the entire intervention (12 acupuncture sessions over 8 weeks), but these improvements declined over time.[22] Another study reported significant improvements in outcome when the acupuncture and sham acupuncture groups were compared to a wait list control group, but no differences when the acupuncture group was compared to the sham acupuncture group.[23] Given the heterogeneity of study findings and clinically minimal effects when acupuncture is compared to sham therapy, a recent meta-analysis concluded that it is premature to recommend this treatment as part of routine care for knee osteoarthritis and suggested that clinicians and patients might consider acupuncture as one option in a multidisciplinary treatment approach.[20]

Managing Patients Who Also Use Complementary and Alternative Medicine

Regardless of their particular beliefs about complementary and alternative medicine, physicians have an ethical obligation to discuss treatment alternatives with their patients. Although physicians should acknowledge their level of knowledge regarding complementary and alternative medicine during these discussions, they should also make sure that the patient has received information about the safety (eg, potency, drug interactions) and efficacy of these treatments.[24] Because patients' complementary and alternative medicine usage may change over time,[25] physicians should periodically review their patients' current regimens.

Since most alternative therapies are unproven, physicians may have legal concerns when they are asked to recommend specific complementary and alternative medicine treatments, provide referrals to practitioners, or tolerate continued use of these therapies. As a general rule, the mere referral to a complementary and alternative medicine practitioner does not expose the referring physician to liability unless the referral itself deprives the patient of receiving appropriate care (ie, referral delays or eliminates an opportunity to receive important care).[26] On the other hand, the physician could be held liable if he or she recommends a complementary and alternative medicine that is associated with serious risks or is known to be ineffective.[27] Thus, when recommending specific complementary and alternative medicine, physicians should review the literature to determine the level of risk for the treatment, discuss the potential risks and benefits with the patient, document this discussion, and continue to monitor the patient conventionally.[27] When referring patients to complementary and alternative medicine practitioners, physicians should also inquire about the practitioner's credentials, competence, and practices.[27]

Final Thoughts

People with rheumatologic conditions often use complementary and alternative medicine to treat their symptoms. To date, epidemiologic studies have focused on describing patients' use of complementary and alternative medicine and identifying predictors of this behavior. Given that many patients do not discuss their use of complementary and alternative medicine with their physicians, future investigations might focus on developing methods such as office-based tools to facilitate patient-provider communication regarding complementary and alternative medicine. Furthermore, complementary and alternative medicine is an evolving field as results emerge from efficacy studies of specific treatments. Clinicians should keep abreast of the findings of these trials because these data will be helpful in managing and advising patients who use such therapies. **NCMJ**

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Use of Nurse Practitioners and Physician Extenders in Rheumatology:

A Western North Carolina Perspective

Kate T. Queen, MD, FACR, CCD

Western North Carolina enjoys tremendous popularity. For years it has been a vacation and recreation destination, but today young and old alike are attracted to the mountains and find our communities an ideal place to consider calling home. Residents of western North Carolina have benefited from a long tradition of excellence, depth, and diversity in the medical community historically centered in Asheville. However, over the past 25 years the demand for quality specialty care closer to home has escalated in smaller, surrounding communities. A growing need for clinicians skilled in the evaluation and treatment of patients with rheumatic diseases and musculoskeletal complaints reflects this demand.

My experience is that of a solo rheumatologist practicing within a multispecialty internal medicine group in a rural mountain community. I struggled unsuccessfully to recruit a second rheumatologist for years and discovered that an alternative strategy for success in meeting the needs of my region was the integration of a midlevel practitioner. The development of collaborative practices with nurse practitioners or physician assistants has been an effective way for others to respond to this sometimes overwhelming demand for care. As we face the challenge statewide of meeting the needs of a "graying" North Carolina and embrace the opportunity to address issues related to health and aging, this model deserves serious consideration.

Who Benefits?

Patients are the most important beneficiaries of this collaborative approach to care. Improved access is a high priority to anyone with pain or impairment in independent function. Collaborative practices have the flexibility to develop strategies to not only expedite the evaluation of new patients but also deal with the needs of established patients promptly when new problems or concerns arise.

Patient satisfaction also improves. Nurse practitioners and physician assistants attracted to outpatient care typically have a special interest in patient education and teaching. This skill and focus is invaluable to patients with rheumatologic conditions who need to learn what to expect from their illness as well as how to avoid, recognize promptly, and respond to complications of their treatments.

> *"… as the demand for care increases and the financial pressures for efficient and effective service intensify, rheumatologists working collaboratively with nurse practitioners and physician assistants have real opportunities to build rewarding relationships."*

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Rheumatologists who adopt this style of practice have much to gain. For a solo rheumatologist like me, the addition of a midlevel practitioner facilitated a healthier balance between the desire to provide quality patient care and follow-up and my own need for personal time and a balanced lifestyle.

It has been demonstrated in a wide variety of clinical settings that the utilization of a midlevel practitioner to maximize productivity has enhanced financial rewards as well. According to the Medical Group Management Association's *Physician Compensation and Production Survey: 2006 Report Based on 2005 Data*, physician assistants and nurse practitioners are able to generate practice income well above their costs.

In a practice setting of mutual respect and collaboration, midlevel practitioners can find great rewards. They have the opportunity to practice within the scope of their training and experience with the back-up and support of their physician. The expansion of new knowledge and therapeutic options makes this a particularly exciting time to be part of a rheumatology team. In addition, the freedom to focus on patient care and supervision without the burden of managing the financial and accounting aspects of practice contributes to the professional satisfaction inherent in their role.

Is There a Significant Difference Between Nurse Practitioners and Physician Assistants?

The background and training of nurse practitioners and physician assistants are not identical. Nurse practitioners are registered nurses who have attended accredited programs to pursue both advanced academic and clinical training. Physician assistants may come from a variety of prior experiences including work in other allied health roles and the military. Physician assistants typically have a baccalaureate degree as well as a degree from an accredited physician assistant training program.

In North Carolina, physician assistants are licensed by the North Carolina Medical Board (www.ncmedboard.org). Nurse practitioners receive their authorization to practice from both the North Carolina Medical Board and the North Carolina Board of Nursing (www.ncbon.com). State laws, including the Medical Practice Act of the North Carolina General Statutes, and the rules of the North Carolina Medical Board clearly delineate many facets of the primary supervising physician's responsibilities.

Individual physicians have substantial autonomy to decide how best to use an extender in their practice. It is important to the successful integration of a midlevel practitioner that his or her scope of practice be identified and that the delegation of medical tasks is appropriate to the skills of the supervising physician as well as the competence level of the physician assistant or nurse practitioner. It is not surprising that this role often expands and evolves over time as the midlevel practitioner matures and demonstrates his or her competency.

Enhancing Success

In the field of rheumatology there are no training programs designed to help a nurse practitioner or physician assistant specifically prepare to join a rheumatology practice. Such training has traditionally been left to the individual physician who seeks to integrate a midlevel practitioner. The Allied Rheumatology Health Professionals, a sister organization to the American College of Rheumatology, has had a strong interest in recent years in providing continuing education opportunities for advanced practice nurses and other midlevel practitioners. However, at the present time, standardized preceptorships to develop the skills and knowledge base unique to rheumatology have not been developed.

Preparing your patients as well as your medical community for the addition of a nurse practitioner or physician assistant is critical to their acceptance, particularly if you are in a region where these practitioners are not found in specialty practices. Your confidence in their knowledge and skills is key to building a foundation for years of successful collaboration.

In addition, this model requires not only an initial commitment to training and integration but an ongoing willingness to review the care they provide and serve as a mentor. I have found this to be one of the most rewarding aspects of collaborative practice but cannot deny that to do this well requires an input of real time and energy. A commitment to provide ongoing supervision of care, to enhance opportunities for learning and professional growth, and to consistently be available to address questions or concerns is, I believe, fundamental to a long-term successful relationship

While a collaborative approach to practice will not appeal to all, as the demand for care increases and the financial pressures for efficient and effective service intensify, rheumatologists working collaboratively with nurse practitioners and physician assistants have real opportunities to build rewarding relationships. It has been my experience that practicing rheumatology with a midlevel practitioner can improve access to care, enhance patient satisfaction and clinical outcomes, and at the same time expand productivity and secure financial success. **NCMJ**

COMMENTARY

The Johnston County Osteoarthritis Project:

An Illustration of a Community-University Partnership for Population-Based Research

Edwin L. Hartman, MD; Janice Woodard, BS; Carol Patterson, MA; Joanne M. Jordan, MD, MPH

Community-based participatory research has been defined as "an approach to health and environmental research meant to increase the values of studies for both researchers and the community being studied."[1] This cooperative approach to research continues to gain recognition and popularity and has particular potential for the future of epidemiological studies.[2] Investigators from the University of North Carolina at Chapel Hill (UNC) and residents in Johnston County, North Carolina have worked together in and benefited from community-focused research for over 23 years. This partnership was an early adopter of the community-based approach to research through formation of the Rural Health Research collaboration, just the beginning of many "firsts" for this partnership.

> *"In order to foster and maintain long-standing grassroots support for the work of Rural Health Research, it is critical for residents to feel that Rural Health Research is serving the interests and needs of the county. In keeping with this, it has been our long-standing philosophy and policy to give back to the community."*

History of Rural Health Research

Rural Health Research is a community-based, university-affiliated research center in Johnston County, a mostly rural county in eastern North Carolina. Preliminary work in the community by UNC investigators began in the late 1970s. A multidisciplinary group of researchers came together with Johnston County residents to develop an ongoing research presence in the county. The participants included the directors of the Thurston Arthritis Research Center, the Center for Health Promotion and Disease Prevention, the Injury Prevention Research Center, and the Cecil G. Sheps Center for Health Services Research. The office of the Vice Chancellor for Health Affairs also provided vitally important input and support. Local

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advisers and participants have included lay and professional community leaders, state and national government officials, county managers, education superintendents, hospital and county health department personnel, and nonprofessional constituents with an interest in health issues.

A critical next step toward the establishment of this endeavor as a local entity came with an award from the Centers for Disease Control and Prevention to the UNC Health Promotion and Disease Prevention Center in 1987. This enabled Rural Health Research to incorporate and open a local research field office in Johnston County, directed and staffed by Johnston County residents. In order to determine the interests of the people in the county, 65 focus groups were held throughout the county with broad representation by race, gender, and age (ranging from 45 to 54 years, 55 to 64 years, and 65 years and older). The medical community was involved and kept informed through a local medical liaison, and awareness of Rural Health Research and its goals was increased through presentations given by the researchers to the county medical society in a meeting held at Johnston Memorial Hospital.

Over the years community-based research has flourished in Johnston County. Rural Health Research benefits from dedicated local volunteers who bring vitality and support to the studies. Local participants are involved in helping to map and enumerate streets for statistical sampling, assisting with project management duties both in and out of the Johnston County office, and serving as key study ambassadors to the county and other local organizations. In 2002 an adjoining research clinic was opened, including a fully-functional radiology suite, a bone density/body composition suite, facilities for phlebotomy and frozen storage of specimens, and multiple examination rooms.

Currently, the local staff includes 9 full-time employees, all Johnston County residents, including the director, administrative assistant, interviewers, data collectors, radiology technologist, and phlebotomist, and a cadre of fully-trained part-time and intermittent employees available for substudies and other tasks as necessary.

Over the years, Rural Health Research has been the site of studies in injury prevention, health care access and utilization, cardiovascular disease, nutrition, and dizziness and physical activity in frail elders. Arthritis and disability have been the primary focus of Rural Health Research since 1990, with over 25 studies conducted. (See Figure 1.) The first of these began in 1985 with an award from the National Institute of Arthritis and Musculoskeletal and Skin Diseases to the Thurston Arthritis Research Center to evaluate the reliability and validity of selected arthritis psychosocial measures used to assess arthritis beliefs, self-care practices, use of health services, and psychosocial health status of lower-income African American and white residents. This study provided the foundation for all subsequent research carried out in Johnston County.

A prospective cohort of osteoarthritis of the knee and hip in Johnston County, known as the Johnston County Osteoarthritis Project, has received continuous funding by the Centers for Disease Control and Prevention since 1990 (recently renewed through 2010) and by the National Institutes of Health since 1993. This study has facilitated the development of additional projects funded by multiple federal agencies, foundations, private philanthropic sources, and industry groups. (See Figure1.) The scope of these studies ranges from the biomedical (eg, development and validation of serum and urine biomarkers of joint metabolism, proteomics, metabolomics, and, most recently, genome-wide association studies) to the psychosocial (eg, the role of psychiatric comorbidity in the pain and disability of arthritis, individual and community social determinants of arthritis outcome, and spirituality). The Johnston County Osteoarthritis Project has been a part of research studies with investigators throughout the nation and the world. Collaboration has served not only to advance science but also to support the continued work of Rural Health Research which would be impossible without the financial backing of numerous investigations.

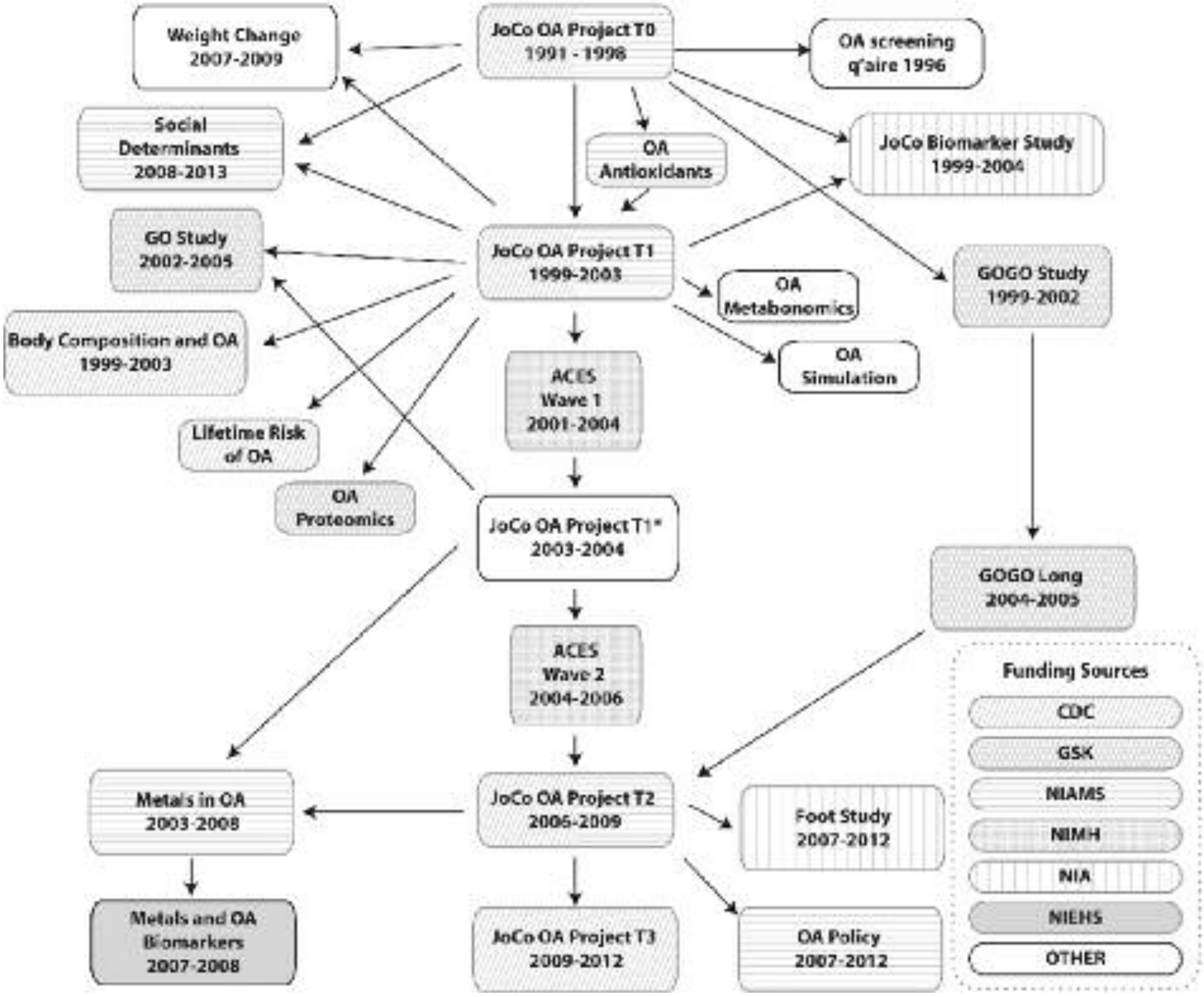
The Johnston County Osteoarthritis Project has contributed other notable "firsts." It was the first longitudinal study of osteoarthritis to include African Americans and it remains the only such study in a rural setting. The study revealed early on that osteoarthritis and its resultant disability were more common than expected.[3-6] Pursuing an explanation for this observation led to the examination of data on overweight and obesity in the study group.[7,8] The Johnston County Osteoarthritis Project also revealed that African Americans were not spared from hip osteoarthritis as had generally been thought.[9,10]

With this history of pioneering into new areas, this study is the largest biracial population-based study to describe associations between radiographic osteoarthritis and osteoarthritis biomarkers and blood and urine markers of the osteoarthritis disease process. It also is the first to recognize that values of these markers, and factors associated with them, varied by gender and racial groups.[11-14] Recognizing that the experience of osteoarthritis has significant psychosocial consequences, the Johnston County Osteoarthritis Project partnered with the Arthritis, Coping and Emotions study to generate one of the largest psychosocial databases for an osteoarthritis cohort of African Americans and Caucasians in the world.[15,16]

Research into the role common environmental exposures play in osteoarthritis over a lifetime produced preliminary results showing that higher blood lead levels are associated with more severe osteoarthritis,[17] and low selenium levels are also associated with osteoarthritis presence and severity.[18,19] The examination of selenium and osteoarthritis was suggested by studies of Kashin-Beck Disease, an endemic osteoarthropathy in China associated with low selenium levels in the soil among other things.[20] The Johnston County analysis was the first large epidemiologic investigation into this relationship in a Western population. These observations have given birth to a new interdisciplinary field of "environmental rheumatology" currently being developed at the Thurston Arthritis Research Center at UNC.

Today, the community connection for the Johnston County Osteoarthritis Project and Rural Health Research remains alive and strong. As one county staff person said, "What impressed me the most about this study was that it came to the community. It

Figure 1.
The Johnston County Osteoarthritis Project and Related Studies



Legend:
JoCo OA Project = Johnston County Osteoarthritis Project
OA screening q'aire = Osteoarthritis screening questionnaire
GO Study = Genetics of Osteoarthritis Study
ACES = Arthritis, Coping, and Emotions Study
GOGO = Genetics of Generalized Osteoarthritis Study
GOGO Long = Genetics of Generalized Osteoarthritis Study, Longitudinal Follow-up
CDC = Centers for Disease Control and Prevention
GSK = GlaxoSmithKline
NIAMS = National Institute of Arthritis, Musculoskeletal, and Skin Diseases
NIMH = National Institute of Mental Health
NIA = National Institute on Aging
NIEHS = National Institute of Environmental Health Science

was more accessible to people who would not have had such an opportunity if they were required to travel. As an interviewer I see how participants begin to think about their arthritis perhaps in new ways as they have the chance to talk about their experiences with us. I think it has to make a positive difference for these people in our community." As the concept of community-based research has evolved to embrace more of the social impact of disease and public health, the Johnston County Osteoarthritis Project has collaborated with other researchers interested in the individual and community social determinants of health and disease.

Giving Back to the Community

In order to foster and maintain long-standing grassroots support for the work of Rural Health Research, it is critical for residents to feel that Rural Health Research is serving the interests and needs of the county. In keeping with this, it has been our long-standing philosophy and policy to give back to the community. This takes many forms. For example, all local employees receive considerable and continuing education in methods of field research, and full-time employees become permanent employees of UNC with its attendant benefits. As much as is possible, we utilize and support local businesses for the work of the center. In addition, the Thurston Arthritis Research Center publishes an annual newsletter in Johnston County (*Johnston County Osteoarthritis Project Update*), and UNC and local colleagues give talks to local groups (eg, Smithfield Veterans of Foreign Wars, Kiwanis, Rotary, Lions Club, Civitan, Johnston Memorial Hospital) to keep the 2-way flow of information active. Project participants receive regular study updates and are invited to open houses in which they have an opportunity to meet with research staff and UNC faculty to learn about arthritis and the progress of the many studies ongoing in the center.

Rural Health Research is a member of the Chamber of Commerce, the Human Services Council, and other local groups. Each year for the past 20 years, the Rural Health Research director has attended the Chamber of Commerce Washington Issues Seminar in Washington, DC. This meeting is sponsored by North Carolina's US senators and representatives and is attended by state representatives, mayors, town managers, other Chambers of Commerce members throughout the state, national representatives and senators, and other national government officials. It is a highly effective forum for bringing local issues to the attention of elected officials in Congress. We have been able to increase awareness of arthritis and disability issues, inform officials about research studies underway in the county, and advance the mission of Rural Health Research as well as the community-based research role of UNC among these representatives and other government officials. **NCMJ**

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Manpower Shortage in Rheumatology

Gregory F. Schimizzi, MD

Several articles have appeared in the literature regarding the looming shortage of various specialties.[1-5] It is surprising that some of the projected shortages in professional manpower include highly visible specialties such as neurosurgery, cardiology, and pediatrics. While shortages in these specialties are a newly recognized problem, a decline in rheumatology manpower has been expected for many years despite an increase in demand for services. The number of fellows in rheumatology has been steadily declining since 1995. In a survey and analysis of manpower in rheumatology done in 2000, the American College of Rheumatology projected a steady decline in the number of clinical rheumatologists until the year 2030.[6] For the year 2010, the needs estimate for rheumatologists is 7500 physicians. The current number of practicing rheumatologists is 2200, and the projected number of practicing rheumatologists for the year 2010 based on new fellows entering practice and those rheumatologists leaving the field is estimated to be 2500.[6]

As the population of the United States ages, there has been an expected increase in the number of people afflicted with arthritis. The Centers for Disease Control and Prevention recently announced that according to their most recent data over 46 million Americans are afflicted with arthritic diseases which are the most frequently occurring chronic illnesses. Arthritic diseases of all types are the leading cause of disability in our country. Rheumatoid arthritis alone affects 1 in 200 Americans and costs the United States approximately $80 to $85 billion dollars per year. It has been projected that by the year 2030 an estimated 67 million Americans will be affected by chronic arthritic diseases.[7]

Ask any rheumatologist or medical group about the difficulty of recruiting a new physician in rheumatology, and you will likely get the same answer from coast to coast. In an era of new and promising therapies and with an increasing number of patients in need of rheumatology care, it seems counterintuitive that a decline in manpower is upon us in this field. But the reasons for our predicament are not as simple or straightforward as one might think. A detailed study commissioned by the American College of Rheumatology and published earlier this year enumerated and analyzed causes for the manpower crisis in rheumatology. According to this report, factors affecting the manpower crisis in rheumatology include technological advances, limited advances in practice design and organization, minimal increases in training positions, changes in population characteristics, low reimbursement rates, and workload capacity changes.[6]

> *"In an era of new and promising therapies and with an increasing number of patients in need of rheumatology care, it seems counterintuitive that a decline in manpower is upon us in this field."*

Technological Advances

An increase in technological sophistication has occurred in the practice of rheumatology just as in other fields of medicine. This technology is very costly and has added to other cost centers (eg, malpractice rates, insurance costs, labor costs, increased costs due to workload) which are contributing to a rapid rise in overhead expenses. The American Medical Association has estimated that in the same years that the Medicare Modernization Act 2003 mandates drastic reductions in physician reimbursements there will be a 25% increase in overhead expenses for physicians.

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Practice Design and Organization

There has been little change in practice organization and efficiency in delivering rheumatologic care. Utilization of family nurse practioners and physician assistants has not increased dramatically over the last decade. This may in part be due to the nature of the specialty. Adoption of electronic medical records systems has been very slow in rheumatology possibly due to the complicated nature of the subspecialty as well as the associated expenses. Furthermore, a high energy of initial activation is associated with electronic medical records, and rheumatologists may not be interested in investing their time or financial resources to install an expensive system when retirement may be only a few years away.

Training Positions

The number of new fellowship-trained rheumatology positions has not kept pace with the demand for rheumatologists over the last 1 to 2 decades relative to the number of older physicians leaving the field and the demand for services. Physicians leave rheumatology primarily due to retirement or death. A few rheumatologists leave active rheumatology practices to accept industry positions. The average age of rheumatologists is approximately 57 years of age. The median age for rheumatologists is 53 years for male physicians in adult rheumatology and 46 years for the female physicians. For pediatric rheumatology the median ages are 51 years and 47 years respectively. There are 378 adult rheumatology fellowship training positions in 105 programs in this country and the fill rate for these positions was about 88% in 2004-2005.

One of the reasons for the reduced supply of new rheumatologists as well as other specialties can be traced back to several previously published reports such as the Graduate Medical Education National Advisory Committee's 1981 recommendation to reduce the number of medical schools and medical school positions based upon forecasts for a 23% surplus of physicians (approximately 145 000) by the year 2000. In response to this and other similar reports, Congress reduced support for medical school education.

Changes in Population Characteristics

Demand for rheumatology services is increasing due to the aging of our population, the increased sophistication of the populace, and the rise in per capita gross domestic product. Richard Cooper and his colleagues observed a strong correlation between the size of the economy measured in gross national product per capita and the demand for specialty physician services. Cooper argued this correlation was indicative of a pending increase in the demand for health care services to the extent that a physician shortage of 50 000 physicians would occur by 2010.

Reimbursement Rates

Reimbursements for rheumatology services have historically been the lowest of all subspecialties. This began to change in 1998 with the introduction of more sophisticated and complex services provided by rheumatologists in their offices. Despite the fact that reimbursements for rheumatology services increased 28% between 1998 and 2002, reimbursements are on the decline again after passage of the Medicare Modernization Act in 2003 and recent changes in reimbursement for ancillary services. These latest changes make rheumatology a less attractive field to prospective fellows. This is especially true for those who have accumulated large loans during their education and training.

Maximal Workload Capacity Changes Among Rheumatologists

Workload capacities for rheumatologists vary with age and sex of the practitioner. Female rheumatologists (whose numbers have been increasing) tend to see fewer patients than male rheumatologists at all ages. Females have peak workload capacities when they are between 40 and 49 years of age. Male rheumatologists have a peak workload capacity between the ages of 50 and 59 years. To some extent, the increase in the number of female fellows entering practices in rheumatology will accentuate the shortage of rheumatology supply.

Solutions

The remedies for the shortage of rheumatologists will not be easily implemented and likely will not be rapidly achieved. Four possible solutions are outlined here.

(1) It will be necessary to increase the number of fellowship positions or add new rheumatology programs. Finding funding for expanding programs will be difficult in times of overall health care cutbacks and without a will on the part of government to not only recognize the problems facing rheumatology and other specialties but to act upon the problems in a meaningful way.
(2) Adoption of newer technologies and/or increased use of physician extenders in the practice of rheumatology will help improve efficiency and increase practice visit capacities.
(3) Inherent in adopting more widespread use of physician extenders there will need to be a commensurate increase in the number of training programs for these professionals.
(4) There must be a concerted effort to advocate for medical liability reform, fair reimbursements, and removal of clerical workloads in an attempt to improve patient access to care while reducing overhead costs that accompany excessive interferences from multiple sources. Reduction of costs and fair reimbursements for services will create an incentive for younger physicians and trainees to consider rheumatology.

The goal of any resolution to a potential shortfall in physicians in any subspecialty should include, above all else, a desire to deliver the highest quality care possible to our patients as efficiently as possible with the best choice of therapies available based on medical evidence. No solution should occur at the expense of continued efforts to find cures for these diseases that disfigure and deform. Treatment must be continued since inadequate or delayed treatment of arthritic diseases not only decrease the quality of life for millions of our patients but also creates hardship for families and late complications that will increase disease management costs. We must never forget that mortality is also increased in many of these patients, and this may be even more significant in those patients who are inadequately treated. **NCMJ**

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North Carolina
MEDICAL JOURNAL

Spotlight on the Safety Net

A Community Collaboration

Kimberly M. Alexander-Bratcher, MPH

Community Health Centers

> *Across North Carolina, communities have come together to form nonprofit health centers governed by the people that use them. For over 30 years these community health centers have ensured that no one is left without a place to turn to when they are in need of medical care, regardless of their ability to pay. The focus of community health centers is quality and comprehensive primary care with a strong emphasis on disease prevention and health maintenance.*[1]

What Is a Community Health Center?

Federally qualified health centers, also known as community health centers, are public or private nonprofit, charitable, tax-exempt organizations. They receive funding from the Public Health Service Act or are deemed by the US Department of Health and Human Services to meet requirements to receive funding without actually receiving a grant. They serve medically underserved areas and are governed by a board whose majority must be users of the center's services and representative of the service area's demographics. They provide, either directly or by contract, a comprehensive scope of preventative and primary health services including translation, transportation, and other support services regardless of the ability to pay. Community health centers have a schedule of charges designed to cover the reasonable costs of operation and consistent with locally prevailing rates that are adjusted based on a patient's income and family size.

Community health centers facilitate access to comprehensive health and social services including outreach, transportation, interpretive, and case management services; services to assist the health center's patients gain financial support for health and social services; referrals to other providers of medical and health-related services; and substance abuse and mental health services.

Community health centers assess the full health care needs of their target populations, form a comprehensive system of care incorporating appropriate health and social services, manage the care of their patients throughout the system, and maintain ongoing referral arrangements with one or more hospitals. Clinicians have admitting privileges and hospital staff membership at their referral hospital(s).

They assure quality special medical, diagnostic, and therapeutic services are available to patients through a system of organized referral arrangements. Community health centers form or join integrated delivery systems and provide comprehensive and continuous care including hours in which the health center is closed. They also educate patients and the community regarding the availability and appropriate use of health services.

Table 1.
Federally Mandated Services Provided by Community Health Centers

Primary medical care
Diagnostic laboratory and radiological services
Preventive Services
- Prenatal
- Perinatal
- Well child

Cancer and other disease screening
Immunizations
Screening for hazards
- Elevated blood levels
- Communicable diseases
- Cholesterol
- Eye, ear, and dental screening for children

Family planning services
Preventive dental services
Emergency medical and dental services
Pharmaceutical services

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Current Statistics

North Carolina's community health centers are comprised of 26 health center grantees, 1 migrant voucher program, 104 clinical services sites, 20 migrant voucher program sites, 7 migrant health center grantees, 3 healthy schools/healthy community grantees, 4 homeless health care grantees, and 2 federally qualified health center look-alike organizations with 6 clinical service sites. In 2006 there were 139 physicians, 80 nurse practitioners and physician assistants, 311 nurses and other medical personnel, and 42 dentists working at community health centers statewide. Those providers saw 333 283 patients for 1 109 600 patient visits. Of those patients, 52% were uninsured, 22% receive Medicaid, 71% live below the 200% of the federal poverty guidelines, and 54% live below 100% of the federal poverty guidelines. There were also 56 585 migrant and seasonal agricultural workers who received services.[2]

Within the past 5 year, community health center patients increased by 36%, patient visits increased by 36%, and uninsured patients increased by 53%. These programs prove to be extremely cost effective by serving these patients for just over $1 per day per patient. North Carolina's community health centers also create jobs and an economic base. They employ more than 1692 full-time employees.[2]

North Carolina Community Health Center Association

Alone, community health centers would struggle for resources, training, and a medium to express their concerns. Collectively, health centers have banded together to secure their common mission through the North Carolina Community Health Center Association (formerly known as the North Carolina Primary Health Care Association).

The NC Community Health Center Association was created in 1978 so that health centers across the state would have a collective voice and representation at the federal, state, and local levels. The NC Community Health Center Association also seeks support from foundations, corporations, and other private entities to increase the access of primary health care to all North Carolinians. Its staff serves on state and national coalitions and task forces to foster collaboration, leverage resources, and avoid duplication of services.

The NC Community Health Center Association is a valuable resource to health centers, providing training and technical assistance in areas such as clinical service delivery, governance, workforce development, and administration. It regularly presents workshops, trainings, and conferences to keep health center staff on the cutting edge of effective and cost-efficient service delivery. The NC Community Health Center Association consistently analyzes key issues facing health centers and provides members with critical information in a timely fashion and helps communities to create new health centers or expand existing ones.

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Running the Numbers

A Periodic Feature to Inform North Carolina Health Care Professionals
About Current Topics in Health Statistics

From the State Center for Health Statistics, NC Department of Health and Human Services
http://www.schs.state.nc.us/SCHS

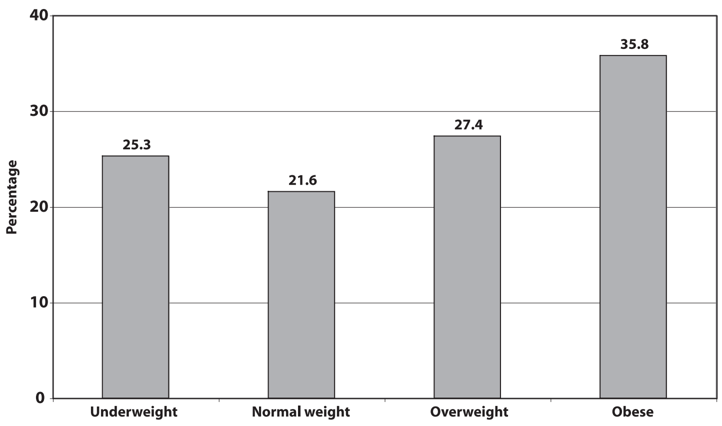
Arthritis Prevalence and Risk Factors in North Carolina

Arthritis is one of the most common chronic diseases and is the leading cause of disability in the United States.[1] Arthritis refers to more than 100 different conditions affecting the joints, surrounding tissues, and other connective tissues. Several common forms of arthritis are gout, osteoarthritis, rheumatoid arthritis, and juvenile arthritis. People with these diseases experience pain, stiffness, and/or limitation of motion. The cause of most types of arthritis is unknown.

The number of adults in North Carolina in 2005 with doctor-diagnosed arthritis (diagnosed by a physician or other health professional) is estimated at 1 754 000; this number is projected to increase to 2 761 000 in 2030.[2] In 2005, there were an estimated 681 000 adults in North Carolina with arthritis-attributable activity limitation.[2] While arthritis is not a leading cause of death in North Carolina, it is an important cause of hospitalization. In 2005 in North Carolina, there were 23 921 hospital discharges with a principal diagnosis of arthropathies (joint diseases) and related disorders (ICD-9-CM codes 710-719). The average length of stay for these hospitalizations was 4.1 days and the associated hospital charges were $675 748 000. Approximately 90% of these charges resulted from hospitalizations with a principal diagnosis of osteoarthritis (degenerative joint disease).

The Behavioral Risk Factor Surveillance System (BRFSS) is a random telephone survey of adults (aged 18 years and older) that collects information on health conditions, health risk factors, and use of health services. It is conducted in all US states and the data are self-reported. In the 2005 North Carolina BRFSS, a number of questions related to arthritis were asked of more than 17 000 adult respondents. According to the 2005 BRFSS, 38.4% of adults in North Carolina had symptoms of pain, aching, or stiffness in or around a joint in the past 30 days. Of these adults whose joint symptoms began more than 3 months earlier, 74.4% had ever seen a doctor or other health professional for their joint symptoms. And 33.0% were limited in any of their usual activities because of their joint symptoms.

Figure 1.
Percentage of Adults With Doctor-Diagnosed Arthritis by Weight Categories, 2005 North Carolina BRFSS



In 2005, 27.3% of adults in North Carolina had doctor-diagnosed arthritis, an increase from 24.8% in 2000. North Carolina's rate was slightly above the 2005 US average of 26.9%. Table 1 shows the 2005 prevalence of self-reported doctor-diagnosed arthritis in North Carolina by selected respondent characteristics. Prevalence is higher among females, American Indians, non-Hispanics, older adults, adults with lower education and income, adults who report a disability, veterans, and adults who report having diabetes or asthma. Figures 1 and 2 show the association of doctor-diagnosed arthritis prevalence with body mass

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index and level of physical activity. Obese adults have a higher rate of arthritis as do adults with lower levels of physical activity.

Figure 3 indicates that adults with doctor-diagnosed arthritis are much more likely than adults without arthritis to report their health as fair or poor and much less likely to report their health as very good or excellent. This association may be partly because adults with arthritis are older and thus have a higher rate of other health problems, too.

The associations shown here do not indicate cause and effect. For example, veterans may have a higher rate of arthritis in part because they are much older on average than other North Carolina adults. Hispanics in North Carolina who speak primarily Spanish are much younger than average and also much less likely than other population groups to have health insurance or a personal doctor, which reduces the chance for a diagnosis. Though physical activity can maintain joint health and reduce the risk of arthritis, the presence of arthritis may lead to lower levels of physical activity. The data shown in this report do indicate population subgroups that can be targeted by arthritis prevention and management programs.

Figure 2.
Percentage of Adults With Doctor-Diagnosed Arthritis by Level of Physical Activity, 2005 North Carolina BRFSS

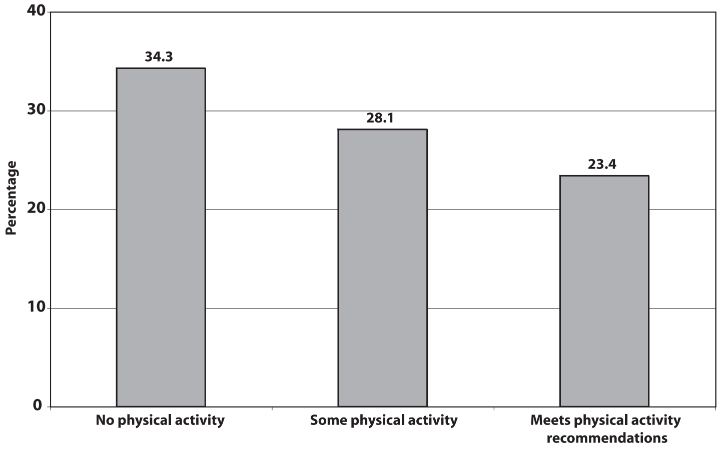

Figure 3.
Percentage of Adults Who Reported That Their Health Was Excellent, Very Good, Good, Fair, or Poor, by Presence/Absence of Doctor-Diagnosed Arthritis, 2005 North Carolina BRFSS

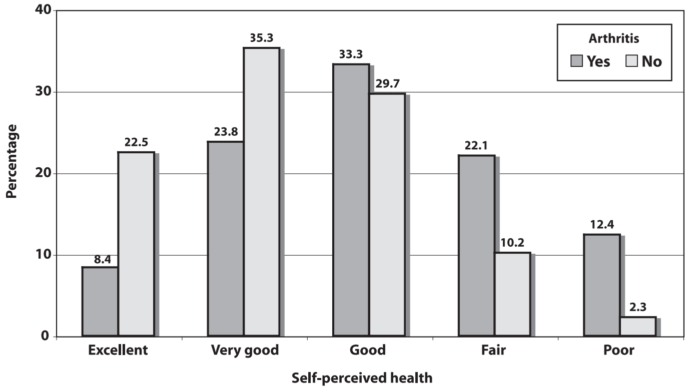

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Table 1.
Percentage of Adults Reporting Doctor-Diagnosed Arthritis by Selected Respondent Characteristics, 2005 North Carolina BRFSS

Characteristic	Percent	Characteristic	Percent
Total Population	27.3	**Education**	
Gender		Less than high school	31.8
Male	22.7	High school or GED	30.2
Female	31.7	Some post high school	27.6
Race		College graduate	21.4
White	29.2	**Household Income**	
African American	27.5	Less than $15 000	38.7
Asian	9.9	$15 000 - $24 999	28.1
American Indian	40.3	$25 000 - $34 999	29.1
Other minorities	7.8	$35 000 - $49 999	25.5
Ethnicity		$50 000 - $74 999	23.5
English-speaking Hispanic	23.8	$75 000+	20.9
Spanish-speaking Hispanic	3.8	**Disability**	
Non-Hispanic	29.2	Yes	52.8
Age (years)		No	18.0
18-24	5.5	**Veteran**	
25-34	9.7	Yes	36.3
35-44	16.2	No	26.0
45-54	33.0	**Diabetes**	
55-64	46.3	Yes	54.6
65-74	55.5	No	24.6
75+	59.0	**Asthma**	
		Yes	43.1
		No	26.2

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Contributed by Paul A. Buescher, PhD,
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Hospital Quality and Patient Safety

Notable News from The North Carolina Center for Hospital Quality and Patient Safety

North Carolina Center for Hospital Quality and Patient Safety

The North Carolina Surgical Care Improvement Project

Substantial variations in the rates of surgery and outcomes of surgical care are well demonstrated.[1] Failure to apply standards of care known to prevent adverse events results in harm to the patient. Research shows that a significant percentage of the 30 million operations performed in the United States each year result in preventable, often life-threatening, complications.

The 1999 Institute of Medicine of the National Academies report *To Err is Human* highlighted a study from a large medical center which found that 5.4% of 44 000 patients who underwent surgery suffered complications; nearly one-half of those complications were attributed to error.[2] Therefore, with 30 million surgical procedures performed each year in the United States, an estimated 1.6 million patients suffer complications as a result of surgical care. In North Carolina alone, 221 326 nonobstretical operations at nonfederal acute care hospitals were performed in fiscal year 2005[3] and if the proportions from the national study hold, approximately 12 000 patients may have suffered surgical complications.

Surgical site infections and cardiovascular, respiratory, and thrombolic complications represent some of the most common postoperative problems. Despite an abundance of scientific knowledge in the medical literature providing evidence-based guidance for prevention of many of these complications, there is substantial evidence that these standards aren't applied reliably in health care today.[4]

As stated in the 2001 Institute of Medicine Report *Crossing the Quality Chasm*, "Between the healthcare we have and the care we could have lies not just a gap, but a chasm."[5] For example, evidence that properly timed antimicrobial prophylaxis is effective has existed for more than 30 years. However, only 56% of Medicare patients received prophylaxis within the appropriate time frame.[6]

Patients who experience postoperative complications have increased lengths of hospital stay, increased readmission rates, and increased mortality.[7,8,9] Recently a number of successful projects have shown that implementation of evidence-based practices can have a significant impact on surgical complications.[10] As a result, over 30 national organizations, including the Centers for Medicare and Medicaid, Centers for Disease Control and Prevention, Department of Veterans Affairs, American College of Surgeons, American Hospital Association, Institute for Healthcare Improvement, and the Joint Commission have aligned efforts aimed at reducing surgical complications and mortality. This collaboration is called the Surgical Care Improvement Project (SCIP).[11]

The Surgical Care Improvement Project is a national quality partnership committed to improving the safety of surgical care through the reduction of postoperative complications. Launched in 2005, the goal of SCIP is to reduce the incidence of surgical complications 25% by the year 2010. The Surgical Care Improvement Project identifies evidence-based processes of care related to prevention of cardiovascular events, surgical site infections, postoperative pneumonia, and venous thromboembolism.[12] (See Table 1.)

In North Carolina, 48 hospitals are working together to improve surgical care processes by participating in the NC SCIP collaborative. These hospitals are committed to reducing complications associated with surgical care; through collaborative participation, they will design systems to reliably implement the care processes of SCIP. In August the 160 hospital representatives came together in Chapel Hill to learn about the SCIP network, share best practices, and begin the work of designing reliable processes of care related to SCIP.

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Table 1.
NC SCIP Process of Care Measures

Prevention of infection	Prophylactic antimicrobial initiated 1 hour before surgical incision (2 hours for vancomycin or fluoroquinolone)
	Prophylactic antimicrobial consistent with published guidelines
	Prophylactic antimicrobial discontinued within 24 hours of surgery end time (48 hours for cardiac patients)
	Blood glucose control in patients undergoing cardiac surgery
	Proper hair removal
	Maintenance of normothermia in colorectal surgery patients
Prevention of venous thromboembolism (VTE)	VTE prophylaxis ordered consistent with current guidelines
	Appropriate VTE prophylaxis administered within 24 hours before and after
Prevention of cardiac events	Administration of peri-operative β-blockers to patients on β-blockers prior to admission

The North Carolina Surgical Care Improvement Project collaborative is led in partnership by the North Carolina Center for Hospital Quality and Patient Safety, the Carolinas Center for Medical Excellence, and the North Carolina Chapter of the American College of Surgeons. Participating hospitals receive consultative support and secure online data collection tools and reports from the partners in addition to networking meetings, teleconferences, and other resources. The North Carolina Area Health Education Centers Program and the Southern Atlantic Healthcare Alliance provide additional support by coaching collaborative hospitals.

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North Carolina Center for Hospital Quality and Patient Safety, Carol Koeble, MD, MS, CPE, Director
PO Box 4449, Cary, NC 27519-4449, 919-677-2400, www.ncha.org/ncchqps

Thanks from the *North Carolina Medical Journal*

Without the voluntary assistance and carefully executed reviews of a number of anonymous reviewers, no journal can offer the kind of peer-review for submitted manuscripts that can assure its readers the highest quality of published articles. We are fortunate for the service of a number of individuals who have given generously of their time and expertise in service to the *North Carolina Medical Journal* this past year, and we are pleased to have this annual opportunity to acknowledge their efforts.

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Marking A Milestone

Highlighting a long-term commitment to improving health care services for North Carolina communities and citizens

A Milestone in Arthritis Care
Alvin Daughtridge

Alvin Daughtridge always held the philosophy that businesses and communities flourish if relationships are built on integrity, cooperation, and trust. According to Daughtridge, "When people park their ego at the door and engage in face-to-face dialogue, problems frequently become opportunities and win-win solutions emerge." In 1999, while serving on the boards of both the Thurston Arthritis Research Center at the University of North Carolina at Chapel Hill (UNC) and Caldwell Memorial Hospital in Lenoir, North Carolina, the vice president of Fairfield Chair Company and life-long community advocate saw an opportunity to put his philosophy into action.

Recognizing the need for Caldwell Memorial to add more specialists at the same time the Arthritis Center was looking for opportunities to expand its outreach efforts across the state, Daughtridge immediately began work to build just such a win-win partnership between the two entities. He knew, however, that opportunity does not always result in success. The newly formed partnership would need to show a strong return on investment in order to succeed and thrive in the long term. To help accomplish that, Daughtridge worked closely with Thurston and Caldwell Memorial to ensure arthritis care would be provided in the area and that the area primary care physicians would offer referrals.

His efforts paid off. In 2001, a new clinic opened its doors and was named the Alvin W. Daughtridge Arthritis Clinic in honor of his vision. Dr John Winfield, retired founding director of Thurston Arthritis Research Center and rheumatologist at the clinic, says, "Alvin was instrumental to bringing arthritis care to Caldwell County and has continued to be a staunch supporter of arthritis research. Alvin has been active in arthritis care and research for many years and the dedication of the arthritis clinic in his name was a much deserved tribute to his efforts." The clinic quickly grew from a 1 to 2 day a month operation to 3 days a week. It also expanded from clinical care to a site location for drug studies and grand rounds.

"I can personally attest that Alvin's efforts have resulted in greater access to improved arthritis care for Caldwell County residents," says Dr Winfield. Daughtridge, a man well-known for his gentle and humble nature, is quick to deflect the credit and offers his own praise of Dr Winfield. "John's effectiveness with his patients is outstanding," he says. "He has made a marvelous difference in the lives of arthritis patients here in Caldwell County."

Throughout his life, Daughtridge has been a tireless community volunteer and advocate in multiple areas including health, business, and education. He has served on the boards of Caldwell County's Cancer Society, Red Cross, and Board of Health and as chairman of the Caldwell County Blood Mobile. He is a former president of the Lenoir/Caldwell Chamber of Commerce and a member of the Lenoir Jaycees, the American Furniture Manufacturer's Association, and the Furniture Shippers Association. A former Caldwell Community College and Technical Institute board member, he has served on the Caldwell Schools Career Center Advisory Council and the Planning Team. Founding chair of Communities in Schools of Caldwell County, other educational endeavors include work with the King Creek Parent Teacher Association, Communities in Smart Start Program, Children's Advocacy Council, and Preschool Interagency Council. Additional civic activities include Caldwell County's United Way, Planning Board, and City/County Services Committee, and the Lenoir Recreation Commission. A member of the Caldwell Baptist Association, Daughtridge is a deacon and Sunday school teacher at Lenoir First Baptist Church.

Daughtridge has described the clinic as a "godsend" to the people of Caldwell County. He was perhaps most pleased, however, to see his philosophy of win-win relationships between business and community come to fruition. "Because of the clinic, more people in North Carolina became aware of the University of North Carolina at Chapel Hill and its arthritis expertise through the Thurston Arthritis Research Center," he said. Dr Joanne Jordan, director of Thurston and chief of the Division of Rheumatology, Allergy, and Immunology at the UNC School of Medicine, says, "Every member of the Thurston staff works to ensure better arthritis care and improved outcomes for the people of North Carolina. We thank community advocates like Alvin Daughtridge who make such efforts possible."

Contributions from Randall Mounce, Thurston Arthritis Research Center, the University of North Carolina at Chapel Hill.

Classified Ads

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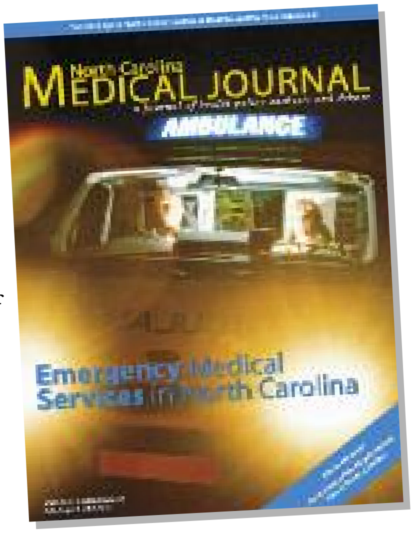
Readers' Forum

To the Editor:



I was delighted to see the research article in your July/August issue on "Awareness of the Bicycle Helmet Law in North Carolina." Hopefully, it will serve as a reminder to the primary care providers in your readership that a little guidance to children and parents alike on the efficacy of helmets can save lives and reduce serious injuries.

Interestingly, the authors seem more pessimistic about compliance with the law than those of us on the NC Child Fatality Task Force who pushed for passage of the law in 2000-2001. The authors seem disappointed that regular helmet use in Pitt County increased in the 5 years after passage from less than 10% just before passage to 40%. Though much more improvement is needed, those of us involved with children's safety issues are encouraged by this significant increase in helmet use, especially since the law does not require those age 16 and older to wear helmets. Thus, parents often are not the role models they need to be.

While acknowledging the limitations of a one-county study, the authors neglect to present statewide data on the measure of greatest importance to the Task Force: bicycle-related deaths in children. In the 6 years prior to consideration and passage of the law (1994-1999) there were 71 bicycle-related deaths among children in North Carolina. In the 6 years since then (2000-2005), there were 43. That's a remarkable 40% reduction in such deaths. Given that the number of children has been increasing each year, it is likely that the death rate has dropped by almost half!

While these data are particularly encouraging, the research article makes it clear that we have a long way to go. Raising awareness is critical. Let's hope the article does just that.

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To the Editor:

Concern has been raised recently by both consumers and physicians about the safety of drugs and implants after release to the market and the widespread television advertising of these new medications and devices. These two issues are important and closely interrelated. Last year, the Institute of Medicine of the National Academies issued a report calling for the Food and Drug Administration (FDA) to increase vigilance for possible drug complications after release. This report also recommended that direct marketing of a new medication to consumers should be restricted for two years after release of the new drug.

There has been an explosion of new and expensive technology in total hip and knee replacement devices. With the increasing prevalence of arthritis in the maturing baby-boomer generation, the orthopaedic device companies have also increased direct marketing of joint replacement products to consumers. Some examples include ceramic hip bearings, metal on metal hip resurfacing, rotating plastic knee replacements, knee devices designed for women only, and computer assisted surgery. Obviously, the orthopaedic device companies must be getting a good return for their advertising budgets. However, do consumer-patients truly benefit from this new expensive technology?

At a recent national meeting of orthopaedic surgeons in San Diego, data were presented on all these new devices. There is yet no proven benefit from these new, more expensive devices compared to standard hip and knee implants. Computer-assisted orthopaedic surgery has yet to improve patients' outcomes. The American Academy of Orthopaedic Surgeons, the Hip Society, and the Knee Society have again called on the Centers for Medicare and Medicaid Services to establish a national registry for hip and knee replacements. Such a registry would identify, at an earlier time, problematic or less effective devices. The United States has a much higher rate of revision (redo) hip and knee replacement surgery than other countries such as Canada, Sweden, and Norway, which have such national registries. With patients changing insurance plans and physicians frequently, only a national registry will detect the problematic devices early. At present, patients and

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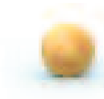

ACIPHEX® \a-sə-ˌfeks
(rabeprazole sodium)
Delayed-Release Tablets

BRIEF SUMMARY
Before prescribing ACIPHEX®, please see full prescribing information.

INDICATIONS AND USAGE
Healing of Erosive or Ulcerative Gastroesophageal Reflux Disease (GERD)
ACIPHEX® is indicated for short-term (4 to 8 weeks) treatment in the healing and symptomatic relief of erosive or ulcerative gastroesophageal reflux disease (GERD). For those patients who have not healed after 8 weeks of treatment, an additional 8-week course of ACIPHEX® may be considered.

Maintenance of Healing of Erosive or Ulcerative Gastroesophageal Reflux Disease (GERD)
ACIPHEX® is indicated for maintaining healing and reduction in relapse rates of heartburn symptoms in patients with erosive or ulcerative gastroesophageal reflux disease (GERD Maintenance). Controlled studies do not extend beyond 12 months.

Treatment of Symptomatic Gastroesophageal Reflux Disease (GERD)
ACIPHEX® is indicated for the treatment of daytime and nighttime heartburn and other symptoms associated with GERD.

Healing of Duodenal Ulcers
ACIPHEX® is indicated for short-term (up to four weeks) treatment in the healing and symptomatic relief of duodenal ulcers. Most patients heal within four weeks.

***Helicobacter pylori* Eradication to Reduce the Risk of Duodenal Ulcer Recurrence**
ACIPHEX® in combination with amoxicillin and clarithromycin as a three drug regimen, is indicated for the treatment of patients with *H. pylori* infection and duodenal ulcer disease (active or history within the past 5 years) to eradicate *H. pylori*. Eradication of *H. pylori* has been shown to reduce the risk of duodenal ulcer recurrence. (See **CLINICAL STUDIES** and **DOSAGE AND ADMINISTRATION** in full prescribing information.)

In patients who fail therapy, susceptibility testing should be done. If resistance to clarithromycin is demonstrated or susceptibility testing is not possible, alternative antimicrobial therapy should be instituted. (See **CLINICAL PHARMACOLOGY, Microbiology** in full prescribing information and the clarithromycin package insert, **CLINICAL PHARMACOLOGY, Microbiology**.)

Treatment of Pathological Hypersecretory Conditions, Including Zollinger-Ellison Syndrome
ACIPHEX® is indicated for the long-term treatment of pathological hypersecretory conditions, including Zollinger-Ellison syndrome.

CONTRAINDICATIONS
Rabeprazole is contraindicated in patients with known hypersensitivity to rabeprazole, substituted benzimidazoles or to any component of the formulation.

Clarithromycin is contraindicated in patients with known hypersensitivity to any macrolide antibiotic.

Concomitant administration of clarithromycin with pimozide and cisapride is contraindicated. There have been post-marketing reports of drug interactions when clarithromycin and/or erythromycin are co-administered with pimozide resulting in cardiac arrhythmias (QT prolongation, ventricular tachycardia, ventricular fibrillation, and torsade de pointes) most likely due to inhibition of hepatic metabolism of pimozide by erythromycin and clarithromycin. Fatalities have been reported. (Please refer to full prescribing information for clarithromycin.)

Amoxicillin is contraindicated in patients with a known hypersensitivity to any penicillin. (Please refer to full prescribing information for amoxicillin.)

WARNINGS
CLARITHROMYCIN SHOULD NOT BE USED IN PREGNANT WOMEN EXCEPT IN CLINICAL CIRCUMSTANCES WHERE NO ALTERNATIVE THERAPY IS APPROPRIATE. If pregnancy occurs while taking clarithromycin, the patient should be apprised of the potential hazard to the fetus. (See **WARNINGS** in prescribing information for clarithromycin.)

Amoxicillin: Serious and occasionally fatal hypersensitivity (anaphylactic) reactions have been reported in patients on penicillin therapy. These reactions are more likely to occur in individuals with a history of penicillin hypersensitivity and/or a history of sensitivity to multiple allergens.

There have been well-documented reports of individuals with a history of penicillin hypersensitivity reactions who have experienced severe hypersensitivity reactions when treated with a cephalosporin. Before initiating therapy with any penicillin, careful inquiry should be made concerning previous hypersensitivity reactions to penicillins, cephalosporins, and other allergens. If an allergic reaction occurs, amoxicillin should be discontinued and the appropriate therapy instituted. (See **WARNINGS** in prescribing information for amoxicillin.)

SERIOUS ANAPHYLACTIC REACTIONS REQUIRE IMMEDIATE EMERGENCY TREATMENT WITH EPINEPHRINE. OXYGEN, INTRAVENOUS STEROIDS, AND AIRWAY MANAGEMENT, INCLUDING INTUBATION, SHOULD ALSO BE ADMINISTERED AS INDICATED.

Pseudomembranous colitis has been reported with nearly all antibacterial agents, including clarithromycin and amoxicillin, and may range in severity from mild to life threatening. Therefore, it is important to consider this diagnosis in patients who present with diarrhea subsequent to the administration of antibacterial agents.

Treatment with antibacterial agents alters the normal flora of the colon and may permit overgrowth of clostridia. Studies indicate that a toxin produced by *Clostridium difficile* is a primary cause of "antibiotic-associated colitis".

After the diagnosis of pseudomembranous colitis has been established, therapeutic measures should be initiated. Mild cases of pseudomembranous colitis usually respond to discontinuation of the drug alone. In moderate to severe cases, consideration should be given to management with fluids and electrolytes, protein supplementation, and treatment with an antibacterial drug clinically effective against *Clostridium difficile colitis*.

PRECAUTIONS
General
Symptomatic response to therapy with rabeprazole does not preclude the presence of gastric malignancy.

Patients with healed GERD were treated for up to 40 months with rabeprazole and monitored with serial gastric biopsies. Patients without *H. pylori* infection (221 of 326 patients) had no clinically important pathologic changes in the gastric mucosa. Patients with *H. pylori* infection at baseline (105 of 326 patients) had mild or moderate inflammation in the gastric body or mild inflammation in the gastric antrum. Patients with mild grades of infection or inflammation in the gastric body tended to change to moderate, whereas those graded moderate at baseline tended to remain stable. Patients with mild grades of infection or inflammation in the gastric antrum tended to remain stable. At baseline 8% of patients had atrophy of glands in the gastric body and 15% had atrophy in the gastric antrum. At endpoint, 15% of patients had atrophy of glands in the gastric body and 11% had atrophy in the gastric antrum. Approximately 4% of patients had intestinal metaplasia at some point during follow-up, but no consistent changes were seen.

Steady state interactions of rabeprazole and warfarin have not been adequately evaluated in patients. There have been reports of increased INR and prothrombin time in patients receiving a proton pump inhibitor and warfarin concomitantly. Increases in INR and prothrombin time may lead to abnormal bleeding and even death. Patients treated with a proton pump inhibitor and warfarin concomitantly may need to be monitored for increases in INR and prothrombin time.

Information for Patients
Patients should be cautioned that ACIPHEX® delayed-release tablets should be swallowed whole. The tablets should not be chewed, crushed, or split. ACIPHEX® can be taken with or without food.

Drug Interactions
Rabeprazole is metabolized by the cytochrome P450 (CYP450) drug metabolizing enzyme system. Studies in healthy subjects have shown that rabeprazole does not have clinically significant interactions with other drugs metabolized by the CYP450 system, such as warfarin and theophylline given as single oral doses, diazepam as a single intravenous dose, and phenytoin given as a single intravenous dose (with supplemental oral dosing). Steady state interactions of rabeprazole and other drugs metabolized by this enzyme system have not been studied in patients. There have been reports of increased INR and prothrombin time in patients receiving proton pump inhibitors, including rabeprazole, and warfarin concomitantly. Increases in INR and prothrombin time may lead to abnormal bleeding and even death.

In vitro incubations employing human liver microsomes indicated that rabeprazole inhibited cyclosporine metabolism with an IC_{50} of 62 micromolar, a concentration that is over 50 times higher than the C_{max} in healthy volunteers following 14 days of dosing with 20 mg of rabeprazole. This degree of inhibition is similar to that by omeprazole at equivalent concentrations.

Rabeprazole produces sustained inhibition of gastric acid secretion. An interaction with compounds which are dependent on gastric pH for absorption may occur due to the magnitude of acid suppression observed with rabeprazole. For example, in normal subjects, co-administration of rabeprazole 20 mg QD resulted in an approximately 30% decrease in the bioavailability of ketoconazole and increases in the AUC and C_{max} for digoxin of 19% and 29%, respectively. Therefore, patients may need to be monitored when such drugs are taken concomitantly with rabeprazole. Co-administration of rabeprazole and antacids produced no clinically relevant changes in plasma rabeprazole concentrations.

In a clinical study in Japan evaluating rabeprazole in patients categorized by CYP2C19 genotype (n=6 per genotype category), gastric acid suppression was higher in poor metabolizers as compared to extensive metabolizers. This could be due to higher rabeprazole plasma levels in poor metabolizers. Whether or not interactions of rabeprazole sodium with other drugs metabolized by CYP2C19 would be different between extensive metabolizers and poor metabolizers has not been studied.

Combined Administration with Clarithromycin
Combined administration consisting of rabeprazole, amoxicillin, and clarithromycin resulted in increases in plasma concentrations of rabeprazole and 14-hydroxyclarithromycin. (See **CLINICAL PHARMACOLOGY, Combination Therapy with Antimicrobials** in full prescribing information.)

Concomitant administration of clarithromycin with pimozide and cisapride is contraindicated. (See **PRECAUTIONS** in prescribing information for clarithromycin.) (See **PRECAUTIONS** in prescribing information for amoxicillin.)

Carcinogenesis, Mutagenesis, Impairment of Fertility
In a 88/104-week carcinogenicity study in CD-1 mice, rabeprazole at oral doses up to 100 mg/kg/day did not produce any increased tumor occurrence. The highest tested dose produced a systemic exposure to rabeprazole (AUC) of 1.40 μg•hr/mL which is 1.6 times the human exposure (plasma $AUC_{0-\infty}$ = 0.88 μg•hr/mL) at the recommended dose for GERD (20 mg/day). In a 104-week carcinogenicity study in Sprague-Dawley rats, males were treated with oral doses of 5, 15, 30 and 60 mg/kg/day and females with 5, 15, 30, 60 and 120 mg/kg/day. Rabeprazole produced gastric enterochromaffin-like (ECL) cell hyperplasia in male and female rats and ECL cell carcinoid tumors in female rats at all doses including the lowest tested dose. The lowest dose (5 mg/kg/day) produced a systemic exposure to rabeprazole (AUC) of about 0.1 μg•hr/mL which is about 0.1 times the human exposure at the recommended dose for GERD. In male rats, no treatment related tumors were observed at doses up to 60 mg/kg/day producing a rabeprazole plasma exposure (AUC) of about 0.2 μg•hr/mL (0.2 times the human exposure at the recommended dose for GERD).

Rabeprazole was positive in the Ames test, the Chinese hamster ovary cell (CHO/HGPRT) forward gene mutation test and the mouse lymphoma cell (L5178Y/TK+/-) forward gene mutation test. Its demethylated-metabolite was also positive in the Ames test. Rabeprazole was negative in the *in vitro* Chinese hamster lung cell chromosome aberration test, the *in vivo* mouse micronucleus test, and the *in vivo* and *ex vivo* rat hepatocyte unscheduled DNA synthesis (UDS) tests.

Rabeprazole at intravenous doses up to 30 mg/kg/day (plasma AUC of 8.8 μg•hr/mL, about 10 times the human exposure at the recommended dose for GERD) was found to have no effect on fertility and reproductive performance of male and female rats.

Pregnancy
Teratogenic Effects. Pregnancy Category B: Teratology studies have been performed in rats at intravenous doses up to 50 mg/kg/day (plasma AUC of 11.8 μg•hr/mL, about 13 times the human exposure at the recommended dose for GERD) and rabbits at intravenous doses up to 30 mg/kg/day (plasma AUC of 7.3 μg•hr/mL, about 8 times the human exposure at the recommended dose for GERD) and have revealed no evidence of impaired fertility or harm to the fetus due to rabeprazole. There are, however, no adequate and well-controlled studies in pregnant women. Because animal reproduction studies are not always predictive of human response, this drug should be used during pregnancy only if clearly needed.

Nursing Mothers
Following intravenous administration of ^{14}C-labeled rabeprazole to lactating rats, radioactivity in milk reached levels that were 2- to 7-fold higher than levels in the blood. It is not known if unmetabolized rabeprazole is excreted in human breast milk. Administration of rabeprazole to rats in late gestation and during lactation at doses of 400 mg/kg/day (about 195-times the human dose based on mg/m²) resulted in decreases in body weight gain of the pups. Since many drugs are excreted in milk, and because of the potential for adverse reactions to nursing infants from rabeprazole, a decision should be made to discontinue nursing or discontinue the drug, taking into account the importance of the drug to the mother.

Pediatric Use
The safety and effectiveness of rabeprazole in pediatric patients have not been established.

Use in Women
Duodenal ulcer and erosive esophagitis healing rates in women are similar to those in men. Adverse events and laboratory test abnormalities in women occurred at rates similar to those in men.

Geriatric Use
Of the total number of subjects in clinical studies of ACIPHEX®, 19% were 65 years and over, while 4% were 75 years and over. No overall differences in safety or effectiveness were observed between these subjects and younger subjects, and other reported clinical experience has not identified differences in responses between the elderly and younger patients, but greater sensitivity of some older individuals cannot be ruled out.

ADVERSE REACTIONS
Worldwide, over 2900 patients have been treated with rabeprazole in Phase II-III clinical trials involving various dosages and durations of treatment. In general, rabeprazole treatment has been well-tolerated in both short-term and long-term trials. The adverse events rates were generally similar between the 10 and 20 mg doses.

Incidence in Controlled North American and European Clinical Trials
In an analysis of adverse events assessed as possibly or probably related to treatment appearing in greater than 1% of ACIPHEX® patients and appearing with greater frequency than placebo in controlled North American and European trials, the incidence of headache was 2.4% (n=1552) for ACIPHEX® versus 1.6% (n=258) for placebo.

In short and long-term studies, the following adverse events, regardless of causality, were reported in ACIPHEX®-treated patients. Rare events are those reported in ≤1/1000 patients.

Readers' Forum continued

physicians can rely only on institutional (Mayo Clinic) or personal surgeon (UNC) databases for this information. Individual problems with devices such as squeaking ceramic hip replacements are likely underreported to the FDA at present. Patients should also realize that the experience and skill of the surgeon is more important for the long-term success of a hip or knee replacement than the use of the newest or most advertised product.

Patients should write their national legislators this year to encourage the FDA and the Centers for Medicare and Medicaid Services to enact a national registry for hip and knee replacements. Television and print advertising of these devices to patients should be discouraged. Until this system is functional, patients with hip and knee replacements should have regular checkups of their artificial joints by their surgeon.

Paul F. Lachiewicz, MD
Professor of Orthopaedics
The University of North Carolina at Chapel Hill

The Arthritis Foundation, Carolinas Chapter

Forty-six million Americans have doctor-diagnosed arthritis. Arthritis is one of the most common diseases in the United States and the leading cause of disability among people 15 years of age and over. By the year 2020, an estimated 60 million people in the US will be affected. North Carolina ranks ninth among the 50 states in estimated prevalence, and arthritis is the most common cause of chronic disease in the state.

The Arthritis Foundation is the only nationwide, not-for-profit health organization providing people with arthritis the resources to control and manage their disease. Through evidence-based exercise programs and educational resources, the Arthritis Foundation is providing help to those who are in need. The Arthritis Foundation Carolinas Chapter serves more than 1.8 million people in North Carolina who have arthritis. The Carolinas Chapter works in collaboration with the North Carolina Arthritis Program to increase awareness of arthritis in the state. The Chapter's main office is located in Charlotte with staff also located in the Triangle and Triad to serve those areas of the state. In addition to offering the Arthritis Foundation's aquatic, exercise, tai chi, and self-help programs, the Carolinas Chapter funds arthritis research.

Over the past 2 years the Arthritis Foundation Carolinas Chapter has funded over $2 million dollars of research at institutions in the Carolinas. At Duke University, Arthritis Foundation-funded researcher Kelly K. Anthony, PhD, and her colleagues are investigating the social and emotional impact of having juvenile arthritis. Juvenile arthritis affects over 300 000 children in the United States and is one of the most common chronic diseases of childhood, occurring nearly as often as insulin-dependent juvenile diabetes. The results of this study at Duke will assist in the development of an early intervention program for the families of children living with juvenile arthritis. It will also provide physicians a better understanding of how to care for children with the disease.

The Arthritis Foundation Carolinas Chapter raises funds for such research with the support of thousands of committed volunteers and sponsors who participate in chapter events such as the signature Arthritis Walks and the Jingle Bell Run. These events are held in cities across the Carolinas including Wilmington, Asheville, Winston-Salem, Greensboro, Raleigh, Durham, Lenoir, and Charlotte. The money raised by these events supports research as well as public policy and public health initiatives, and the events focus on the importance of exercise in the management and treatment of arthritis. People with arthritis need to know they do not face this disease alone. For information or to get involved, call the Arthritis Foundation at 1-800-883-8806.

Gail Norman is president and CEO of the Arthritis Foundation Carolinas Chapter. She can be reached at gnorman@arthritis.org or 4530 Park Road, Suite 230, Charlotte, NC 28209.

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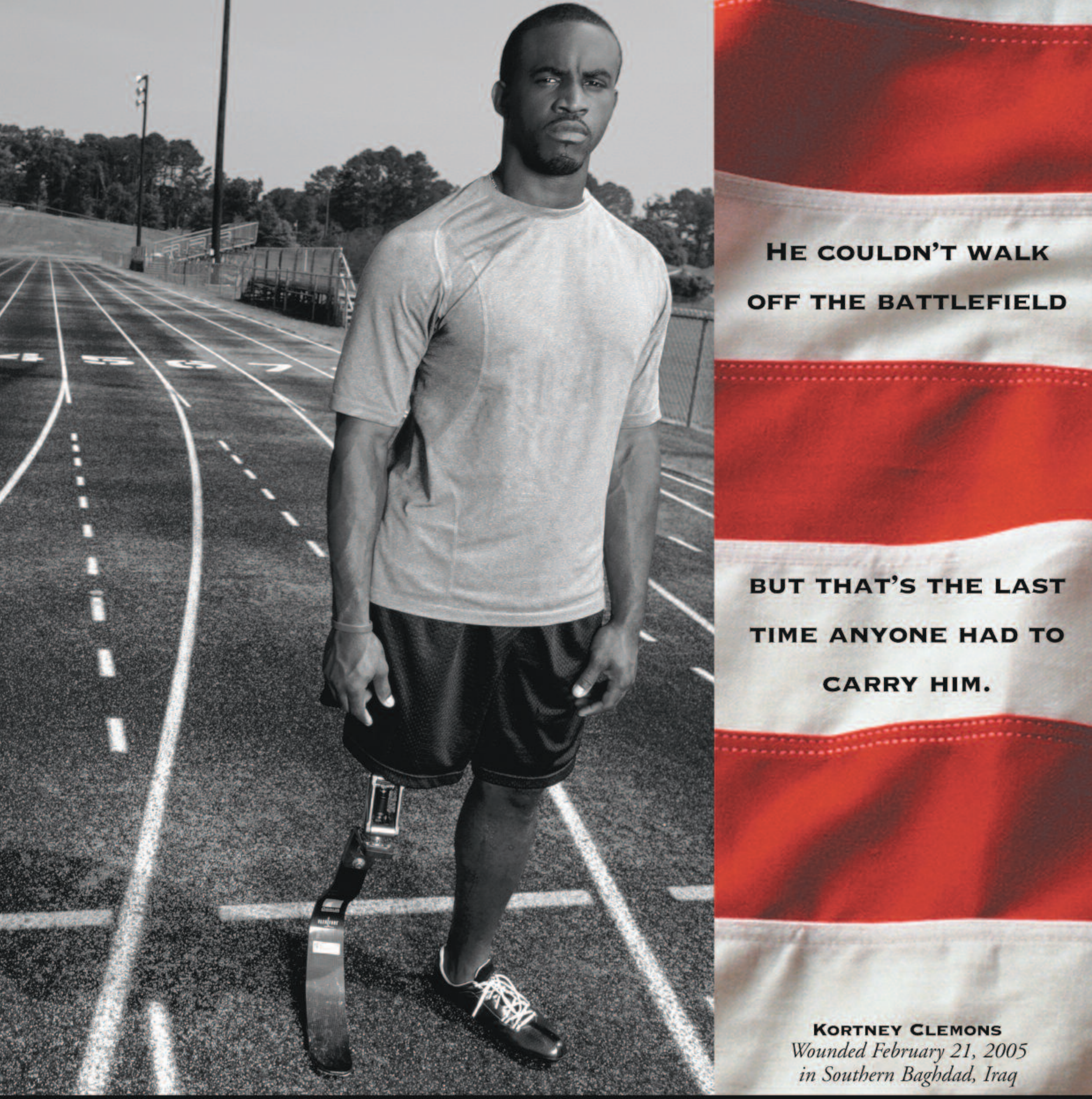
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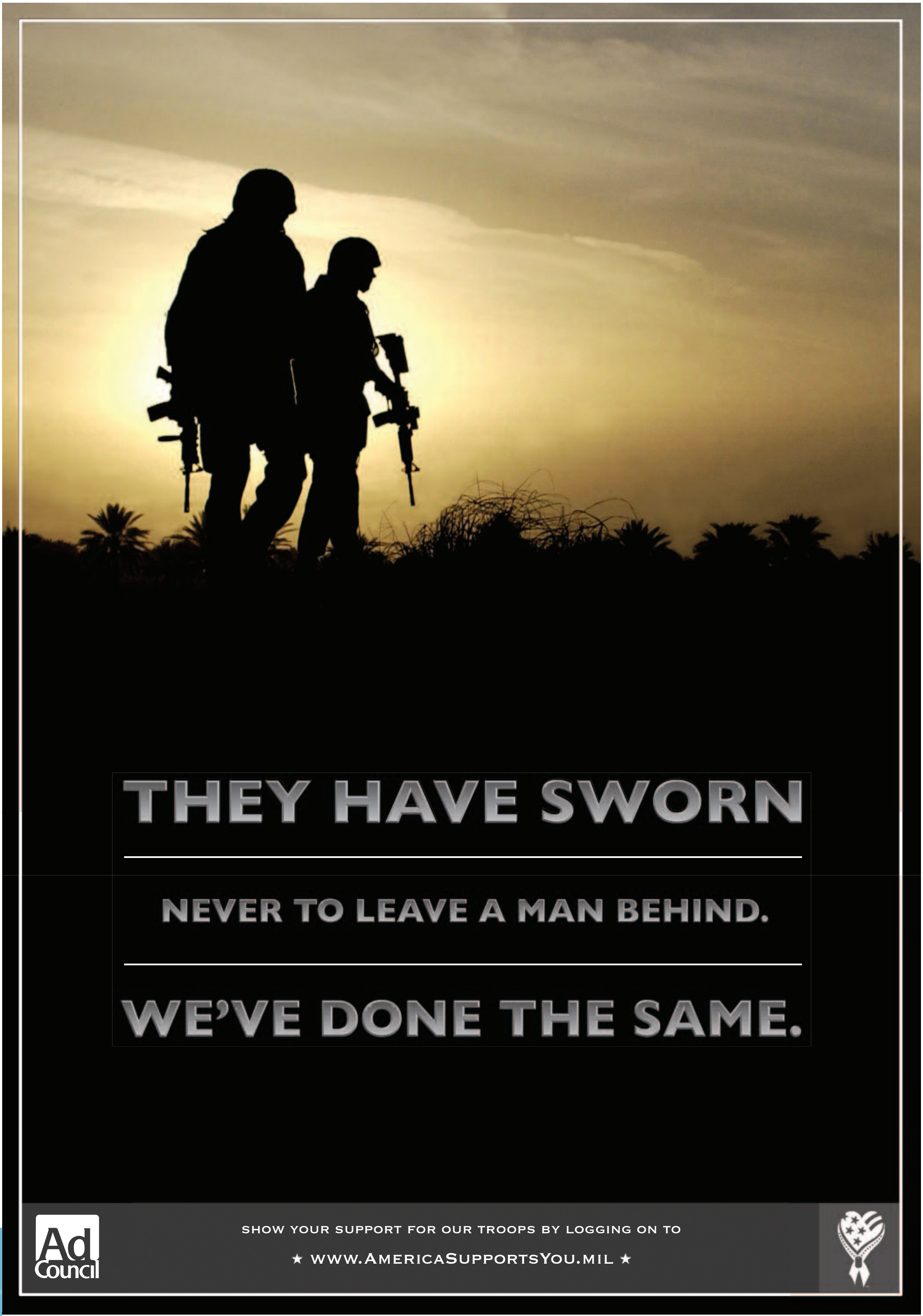

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January/February 2008, Volume 69, Number 1 **Published by the North Carolina Institute of Medicine and The Duke Endowment**

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COMMENTARIES

DEPARTMENTS

> *"…over 14 300 active duty service members and veterans of the Global War on Terror have sought VA health care in North Carolina since September 11, 2001."*

ARTICLE

2007 Costs and Coverage of Antiretrovirals Under Medicare Part D for People With HIV/AIDS Living in North Carolina

Sohini Sengupta, PhD, MPH

Abstract

Background: *Effective January 1, 2006 Medicare Part D became a new source of prescription drug coverage for people with HIV/AIDS in the United States. The implementation of Part D has affected access to antiretrovirals for people with HIV/AIDS. In North Carolina, access can be difficult because of the state's struggling safety net programs and the growing HIV-infected populations among Blacks and in poor rural counties. This analysis examines Medicare Part D antiretroviral coverage in 2007 for beneficiaries with HIV/AIDS in North Carolina, particularly those who did not qualify as dual eligibles or for a full low-income subsidy.*

Methods: *Data describing program coverage were obtained from the Web site www.medicare.gov and descriptive analyses were performed to assess changes in antiretroviral coverage in Part D prescription drug plans in North Carolina.*

Results: *Most of the 26 antiretrovirals are covered in some way by 76 North Carolina prescription drug plans. There may be variability in coverage however associated with (a) antiretroviral classification within formularies; (b) drug premiums; (c) whether premiums can be waived; (d) annual deductibles; and (e) whether coverage is provided in the "doughnut hole."*

Limitations: *The data may not reflect actual patterns of drug use and realized access to the drugs. The findings are limited to antiretroviral coverage in North Carolina's Part D offerings but could be generalized to other states with similar prescription drug plan costs and coverage.*

Conclusion: *These concerns continue to pose significant challenges to accessing antiretrovirals for Part D beneficiaries with HIV/AIDS in North Carolina. Variability demonstrated within prescription drug plans will continue, and beneficiaries with HIV/AIDS who do not qualify as dual eligibles or for low-income subsidies will need to evaluate these issues when selecting a prescription drug plan in future enrollment periods.*

Key Words: *HIV, AIDS, Medicare, antiretrovirals, health services accessibility*

In many states, the implementation of Medicare Part D in 2006—a new source of prescription drug coverage for eligible beneficiaries—had the potential to improve access to care for people with human immunodeficiency virus (HIV) or acquired immune deficiency syndrome (AIDS) given the critical role of antiretroviral treatment in their care. Along with state-sponsored AIDS Drug Assistance Programs (ADAPs), Medicaid, and industry-sponsored Patient Assistance Programs, Part D could strengthen the tenuous health care safety net[1] by providing drug coverage for people with HIV/AIDS who are under the age of 65 years and who qualify for Social Security Disability Insurance payments (and thus Medicare) as a consequence of HIV-related disabilities.[2] Concerns persist, however, that Medicare Part D jeopardizes access to AIDS care for some patients because Medicaid, as of 2006, no longer provided drug coverage for dual eligibles (persons on both Medicare and Medicaid);[3] some states require all of their ADAP clients to enroll in Part D;[4] and a new kickback statute may make companies sponsoring Patient Assistance Programs criminally liable if they compete with the Part D program.[5]

North Carolina is an example of a state where Medicare Part D could have important consequences for the safety net as Part D becomes a source to cover AIDS-related treatment for the poor with HIV/AIDS. In North Carolina access to antiretrovirals is an ever-increasing problem because of increases in the number of people infected by HIV and the state's struggling ADAP and

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Patient Assistance Programs. HIV-infection growth rates are growing rapidly among Blacks and those living in poor rural counties. As of December 31, 2006 North Carolina reported 15 746 AIDS cases with 67% of those cases among Blacks (well above the national average of 40%) at an annual rate of 36.6 per 100 000.[6] In the same surveillance report, two rural counties in North Carolina—Wilson and Edgecombe counties—had 3-year average incidence rates from 2004-2006 of greater than 30 per 100 000.[6] As the number of AIDS cases continues to increase, the role of Part D will grow over time. Indeed, the proportion of those required to use Part D in North Carolina will expand for 3 major reasons: (a) ADAP clients may have no other choice but to enroll in a prescription drug plan (PDP) under Part D;[4] (b) the roughly 18% who are dual eligibles[7] are automatically enrolled into prescription drug plans; and (c) the future of company-sponsored Patient Assistance Programs remains uncertain.[5] This article will describe the 2007 landscape of prescription drug plans covering antiretrovirals in North Carolina with a focus on the coverage and cost implications for HIV-positive beneficiaries, particularly for those who do not qualify as dual eligibles or those who may not qualify for a full low-income subsidy to help with paying the out-of-pocket costs for their antiretrovirals.

Medicare Part D Vernacular

Medicare Part D has its own nomenclature. Table 1 presents terms and definitions that will be used throughout this article.[8]

Methods

Data were obtained from the Web site www.medicare.gov in the period May 16-18, 2007. The number of PDPs offered in North Carolina and their general out-of-pocket costs were identified under "Learn More About Health Plans In Your Area" for North Carolina.[9] The result was a list of the number of stand-alone PDPs and Medicare Advantage-Prescription Drug (MA-PD) plans, their monthly premiums, annual deductibles, and whether or not they cover any classifications of medication in the "doughnut hole." The doughnut hole refers to the gap in coverage when no prescription drug benefit is available; an enrollee must pay a designated amount of out-of-pocket drug expenses before coverage continues.[8] Stratifying these PDPs by type, descriptive statistics were calculated that included median and ranges for monthly premiums and frequencies for annual deductible categories, number of PDPs covering generics in the doughnut hole, and number of PDPs offering $0 monthly premiums to beneficiaries who qualify for a full low-income subsidy.

Next, 26 antiretrovirals approved by the US Federal Drug Administration were selected under "Formulary Finder" for North Carolina within www.medicare.gov.[10] The result is a list of the PDPs that cover all or a majority of the 26 antiretrovirals. In accessing each PDP, additional information is provided about each antiretroviral's formulary status classification and whether or not there are any restrictions set by the PDP for each antiretroviral. Two analyses were conducted describing

Table 1.
Medicare Part D Glossary

Coverage gap (or "doughnut hole")	The coverage gap is the period when beneficiaries pay 100% of their Part D medication expenditures. In 2007, the coverage gap begins when the total spending for drugs reaches $2400, exclusive of the beneficiary's monthly premium, and ends when the beneficiary has reached $3850 in true out-of-pocket costs (TrOOP). Afterwards, beneficiaries pay 5% of their costs as coinsurance or copayments.
Dual eligible	An individual who is eligible for both Medicare and Medicaid coverage. In the past, Medicaid paid for drugs for this population. Dual eligibles will now receive most of their prescriptions from a Part D plan. Their premiums and deductibles will be fully subsidized and their copayments will be zero or nominal (approximately $3 for brand/$1 for generics).
Formulary	A list of specific drugs covered by a Part D prescription drug plan (PDP).
Stand-alone prescription drug plan	The most common PDP that Medicare beneficiaries could enroll in if they wish to stay in traditional Medicare and receive drug coverage.
Low-income subsidy (or extra help)	Financial assistance that lowers the premiums and copayments for beneficiaries with income limits defined as a percentage of the federal poverty guidelines (FPG). To qualify for a full low-income subsidy, beneficiaries need to be below 135% FPG, or $13 784 for an individual and $17 820 for a couple in 2007. Full subsidy pays for the entire premium and deductible for recipients and nearly all of the cost-sharing below the out-of-pocket threshold.
Medicare Advantage Prescription Drug Plan (MA-PD)	A private managed care plan established under Medicare Part C (formerly known as Medicare + Choice) that also provides standard Part D drug coverage.
Prescription drug plan (PDP)	Also known as "Part D plans," can be either stand-alone or MA-PD.
True out-of-pocket spending (TrOOP)	The amount a beneficiary must pay on covered drugs to reach catastrophic coverage. An individual's payment of the deductible, coinsurance, and/or copayments and drug costs in the doughnut hole count towards TrOOP. For 2007 the TrOOP limit is $3850. Currently, the Part D premium and ADAP subsidies do not count towards TrOOP.

Source: A Medicare drug benefit glossary. MedicareRxMatters Web site. http://www.medicarerxmatters.org/People/Glossary/index.asp#partial_subsidy. Accessed May 27, 2007.

antiretroviral coverage and cost-sharing responsibility within North Carolina PDPs. The first analysis focused on the number of PDPs classified by formulary status and restrictions (prior authorization and quantity limits) set by PDPs for each of the 26 antiretrovirals. Analysis involved producing a summary table that was a total count of the number of PDPs (a) in each tier of the formulary status and (b) that had quantity limits or prior authorization for each of the 26 antiretrovirals. The second analysis looked at antiretroviral coverage classified by formulary status for each North Carolina PDP. The first step of this analysis involved calculating a total count of the number of antiretrovirals covered in each tier for each PDP. The second step involved stratifying the PDPs by type (stand-alone or MA-PD) and by the number of antiretrovirals they covered within each tier. These data were presented in bar graphs to demonstrate clustering patterns of the number of antiretrovirals covered by the PDPs.

Results

Overview of North Carolina Prescription Drug Plans

A total of 51 stand-alone prescription drug plans and 41 MA-PD plans are offered in North Carolina. Fifty of the stand-alone PDPs cover all or a majority of the antiretrovirals; only 26 of the MA-PD plans offer this extent of coverage. (See Table 2.)

Table 2.
Summary of North Carolina's Prescription Drug Plans Covering All or the Majority of Antiretrovirals

					Annual Deductible		
PDP Type	**N**	**Monthly Premium** Median (Range)	**Doughnut Hole Coverage Generics**	**$0 Premium For Low Income Subsidy**	**$0**	**$1 to $264**	**$265**
Stand Alone	50	$36.05 ($17.80 - $85.90)	30%	42%	62%	6%	32%
Medicare Advantage (MA-PD)	26	$21.80 ($0.00 - $44.90)	19%	0%	81%	8%	12%

Source: Medicare Prescription Drug Plan Finder: Plans in Your Area. http://www.medicare.gov/MPDPF/Public/Include/DataSection/Results/ListPlanByState.asp. Accessed May 16, 2007.

Monthly drug premiums for the 50 stand-alone PDPs range from $17.80 (Humana PDP Standard) to $85.90 (Humana PDP Complete). For the MA-PD plans, monthly drug premiums could be $0, but the drug benefit premium is usually incorporated into the overall health care premium.[9] Medicare Advantage Prescription Drug plans with monthly drug premiums range from $5.70 (Security Horizons Medicare Complete Choice) to $44.90 (Partners Medicare Options Enhanced).[9] Annual deductibles range from $0 to $265. Forty-two percent of the stand-alone plans and none of the MA-PD plans allow for beneficiaries to pay a $0 monthly drug premium if the participant qualifies for a full low-income subsidy. Thirty percent of the stand-alone and 19% of the MA-PD plans offer coverage of generics in the doughnut hole which means that beneficiaries with these plans only would need to pay copays for Tier 1 drugs.

Out-of-pocket costs have changed since Part D's inception. In 2006, only one of the stand-alone PDPs—Humana PDP Complete—offered coverage of brand-name drugs for participants caught in the doughnut hole. The plan, however, converted to only covering generics and increased the monthly premium from $50 to $85 in 2007 as a way to reduce costs.[11] Variability also is demonstrated both within and across insurance companies (data not shown). For example, Humana offers Humana PDP Complete and Humana PDP Standard. Humana PDP Complete has a no annual deductible and generics are covered in the doughnut hole, but it does not offer $0 monthly drug premiums for beneficiaries who qualify for a full-low-income subsidy. In contrast, Humana PDP Standard has a $265 annual deductible and does not cover generics in the doughnut hole, but it offers $0 monthly drug premiums for beneficiaries who qualify for a full-low-income subsidy. Variability is quite significant across insurance companies. For example, Partners Medicare Options Enhanced has a $0 annual deductible and generics are covered in the doughnut hole, whereas Security Horizons Medicare Complete Choice also has a $0 annual deductible but does not cover generics in the doughnut hole.

Analysis 1 evaluates the number of PDPs classified by formulary status, prior authorization, and quantity limits for each antiretroviral. A total of 26 antiretrovirals were selected that are considered standard of care to treat HIV-infected patients; 24 are brand-name drugs and 2 are approved generics. (See Table 3.)

As mentioned, 50 stand-alone PDPs and 26 MA-PD plans cover all or the majority of the 26 antiretrovirals; 6 PDPs (3 stand-alone and 3 MA-PDs) do not cover Videx (Didanosine) and 2 MA-PD plans do not cover Reyataz (atazanavir sulfate). Both of these antiretrovirals are used to treat naïve patients, and Reyataz (atazanavir sulfate) is one of the preferred protease inhibitors.[12]

Within each PDP, the antiretroviral formulary's cost-sharing is classified into tiers. Tier 1 represents the lowest cost-sharing responsibility, and Tier 4 represents the highest cost-sharing responsibility. Tier 1 drugs are usually generics with copays anywhere from $0 to $10, or 25% of the drug's cost. Tier 2 drugs are delineated as "Preferred Brand" or "Formulary Brand" with copays ranging from $17 to $66, or 25% of the

Table 3.
Approved Antiretrovirals Covered by North Carolina's Prescription Drug Plans

Protease inhibitors

Agenerase (amprenavir, APV)
Aptivus (tipranavir, TPV)
Crixivan (indinavir, IDV)
Invirase (saquinavir mesylate, SQV)
Kaletra (lopinavir and ritonavir, LPV/RTV)
Lexiva (Fosamprenavir Calcium, FOS-APV)
Norvir (ritonavir, RTV)
Reyataz (atazanavir sulfate, ATV)
Viracept (nelfinavir mesylate, NFV)

Nonnucleoside reverse transcriptase inhibitors

Rescriptor (delavirdine, DLV)
Sustiva (efavirenz, EFV)
Viramune (nevirapine, NVP)
Viread (tenovir disoproxil fumarate, TDF)

Nucleoside reverse transcriptase inhibitors

Combivir (lamivudine and zidovudine)
Emtriva (emtricitabine, FTC)
Epivir (lamivudine, 3TC)
*Retrovir (zidovudine, AZT)
Trizivir (abacavir, zidovudine, and lamivudine)
*Videx (didanosine, DDI)
Zerit (stavudine, d4T)
Ziagen (abacavir sulfate, ABC)
Epzicom (abacavir and lamivudine)
Truvada (tenovir disoproxil fumarate and emtricitabine)
Retrovir IV (zidovudine IV)

Fusion inhibitors

Fuzeon (enfuvirtide, T-20)

Single tablet regimen

Atripla (efavirenz, emtricitabine and tenovir disoproxil fumarate)

Source: United States Department of Health and Human Services Panel on Antiretroviral Guidelines for Adults and Adolescents. Guidelines for the Use of Antiretroviral Agents in HIV-1-Infected Adults and Adolescents. Washington, DC: Department of Health and Human Services; 2006.

Note: Brand name of antiretrovirals followed by their generic names in ( ).

* Indicates antiretrovirals that have generic versions approved by the Federal Drug Administration.

drug's cost. Tier 3 drugs are delineated as "Non-Preferred Brand" or "Brand" with copays anywhere from $40 to $60, or as high as 75% of the drug's cost. Tier 4 drugs also are called "Specialty" with copays anywhere from 25% to 33% of the drug's cost.[13] Each PDP also indicated whether or not any restrictions were imposed on the antiretrovirals in the form of quantity limits or prior authorization, factors that may further affect access to specific drugs.

In Table 4 the data are organized to demonstrate the variability in which antiretrovirals are classified into the formulary status of the 76 North Carolina PDPs, beginning with the 2 generic antiretrovirals—Retrovir (zidovudine) and Videx (didanosine)—that have been classified into Tier 1 by the highest number of PDPs.

Retrovir (zidovudine) is classified in Tier 1 for all 76 PDPs, but Videx (didanosine) is not covered by 6 PDPs; it is classified as Tier 3 for 5 of the PDPs. The majority of the PDPs cover the Brand antiretrovirals at Tier 2. The cost-sharing for Atripla, Aptivus, Retrovir IV, and Fuzeon will be the highest since they are classified more often in Tier 3 and Specialty; Fuzeon is classified as Specialty in 64 of the PDPs. Only 4 of the antiretrovirals—Aptivus, Emtriva, Reyataz, and Fuzeon—are subject to quantity limits. Some PDPs use quantity limits to restrict how much of a drug they will dispense at one time. Plans commonly limit dispensing to a one month supply or 90 to 100 days for so-called "maintenance drugs" for persons with chronic conditions such as HIV/AIDS.[14] Only Fuzeon is subject to prior authorization which is a process whereby plans require clinical justification before dispensing a drug.[14]

Analysis 2 evaluated antiretroviral coverage classified by formulary status for North Carolina PDPs. Figure 1 illustrates antiretroviral coverage within the 76 PDPs' formulary status by presenting a summary of PDPs (stratified by type) by the number of antiretrovirals they cover in Tier 1 through Tier 4.

What is evident when looking at the 4 graphs is that all 50 stand-alone PDPs and 26 MA-PD plans cover one or more antiretrovirals in Tier 1 or Tier 2. For the Tier 1 graph, most of the PDPs cover 1-2 drugs (generics); only one MA-PD plan covers 24 of the antiretrovirals at Tier 1. In the Tier 2 graph, most of the PDPs cover between 19 and 23 of the antiretrovirals; one MA-PD plan covers 24 antiretrovirals at Tier 2. The Tier 3 and Tier 4 graphs show that very few of the antiretrovirals covered are categorized in these Tiers by the PDPs. Twenty stand-alone PDPs and 9 MA-PD plans cover no antiretrovirals in Tier 3 and the same is true for Tier 4 antiretroviral coverage among 9 stand-alone PDPs and 4 MA-PD plans. Although 2 of the stand-alone PDPs cover 17 antiretrovirals in Tier 3, and 5 stand-alone PDP and 5 MA-PD plans cover 15 of the antiretrovirals at Tier 4, the largest clustering of PDPs illustrated have only between 1 and 3 antiretrovirals in both Tier 3 and Tier 4.

Discussion

Similar to another study of prescription drug plans conducted in 2006,[13] the 2007 landscape of Medicare Part D PDPs covering antiretrovirals in North Carolina continues to demonstrate several barriers for beneficiaries with HIV/AIDS living in the state and particularly for those who are not dual eligibles or who may not qualify for a full low-income subsidy. The barriers relate to changes and variability within and across Part D prescription drug plans that affect affordability, access, and

Table 4.
Number of Prescription Drug Plans Classified by Formulary Status, Prior Authorization, and Quantity Limits for Each Antiretroviral

	Formulary Status					
Name of Antiretroviral	**Tier 1**	**Tier 2**	**Tier 3**	**Specialty**	**Quantity Limits**	**Prior Authorization**
Retrovir (Zidovudine)	76	0	0	0	0	0
Videx (Didanosine)[a]	65	0	5	0	0	0
Crixivan	1	73	2	1	0	0
Epivir	1	73	2	0	0	0
Viramune	1	73	2	0	0	0
Zerit	1	70	5	0	0	0
Rescriptor	1	70	5	0	0	0
Emtriva	1	68	7	0	9	0
Sustiva	1	68	7	0	0	0
Ziagen	1	68	7	0	0	0
Viread	1	63	2	10	0	0
Lexiva	1	59	3	13	0	0
Agenerase	1	57	5	13	0	0
Combivir	1	57	5	13	0	0
Epzicom	1	57	5	13	0	0
Invirase	0	57	4	15	0	0
Norvir	1	57	5	13	0	0
Trizivir	1	57	5	13	0	0
Viracept	1	57	3	15	0	0
Reyataza	1	57	3	13	9	0
Kaletra	1	55	5	15	0	0
Truvada	1	51	11	13	0	0
Aptivus	1	41	13	21	6	0
Retrovir IV	1	40	32	3	0	0
Atripla	1	33	14	28	0	0
Fuzeon	0	5	7	64	17	10

Source: Formulary finder for prescription drug plans. http://formularyfinder.medicare.gov/formularyfinder/. Accessed May 16, 2007.

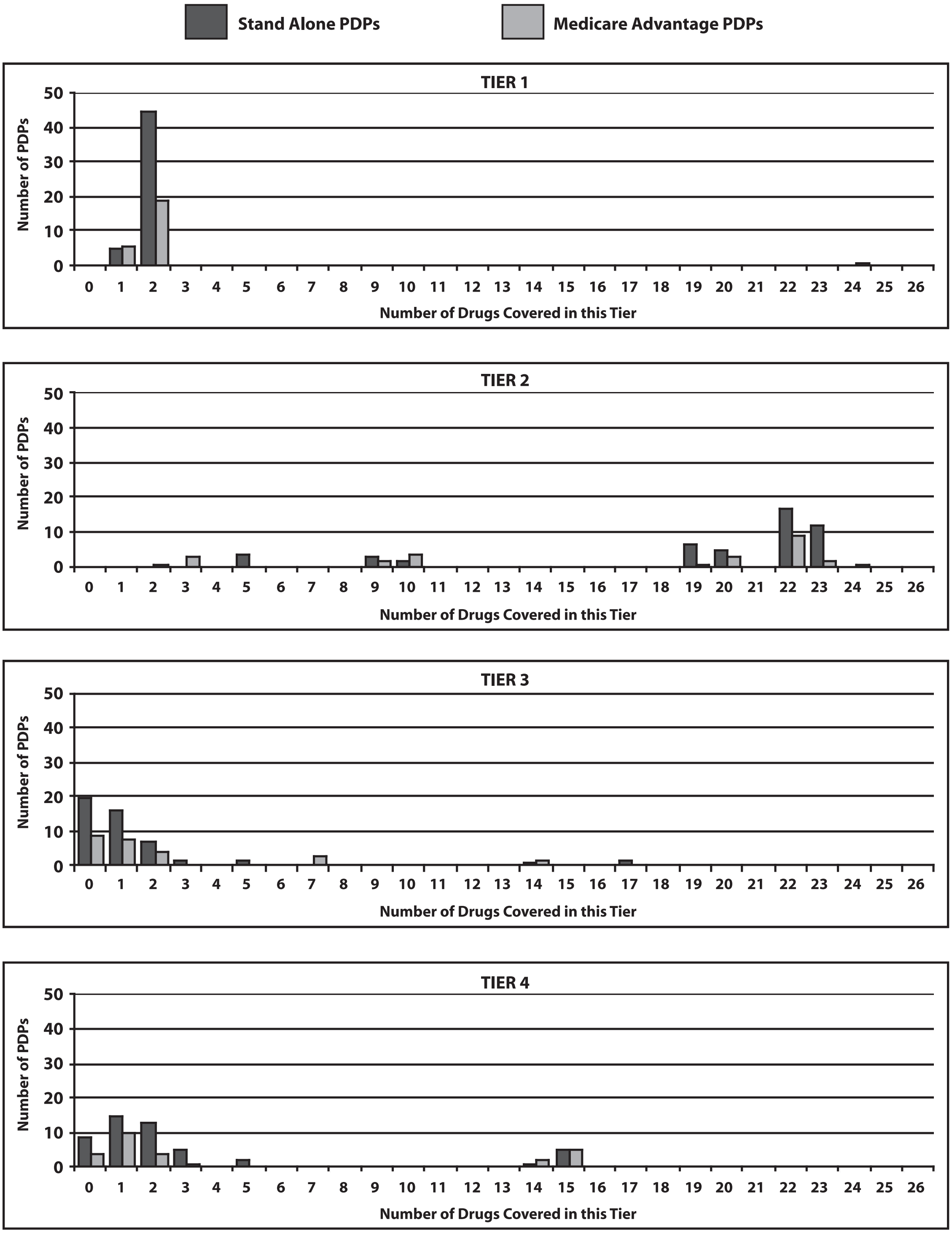
Note: Most antiretrovirals are covered by 76 PDPs; n = 76 when totaling number in each column under "formulary status."

[a] Videx (didanosine) is not covered by 6 PDPs (n = 70), and Reyataz is not covered by 2 PDPs (n = 74).

utilization. Because of these barriers, state-sponsored ADAPs and industry-sponsored Patient Assistance Programs must continue to assist HIV-positive individuals for whom Part D is unaffordable. According to James Coburn, JD, a senior policy analyst with Health & Disability Advocates, the good news is that ADAP in North Carolina has recognized this problem and is allowing enrollees who were required to sign up for Part D to obtain their HIV-related medications from ADAP while in the doughnut hole.[15] These costs covered by ADAP, however, do not count toward true out-of-pocket expenses—the amount a beneficiary must pay on covered drugs to reach catastrophic coverage—although recent Congressional hearings have been held that may change this current rule.[16] Another disadvantage with using North Carolina ADAP is that the program requires prior authorization of Fuzeon,[17] which in comparison is required by only 10 of the 76 PDPs covering antiretrovirals. Moreover, we do not know for how long ADAPs and Patient Assistance Programs will be able to bridge the safety net gap at the state and national levels.

The descriptive analyses presented in this paper focus on antiretroviral coverage and costs in Medicare Part D after 2007 enrollment. On a positive note, the majority of the 26 FDA-approved antiretrovirals are covered by 76 North Carolina PDPs in Tiers 1 and 2, and most of these PDPs do not require quantity limits and prior authorization for these antiretrovirals. Challenges remain, however, relating to the

Figure 1.
Number of Prescription Drug Plans (PDPs) by Number of Antiretrovirals Covered in Each Tier[9,10]



persistent and changing variability within these PDPs. The analysis demonstrated significant variability in antiretroviral classification in the formulary; only one MA-PD plan covered 24 antiretrovirals in Tier 1 whereas the majority of PDPs covered most antiretrovirals at Tier 2, and nearly 25% of the PDPs covered most antiretrovirals in Tiers 3 and 4. Furthermore, the one MA-PD plan covering 24 antiretrovirals in Tier 1—AETNA Medicare Open Plan—was not available to the 3 urban and rural counties in North Carolina with the highest cumulative AIDS cases (urban Mecklenburg and Wake counties and rural Pitt County) (data not shown). It is unclear how insurance companies make decisions about antiretroviral placement within the formulary status of PDPs since there is no correlation between antiretroviral placement and drug manufacturer (data not shown). Indeed, classifying most of the antiretrovirals at Tier 2 or greater makes the cost-sharing responsibility unaffordable for people with HIV/AIDS with incomes more than 150% of federal poverty guidelines. A second concern relates to the variability of other out-of-pocket costs when comparing PDPs. The analysis demonstrated that even within an insurance company there is variability pertaining to monthly drug premiums, annual deductibles, generic coverage in the doughnut hole, and availability of $0 monthly premiums for beneficiaries qualifying for a low-income subsidy.

The implications of these out-of-pocket costs can be demonstrated in a case example of a North Carolina beneficiary with HIV/AIDS whose income is $1700/month (200% federal poverty guideline) and who is enrolled in AARP MedicareRX (one of the top PDPs nationally in 2006[18]). This person would not be eligible for Extra Help, the low-income subsidy. The out-of-pocket costs would include a $30 monthly premium that cannot be waived, no annual deductible, no coverage within the doughnut hole, and a cost-sharing responsibility per drug of roughly 25% to 33% (based on Tier 4 estimates). Without knowing this PDP's specific summary plan description, the beneficiary's annual cost-sharing responsibility, assuming the simplest antiretroviral regimen, Atripla ($1150.88 for a 30-day supply[19]), would be $360 in total monthly PDP premiums which cannot go towards true out-of-pocket expenses, and $4258.03 in coinsurance. Table 5 roughly estimates this beneficiary's monthly out-of-pocket costs for Atripla in 2007.

Thus, this person would be spending 23% of his or her income to pay for out-of-pocket Part D drug costs (including premiums). Seventy percent of those out-of-pocket costs would be spent during the doughnut hole. In reality, the annual costs would be much higher if this person was taking a combination of antiretrovirals and other medications to manage his or her disease, given that the 5% copays after the doughnut hole could be significantly higher.

Table 5.
Estimated Beneficiary Out-of Pocket Costs for Atripla, by Month, 2007

Month	25% Coinsurance (until $2400)	100% Pay (doughnut hole until $3850 TrOOP* limit)	5% Coinsurance (catastrophic limit)	Monthly Payment (excluding premium)
January	$287.72	$0.00	$0.00	$287.72
February	$287.72	$0.00	$0.00	$287.72
March	$24.56	$1052.64	$0.00	$1077.20
April	$0.00	$1150.88	$0.00	$1150.88
May	$0.00	$1046.48	$5.22	$1051.70
June-December	$0.00	$0.00	$57.54	$57.54
Total annual coinsurance				$4258.03
Total (coinsurance + $360 premiums)				**$4618.03**

* TrOOP - true out-of-pocket expenses

The case example indirectly addresses the relationship between affordability, access, and utilization. As mentioned, people with HIV/AIDS may take a number of HIV and non-HIV-related medications to manage their HIV and comorbid conditions. It is not unusual for people with HIV/AIDS to change their medication regimens one or more times even within a year. A person with HIV/AIDS, however, cannot change to another PDP mid-year. Thus, he or she may discover the new medication is either not offered, offered at a higher tier, or offered with restrictions in his or her current PDP. This situation not only could make a change in regimen financially unaffordable, but also the patient could decide to stop taking an antiretroviral or stretch out the prescription of an antiretroviral to save money, leading to serious consequences of medication noncompliance and HIV resistance.

With so many issues to consider, how does a North Carolina beneficiary with HIV/AIDS choose a PDP from among the 76 with antiretroviral coverage? This paper may be useful in helping consumers and their advocates recognize the numerous factors —plan availability, antiretroviral tier classification, monthly premium costs, annual deductibles, and generic coverage (for HIV or non-HIV medications) offered in the doughnut hole—that need to be taken into consideration before selecting a PDP. The process of selecting a PDP could be very daunting for beneficiaries with HIV/AIDS who, compared to the majority of elderly Medicare beneficiaries, are more likely to be poorer and less well-educated. Indeed, HIV clinicians must continue to assist patients in understanding these issues and facilitate better access to affordable antiretrovirals within the struggling safety net for years to come. **NCMJ**

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ARTICLE

Tuberculosis Knowledge, Attitudes, and Beliefs Among North Carolinians at Increased Risk of Infection

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Abstract

Objective: *The purpose of this study was to capture and describe knowledge, attitudes, and beliefs about tuberculosis (TB) among persons at high risk for TB infection.*

Methods: *We conducted 11 focus groups in 3 different populations at high risk for TB infection: Spanish-speaking immigrants, homeless shelter residents, and persons attending a drug/alcohol rehabilitation center. A standardized list of open-ended questions was used to guide discussion. Using grounded theory, transcripts of the focus group sessions were reviewed by 4 independent reviewers to identify emergent themes.*

Findings: *Participants (N=52) generally understood that TB is an infectious disease that frequently affects the lungs and can be fatal if untreated. They also knew that a skin test can be used to diagnose TB. However, participants frequently had incorrect beliefs regarding the cause, transmission, and treatment of TB. Many participants thought that TB is transmitted in the same fashion as other infectious diseases such as human immunodeficiency virus or aquired immune deficiency syndrome (HIV/AIDS). A general sentiment of fear and aversion toward persons ill with TB was expressed.*

Limitations: *Focus groups were a convenience sample and subjects were not necessarily representative of the underlying populations.*

Conclusions: *Tuberculosis knowledge among high-risk populations is suboptimal, and false beliefs regarding transmission and treatment were common in this study. Knowledge regarding transmission of other infectious diseases such as HIV/AIDS was frequently translated into incorrect knowledge regarding TB. Stigma continues to be a barrier to TB diagnosis and treatment.*

Key words: *Health knowledge, attitudes, practice; focus groups; tuberculosis; homeless persons; emigration and immigration; alcoholism; substance-related disorders*

Tuberculosis (TB) is a significant cause of morbidity and mortality worldwide. Eight million persons become ill with TB and 2 million die of TB worldwide each year.[1] However, in the United States, TB has become relatively uncommon; 13 779 tuberculosis cases were reported in 2006, representing an incidence rate of 4.6 cases per 100 000 population. However, TB is still a significant problem in certain high-risk groups including the foreign born, persons who abuse alcohol or illicit drugs, and the homeless. In 2006, of persons with active TB in the US, 57% were foreign born, 14.2% reported abusing alcohol within the previous 12 months, and 6.2% were homeless.[2]

Tuberculosis remains a problem because infected, asymptomatic persons serve as a reservoir for future disease. When an individual with pulmonary TB coughs, sneezes, or speaks, respiratory droplets containing viable *Mycobacterium tuberculosis* bacteria are aerosolized. A susceptible host can inhale these droplets and become infected. In most cases, the immune response controls this primary infection. As a result of this imperfect immune

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response, the infected individual remains asymptomatic but frequently harbors viable TB bacteria. This individual is then said to have latent tuberculosis infection (LTBI). Persons with LTBI may remain well (and not contagious), but approximately 10% become ill with active TB during their lifetime and may then infect others.[3] The detection and treatment of LTBI is thus essential to TB eradication efforts. Latent TB infection is currently diagnosed by tuberculin (purified protein derivative) skin testing, although blood tests to diagnose LTBI are becoming available.[4] Persons with LTBI, defined as having a positive tuberculin skin test without clinical or radiographic signs of disease, can be treated with isoniazid to reduce the risk of progression to active TB. Treatment of LTBI with 6 to 9 months of daily isoniazid reduces the likelihood of progression to active disease by up to 90%.[5] Unfortunately, a relatively low proportion of persons with LTBI complete a full course of therapy. In a general public health clinic population, only about 60% of patients prescribed isoniazid completed a full course, and in homeless populations completion rates have been as low as 15-20%.[6,7]

Understanding TB knowledge and beliefs among high-risk groups may significantly enhance efforts to diagnose and treat both active TB and LTBI in those groups. Several studies have examined TB knowledge and beliefs in selected populations,[8-15] but data are lacking for some high risk groups in the United States. We conducted 11 focus groups comprised of persons from groups at high risk for TB as part of a larger effort to understand and improve adherence to LTBI therapy.

Methods

Study Design

Eleven focus groups were assembled in order to gather data about TB knowledge, attitudes, and beliefs. Focus groups have been used extensively in primary care settings to explore patients' and practitioners' perceptions and opinions of illness, services, and programs.[16] Participation in the focus groups was voluntary and anonymous. Food was offered at some of the sessions, but participants did not receive any monetary compensation for participation. Both the Duke University Medical Center Institutional Review Board and Wake County Human Services approved the study protocol.

Table 1.
Emergent Themes and Illustrative Focus Group Quotations

Tuberculosis is communicable and serious	"…it is communicable and can be deadly" "It will kill eventually." "It's life-threatening if not treated." "highly infectious" "easily spread"
Tuberculosis can affect anyone	"I think society in general can get it [TB]." "I would say that if you are exposed to anyone in the general public you are at risk, it doesn't discriminate."
Tuberculosis is more likely to affect people who are not like me	"People from other countries [are more likely to get TB]" "Street people [are more likely to get TB]"
Tuberculosis stigma	"People would feel ashamed about TB at a hairdresser, or store."
Health care costs are significant barriers to receiving good health care including tuberculosis care	"I'm supposed to be on all kinds of medications but I can't afford the prescriptions 'cause I don't have insurance." "I feel like the more money or more insurance you have the better doctor care you get."
Perception of responsibility for health affects the likelihood of taking treatment for tuberculosis	"Of course you are going to have people who aren't going to take it [treatment for LTBI] no matter how bad it is, 'cause they are just that way. But people who care about themselves and their health and their family are going to do it. You can't make people care, but they either care or they don't but the ones who do I think if they have the right information, if they were educated, they would."
Incentives (financial or emotional) will increase adherence to latent tuberculosis infection treatment	"Society loves money, pay them [persons who need TB/LTBI treatment.]" "Give them encouragement for taking the pills." "Spend time with the person so they don't feel so alone."
Persons who do not have regular, healthy practices will not take tuberculosis / latent tuberculosis infection treatment	"I think the biggest problem is, is that right now a lot of people who would have to take it [the TB treatment], their lifestyle doesn't really coincide with doing things at a normal time, like taking the medicine every day is like taking a bath every day, well a lot of people on the street don't take a bath every day it would be hard to get them to do something on a regular basis all the time."

Focus Group Participants, Data Collection, and Analysis

Focus groups were conducted at various sites in Chapel Hill, Durham, and Raleigh, North Carolina. (See Table 1.) The participants in the focus groups were selected from 3 populations with relatively high rates of latent TB infection and active disease: foreign-born Hispanics, homeless persons, and persons with a history of illicit drug or alcohol abuse. Participants represented a convenience sample of persons at the site who were willing to participate at the time the facilitator was present.

Three focus group sessions targeting Hispanic immigrants were conducted at a local church, an elementary school, and a community center. Six sessions targeting homeless persons were conducted at 4 homeless shelters. Two sessions targeting persons with drug/alcohol abuse problems were held at a drug/alcohol rehabilitation facility. Focus groups included a median of 5 participants (range 2-6) with a total of 52 participants in the study. The racial/ethnic composition of participants included

21 Caucasians, 15 African-Americans, and 16 Hispanics. Five sessions included only males, 2 included only females, and 4 included both males and females (30 male and 22 female participants total). Participants at the homeless shelters and the rehabilitation facility did not provide demographic information. Among the Hispanic participants, 5 persons were under 30 years of age (range 25-52 years), and 6 had been in the United States under 5 years (range 6 months-16 years). Ten were from Mexico, 2 from Colombia, and 1 each from the Dominican Republic, Peru, and Honduras, while the country of origin for 1 subject was unknown. A standardized list of questions was used to guide the discussions. (See Box 1.) All sessions were audio-recorded and transcribed. The Spanish transcripts were translated by one bilingual person, and a second bilingual person reviewed the original transcripts and the translation for accuracy.

Box 1.
Focus Group Questions

1 What have you heard about TB?
2 Have you heard any other names for TB?
3 In your opinion, how serious is TB?
4 What is the cause of TB?
5 How do you get TB?
6 What kinds of people get TB?
7 What would you think about a person with TB?
8 How can a person find out if they have TB?
9 Where would you go to get a TB test?
10 Would you like a nurse to knock on the door and offer it to you?
11 What are the chances that a person with TB infects others?
12 Have you ever known anyone with TB?
13 Do you think you are at risk of getting TB?
14 If you thought you were at risk for getting TB, would you do what you could to get tested?
15 What is the best treatment for TB?
16 Can TB be cured?
17 Where would you go for treatment if you (or someone you knew) thought they had TB?
18 Do you have any concerns about receiving medical treatment in the US?
19 Would you take a pill every day for 9 months to prevent a disease (even if you didn't feel sick)?

TB = Tuberculosis

Using grounded theory,[17] the 4 reviewers (LM, LG, JS, and TO) read the English versions of the transcripts independently, initially looking for key words and emerging themes. After half the focus groups had been completed and transcribed, the researchers compared and combined their independent analyses. This procedure permitted exploration, expansion, and testing of themes in subsequent focus groups. An extensive list of key words and themes was maintained and revised throughout the process resulting in a final analysis template which allowed the researchers to organize and code the data. All the transcripts were coded using the analysis template, making it easier to organize and manage the qualitative data. At this stage of the analysis, all the researchers met several times to examine similarities and differences across and within the identified themes. Several iterations of the findings were circulated among the research team for clarification and consensus before they were considered final.

Results

What Did the Participants Know About Tuberculosis?

Signs, symptoms, and contagiousness. Participants understood that tuberculosis is a disease associated with significant morbidity and mortality. There was also generalized knowledge among the participants in each group about the signs and symptoms of active TB: persistent cough, coughing or spitting up blood, fever, and night sweats were all mentioned. Although most participants did not report having known anyone with TB, they thought a person with TB would look very ill: "I picture them being lethargic, pale, bad cough, dark circles under their eyes" and "Coughing, shortness of breath, run down easy, someone who could only do like four hours of work instead of eight a day, drained and tired." Those who had observed someone with active TB depicted similar images: "She looked like a walking cadaver." Most group participants knew that TB was infectious. Participants most commonly responded that TB was spread by the cough of an infected person: "It's mostly airborne. I mean people cough. Like you could be in a cab with somebody and they cough and you can get it that way."

Skin Testing. Participants knew there was a skin test that could be used to diagnose TB. Participants also knew the test was available at a physician's office, clinic, hospital, or health department. Many of the participants had previously undergone tuberculin skin testing. All participants indicated they would be willing to be tested for TB if they thought they were at risk of having TB.

What Did The Participants *Not* Know About Tuberculosis?

Cause and Transmission. The most obvious knowledge deficits were in the areas of causation and transmission of TB. At least one person in each group responded that TB was caused by either a bacteria or, even more commonly and erroneously, by a virus. Other suggested causes of TB were smoking, "malnutrition," "sleeping in cold breezy places and wet floors," and "uncleanliness." At least one person in each group knew TB could be transmitted when an infected person coughs. Several participants indicated TB could be transmitted by using the same glass or utensils as the infected person, by holding hands with an infected person, from dirty needles, by blood, and even "like AIDS."

BCG vaccine. The Spanish-speaking groups were asked if they knew about a vaccine for TB. Few participants were aware of the existence of such a vaccine. Confusion between the vaccine and the TB skin test was common.

Treatment. Participants did not have a good understanding of TB treatment. Many were unsure whether there was a treatment for TB; in all groups there was mixed knowledge about whether there was treatment. Of those participants who thought there was a treatment, most simply said it was a medication of some type. A couple of participants mentioned that it required taking antibiotics for 9 months, which is the standard length of therapy for LTBI. One Spanish-speaking participant answered that vitamins were the treatment. Several participants thought treatment was only available if the disease was diagnosed relatively early in its course.

Attitudes and Beliefs About the Diagnosis and Treatment of Tuberculosis

Participants did not verbalize any overt prejudice or negative attitudes about people with TB: "It's not their fault." In addition, the majority of those who responded to the question "Who gets TB?" answered that anyone can get it: "I think society in general can get it," and "I would say that if you are exposed to anyone in the general public you are at risk, it doesn't discriminate." While few participants expressed any negative attitudes towards someone with TB, some participants stated that certain groups of people were more likely to have TB than others. For example, the men in the alcoholic recovery group said that "street people" and the "homeless" are more likely to be infected. Many participants commented that persons with AIDS and depressed immune systems are at increased risk of acquiring TB. Several Spanish-speaking participants said that "people from other countries," and people of other races tend to have it. Other groups more likely to have TB mentioned by the participants were older people, asthmatics, those who smoked or drank alcohol, those who lived in big cities, those with a low income, those who did not receive the vaccine, those who lived in "harsher environments," and those who were malnourished.

Many participants voiced that their first inclination was to "stay away" from someone diagnosed with TB. Few participants acknowledged having known anyone with TB. A few participants had childhood memories of persons with TB:

> *I remember my momma saying to me not to let certain people cough on me or spit on me 'cause he got TB stuff so we used to stay away from him because he was a cougher and a spitter 'cause he was contagious, so she told us to stay away from him 'cause he was contagious.*

Trust of the Health Care System and Health Care Professionals

Participants in all groups stated that in general they trusted medical professionals to provide appropriate care. Furthermore, participants indicated they had greatest trust in physicians who were specialists in treating their specific illness. A few participants expressed negative feelings and distrust toward specific medical institutions but not toward physicians or other medical providers in general. Despite this trust, participants were not enthusiastic about having a nurse come to their home for TB testing. Several participants were afraid of an unknown person coming to their door, and some participants also voiced fears of being stigmatized by neighbors because a nurse was visiting the house.

Participants in the Spanish-speaking focus groups were asked whether they would seek out a traditional healer ("curandero") for medical care. Participants were skeptical of the ability of *curanderos* to treat medical illness and did not express a great deal of trust for traditional healers. However, several Spanish-speaking participants stated they would go to a "naturalist" to supplement traditional medical care.

The cost of health care was an important issue for participants and was mentioned in all 11 focus groups. In all focus groups, health care costs were felt to be too high and represented a significant barrier to seeking care. However, Spanish-speaking participants also stated they knew they would receive health care in the United States regardless of their ability to pay for it, which was not true in some of their countries of origin.

Prejudice and Stigma

While most participants explicitly stated that TB could affect anyone and did not discriminate on the basis of race or socioeconomic factors, TB was usually described as a disease that affected persons belonging to a social group different from that occupied by the speaker. For example, members of the men's alcoholic recovery group stated they were at risk of being infected with TB because they were regularly in contact with "street people" and unknown people in Alcoholics Anonymous meetings. The homeless women said that people of "low income" and "low social status" were more susceptible to being infected with TB. One nonimmigrant participant said the incidence of TB has increased because immigration has increased. A Hispanic immigrant described a Chinese acquaintance being ill with TB. This projection of disease onto other social groups, particularly groups perceived as less desirable in the eyes of the participant, is evidence for the persistent stigma associated with TB:

> *There was a drunk in my town that died and he was lying on the corner coughing. That is, but he wasn't anyone I knew… we just knew he had TB, but…Oh, he was so skinny, you could see his skeleton. He didn't… he just had his skin hanging off, but I don't remember… I was little. I remember that we weren't to go near him. He was always on the corner.*

Participants also expressed a strong aversion to persons with TB. Many participants responded "Stay away" to the question "What would be your reaction to someone who you found out has TB?"

Willingness to Take Medication

Most participants responded when asked that they would be willing to take 9 months of oral medication to prevent TB (LTBI treatment). However, when the question was rephrased, emphasizing that LTBI treatment would consist of taking medication when one did not feel sick, the responses changed. For example, when subjects at one of the homeless shelters were asked "Would you be willing to take a drug every day for 9 months to prevent TB?" they answered unanimously in the affirmative. However, when asked, "Would you be willing to take a drug every day for 9 months if a doctor told you that you had TB even though you felt well and not sick?" they answered "it depends" or "not without a lot of tests."

Participants had various suggestions to improve patient adherence to LTBI therapy. Suggestions ranged from showing graphic pictures of people dying with TB to offering education about TB. One participant suggested that bringing LTBI therapy to the patient, rather than making the patient pick it up at the health department, would improve adherence. Many participants stated that incentives, including food and money, would be effective for increasing rates of LTBI treatment adherence. Emotional support by health care providers also was mentioned: "Give them encouragement for taking the pills" and "Spend time with the person so they don't feel so alone."

Several participants felt that persons who were in the habit of taking medications or vitamins every day would be more able to remember to take LTBI therapy. Conversely, participants were skeptical that persons who do not have regular, healthy practices could be expected to take medication every day:

> *I think the biggest problem is, is that right now a lot of people who would have to take it [the TB treatment], their lifestyle doesn't really coincide with doing things at a normal time, like taking the medicine every day is like taking a bath every day, well a lot of people on the street don't take a bath every day it would be hard to get them to do something on a regular basis all the time.*

Locus of Responsibility for Health

Participants' perceptions of who is primarily responsible for their health had important effects on attitudes toward TB prevention and treatment. Many participants felt responsibility for health care rests primarily with the individual:

> *Of course you are going to have people who aren't going to take it [treatment for LTBI] no matter how bad it is, 'cause they are just that way. But people who care about themselves and their health and their family are going to do it. You can't make people care, but they either care or they don't but the ones who do I think if they have the right information, if they were educated, they would.*

However, other participants placed the responsibility for TB prevention with health care providers and the health care system. For example, one participant said that she distrusted a local hospital, and when she was asked if this could ever affect her seeking out treatment there if necessary for TB, she responded "No, I would still go, but it would be up to them to do it all." Several participants believed that it is the health care professional's job to convince, coax, and bribe persons with LTBI or active TB into making healthful choices: "Society loves money, pay them." A summary of emergent themes with illustrative quotations is provided in Table 1.

Discussion

Misconceptions About Tuberculosis

As in reported studies,[8,11,15,18,18] we found participants had many inaccurate perceptions of TB cause and transmission. They frequently believed TB was transmitted by fomites, direct contact with another person's skin, and sharing eating utensils. These beliefs have been reported in a number of different populations including migrant farm workers[14] and Vietnamese refugees.[9] Participants inappropriately applied what they knew about other common diseases to TB. In particular, participants often applied what they knew about the spread of HIV to TB, and several participants said TB was transmitted "like AIDS." Like the present study, homeless persons surveyed in San Francisco similarly applied HIV concepts to TB transmission.[13] Participants appeared to apply knowledge of other diseases to TB; for example, "TB is only curable if caught early" may reflect knowledge about cancer. Although these statements attest to the efficacy of public health education efforts for other diseases, the resultant misinformation may have unintended deleterious consequences for TB control efforts. If TB is perceived (as it was by at least one participant) as an incurable disease (like HIV at present), patients will be discouraged from seeking care, thus delaying diagnosis with resultant increased transmission and morbidity.[12] Furthermore, perceptions that hand washing or other general hygienic measures prevent TB infection may give persons a false sense of security that they are protected from TB disease.[9] Tuberculosis education should stress the distinctions between TB and other diseases and must include information about cause, transmission, and treatment of LTBI and active TB.

Stigma

Stigma may have a significant impact on a person's willingness to be tested and treated for TB.[14,19] In a Chicago survey of African Americans with TB, study participants overwhelming reported feelings of embarrassment and isolation among their community, family, friends, and coworkers.[20] In another survey of Latinos receiving LTBI treatment, 17% of participants reported having TB was an embarrassment in their country of origin.[8] Stigma may result in severe social consequences; in one study in Mexico City 50% of hospitalized TB patients were not received back into their homes after hospital discharge.[21] Fear of being stigmatized by family, friends, coworkers, and community may be an important potential predictor for whether the patient initiates and completes therapy for LTBI.

Participants' Ideas on Adherence to Latent Tuberculosis Infection Therapy

Participants' ideas of what would affect an individual's likelihood to complete LTBI therapy can be divided into 3 groups: habits, social factors, and motivation. Health care-related habits may play a significant role in LTBI treatment adherence. A recent study of adherence to LTBI noted a positive univariate association between having a primary care physician and completion of LTBI treatment, and the belief that seeing a health care worker regularly keeps one healthy was also associated with treatment completion.[22] Social factors, including availability of stable housing, have been associated with likelihood to complete LTBI treatment.[23] Motivation is also clearly important when considering likelihood to complete LTBI treatment. Patients who feel they are at risk to develop active TB are more likely to complete LTBI treatment whereas those who expressed aversion to venipuncture (used in some patients for liver function monitoring) were less likely to complete treatment.[22] Understanding where different patient groups place responsibility for their health may be a key factor in designing strategies to improve adherence to LTBI treatment in these groups. The emotional dynamics between a particular health care provider and patient play an important role in patients' perceptions of responsibility for their health and resultant motivation to adhere to a treatment plan.[24] A study of Haitian immigrants demonstrated the importance of emotional needs related to the treatment of LTBI, and the authors concluded that a "personal approach" was an important aspect of treatment.[10] Some studies suggest that directly observed therapy, which provides for frequent one-on-one encounters between patients and health care workers, increases completion rates for LTBI treatment.[25] At least one study demonstrated that monetary incentives improve adherence to LTBI therapy among homeless persons.[23] The current study suggests the hypothesis that patients' attitudes toward emotional or financial incentives could predict initiation and completion of LTBI treatment.

Strengths and Limitations

The findings of this study are strengthened by the fact that our focus groups were assembled from 3 different high-risk populations and conducted in diverse settings. The demographic mix was also diverse with a balance of gender and ethnic groups. A standardized set of questions was used to guide the groups. In addition, the focus group transcripts were reviewed independently by 4 persons to identify recurring themes.

There were several limitations of this study. The subjects represented a convenience sample and may not be representative of their respective populations. The number of participants in each focus group was relatively small, with a small number of total participants from the drug/alcohol treatment centers, which may result in suboptimal theme saturation and reduced generalizability of the results. Furthermore, persons participating at the homeless shelters and drug rehabilitation facilities refused to provide demographic data. The 8 English-speaking focus groups were conducted by a white female, which may have affected the group dynamics. A focus group facilitator of a different sex, race, or age might possibly have provided a more conducive environment to talking about such a sensitive subject. Obviously, there are many high-risk populations that were not represented in this study (eg, non-Hispanic foreign-born persons, prisoners), but the 3 populations chosen are frequently targeted by TB control programs in the United States.

Implications

The information presented here regarding TB knowledge, attitudes, and behaviors in 3 key high-risk populations is a first step in understanding how to reduce the burden of TB in these populations. This study of 3 populations at relatively high risk for LTBI has identified several possible predictors of initiation and completion of LTBI therapy: (1) knowledge of cause, transmission, and treatment of LTBI; (2) stigma associated with TB; (3) health maintenance practices; and (4) financial and emotional needs. We intend to use these potential predictors to develop a survey that will be administered to persons with LTBI prior to initiation of LTBI treatment. Survey responses can then be correlated with adherence to LTBI treatment, and specific interventions can be developed to improve LTBI adherence when specific knowledge deficits, attitudes, or beliefs are expressed. **NCMJ**

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Call for Papers

John W. Williams Jr, MD, MHS
Scientific Editor, *North Carolina Medical Journal*

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POLICY FORUM

Taking Care of Those Who Serve

> *"Through carefully crafted polices, education of our clinical workforce, and intelligent research investments, North Carolina can excel in meeting its obligation to support the health needs of its citizen soldiers."*

COMMENTARIES

INTRODUCTION

Policy Forum:
Taking Care of Those Who Serve

There has been a steady flow of information from the War on Terrorism since Operation Enduring Freedom began in October of 2003. As the war expanded into Iraq and continues today, more American families and communities are feeling its impact. Children, spouses, parents, friends, and neighbors are regularly leaving for war and returning from combat. Safety and health in the war zone are the greatest concerns of those seeing loved ones leave. They hope their soldiers will never need medical care during their service but are comforted to know that, if needed, the military will provide them with immediate and necessary care.

Once our soldiers return home, those with serious physical injuries will need ongoing care. In addition, those who served without obvious physical harm may also need assessment and attention. As noted in this issue of the *Journal*, as many as 20% of active and 40% of reserve soldiers returning from a combat theater may have a mental illness and should have mental health services available to them. Fortunately, the Veterans Health Administration (VHA) is prepared to address both the physical injuries and mental illnesses of our soldiers.

This issue of the *Journal* describes how VHA has identified the mental health and physical needs of our returning soldiers and is responding to these needs by modifying both its assessments of soldiers and services for soldiers. The Veterans Health Administration also has developed new mental health screenings, instituted a second mental health screening, and is strongly encouraging military personnel to seek care for more than just bodily injuries. It is doing more to reach out to families of deployed service members to be sure they have access to community supports while their loved ones are abroad.

Despite the presence of multiple VHA facilities in North Carolina, many servicemen and women are accessing care outside of VHA. For example, National Guard and Reserve personnel frequently live in communities away from a base or a VHA facility and are more likely to access care in a private practitioner's office. This pattern of care seeking is particularly relevant for our readers practicing medicine across North Carolina. Included in the commentaries in this issue of the *Journal* are resources and recommendations for providers serving returned soldiers: Recognize your patients' connections to the military. If possible, identify returning soldiers and ask questions of them and their families to assess how reintegration or reunification may be affecting their health and well-being. When concerned about a patient, access resources such as those outlined in these commentaries that may help in determining the need for referrals or additional care.

Our military forces and their families have made and continue to make great sacrifices for our state and nation. We hope this issue of the *Journal* offers examples and information that can help providers across the state offer the best care to these brave and much valued members of our communities.

Thomas C. Ricketts III, PhD, MPH
Editor-in-Chief

Kristen L. Dubay, MPP
Managing Editor

Serving the Health Needs of Our Military and Veterans

John W. Williams Jr, MD, MHS

"...to care for him who shall have borne the battle, and for his widow and his orphan."
— Abraham Lincoln, Second Inaugural Address

War has a profound adverse affect on public health.[1] In times of war rates of infectious diseases, malnutrition, mental illness, and mortality increase for both combatants and civilian noncombatants. Weapons of war are associated with increased malignancies (eg, Agent Orange, atomic weapons), chronic illnesses such as Diabetes mellitus (eg, Agent Orange), sensory impairment (eg, decreased hearing in artillery gunners), and of course, traumatic injuries. In the past 100 years, the US has been directly involved in 6 major wars (World War I, World War II, Korea, Vietnam, the Persian Gulf, Iraq) and fielded active combatants in other conflicts (Grenada, Panama, Somalia, Bosnia and Herzegovina, Afghanistan). We have been at war in Iraq since March 19, 2003 where over 1 500 000 Americans have been deployed.[2] Thankfully, most of these troops will return home unscathed, but for those who are injured the nature of the injuries are presenting new challenges for the health care system.

North Carolinians play an important role in supporting our military forces, hosting major military bases at Fort Bragg, Pope Air Force Base, Seymour Johnson Air Force Base, and Camp Lejune. Many of our citizen soldiers from the ranks of the active reserve and the National Guard have been called up. In the health care sector, North Carolina clinicians care for our troops, their families, and our veterans. Given the major presence of the military in North Carolina, we are devoting this issue of the *North Carolina Medical Journal* to the health and health care of our active duty and retired military forces. We hope that by shining a spotlight on the health effects of war we will help North Carolinians better serve our military personnel and veterans, encourage the private sector and military medicine to share best practices, and stimulate policy makers to proactively plan for the effects of war on our communities and health care system.

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Who Are Our Military Personnel and Veterans?

America's fighting forces number 1.4 million men and women from all across the nation with the largest proportion, over 40%, coming from the southern United States. Of these,

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106 838 are based in North Carolina, the fourth largest concentration of active duty members in the continental US (Department of Defense Public Affairs Office, oral communication, November 2007). During the Vietnam War, the average soldier in a combat unit was 19 or 20 years old, male, and unmarried. Less than 0.5% of the 2 594 000 who served in Vietnam were women; most of these were nurses.[3] Since the advent of the all-volunteer military in 1973, its composition has changed substantially. Today, our active duty military are older (median age 39.5 years), more educated, more female (14.6%), more likely to be married (50%), and more ethnically diverse (35% minorities). Both the wealthy and the most socioeconomically disadvantaged members of society are underrepresented.[4]

When active duty military exit the service they become veterans. For some, the word veteran evokes unfortunate images of "down and out" individuals, images that are reinforced by movies such as *Born on the Fourth of July*. Data from the US Census Bureau paint a sharply different picture.[5] Just over 10% (23 425 051) of American adults and 11.4% of North Carolina adult civilians are veterans of the armed services. Approximately one-third are Vietnam veterans; the next largest group (18.7%) are veterans of the Gulf War. Veterans are disproportionately male (93%) and younger than the civilian population. Compared to the entire American adult population, veterans are more likely to be White (84.7% vs 75.0%), have some college education (58.3% vs 53.8%), and live above the poverty level (94.1% vs 88.3%) despite having higher rates of disability (26.8% vs 17.3%). Among individuals age 18 to 64 years, employment rates are almost identical to the civilian population. Given the changing demographics of our active duty forces, we can expect the future composition of our veteran population to be more ethnically diverse and more female.

These changing demographics have important implications for our communities. In past wars, we agonized as our sons marched off to war. Now it is increasingly likely that our spouses and daughters will be marching beside them. Consequently, the disruptive effects of war may be magnified for families and communities. From a public health perspective, we need to consider how best to meet the needs of families who keep the home fires burning and be prepared to care for wounded warriors and facilitate reintegration into civilian life. In this issue of the *Journal*, Denisse Ambler describes the effect of war on military families, and Steven Moore describes the Citizen Soldier Project, a federally-funded program to build bridges between community resources and families in North Carolina.

The Price of War: Effects on Health

As of late 2007, over 28 000 service members had been wounded in Iraq.[6] Most were treated and returned to duty within 72 hours, but over 3000 had serious injuries requiring intensive, long-term care including severe traumatic brain injuries, amputations, burns, blindness, or polytrauma. Traumatic brain injury (TBI), a signature injury because of its higher incidence in this war is estimated to affect about 50% of soldiers injured in combat; most TBI is classified as mild. Traumatic brain injury may cause headaches, sleep disturbances, and sensitivity to light and noise. Adverse effects on cognition include disturbances in attention, memory, or language as well as delayed reaction time during problem solving. Depressed mood, anxiety, impulsiveness, and emotional outbursts are particularly troubling symptoms and may overlap with the symptoms of posttraumatic stress disorder (PTSD).[7] The long-term consequences of mild to moderate TBI are not fully known but current estimates are that one-third of TBI affected individuals will develop chronic symptoms. Compared to other major medical problems, we know relatively little about effective care for these individuals. George Jackson, Natia Hamilton, and Larry Tupler describe TBI in greater detail in this issue of the *Journal* and give recommendations for a brief screen and regional treatment resources. Kenneth Goldberg describes the epidemiology of health problems in Operation Enduring Freedom (OEF) and Operation Iraqi Freedom (OIF) veterans seeking care at the Veterans Health Administration (VHA).

Mental illnesses, the so-called "hidden injuries," are much more prevalent than major physical injuries, but like physical injuries, they are associated with combat exposure.[8,9] In a study of 88 235 Army soldiers and Marines returning from Iraq, clinicians identified 20.3% of active and 42.4% of reserve component solders as requiring mental health treatment.[10] Our citizen soldiers are reporting extraordinarily high rates of psychic trauma. Importantly, longitudinal studies are showing high rates of emergent PTSD symptoms that are manifest 3 or more months after return and perhaps after returning to civilian life.[10,11] In addition, the proportion of soldiers reporting interpersonal conflict (14% active and 21% reserve components) increased from time of return to follow-up assessment. Despite the high levels of morbidity, relatively few soldiers seek mental health treatment, and there is a substantial time gap between when a returning solider perceives the need for mental health services and the time the soldier receives them. In particular, soldiers report an unmet need for greater therapy/counseling, skills training, and information about mental health problems.[8,12] In this issue, Captain Michael Latzka describes an innovative Army program to bolster mental health services at 15 bases for active duty military seen in primary care settings.

The high rates of psychiatric symptoms in active duty military are supported by early data on OEF/OIF veterans who seek care in the VHA health care system. Through September 2005, 25% of the 103 788 OEF/OIF veterans seen at VHA received a mental health diagnosis.[13] Most initial diagnoses (60%) were made in nonmental health settings. Posttraumatic stress disorder was the single most common mental health diagnosis, but over one-half of patients had more than one mental health diagnosis. Neither the military nor VHA were fully prepared to cope with these extraordinary rates of mental illness. In response to the epidemiological data, VHA is attempting to expand its capacity and resources in mental health services. In this issue, Harold Kudler and Kristy Straits-Tröster present a practical clinical summary on the recognition and management of PTSD.

Edward Post and William Van Stone describe a VHA program to expand and better integrate mental health and primary care services. Both VHA and Army efforts to bolster mental health services are based on over a decade of rigorous research showing that care management models improve outcomes for patients with depression, an approach that is also showing promise for other mental health conditions.[14] These data have important implications for the state of North Carolina. Since the minority of veterans access the VHA health system, most veterans will be cared for in the private medical system. Few practices routinely screen for depression, PTSD, or TBI, and current reimbursement policies do not support evidence-based care management programs. Our public mental health services are already stretched thin and are unlikely to readily absorb the influx of new patients. Unmet mental health needs would likely have important negative impacts on our citizen soldiers, their families, and their employers.[15,16] North Carolina needs to carefully plan for increased mental health needs and monitor the accessibility and quality of services delivered.

Where Do Active Duty Military, Their Dependents, and Veterans Get Health Care?

"It is almost cliché now to find examples of a wounded Marine having initially been treated by a Navy Corpsman find himself medevac'ed by an Army helicopter to undergo emergency surgery at an Air Force Theater Hospital."[2] In the Vietnam era, 5 out of every 8 seriously injured service members survived; today, 7 out of 8 survive, many with injuries that in previous wars would have been fatal. In addition to better protective equipment, important operational and medical advances are saving lives and may have applications to civilian medicine. Past wartime medical advances included the rapid expansion in the use of penicillin in World War II and using emergency evacuation by helicopter in Korea and Vietnam. This latter advance was adopted by civilian trauma care with great success. In the current war, Forward Surgical Teams establish a functional hospital and operating team within 60 minutes of the combat zone.[17] For penetrating injuries, these teams have adopted a new approach of "damage control"—just enough surgery to stabilize the patient and then transfer to a higher level of care. In Vietnam, the average time from battlefield to arrival in the United States was 45 days; it is now less than 4 days. This change in management has improved survival rates, and some of the specific surgical approaches are being adopted in US trauma units. The crucible of war often stimulates medical advances that are applicable to civilian medical care.

As with much US medical care, health services for active duty, retired military, and veterans are provided by a complex web of services. The major health care options for nondeployed military and their dependents are the 68 military treatment facilities, the 154 military outpatient clinics, and TRICARE. TRICARE is the civilian care component of the Military Health System. TRICARE is a regionally managed health care program for active duty, activated Guard and Reserves, and retired members of the uniformed services, families, and survivors. In North Carolina, Womack Army Medical Center and its affiliated primary care clinics serve the greatest numbers of military service members.

The Veterans Administration (VA) was established in 1930 to consolidate and coordinate government activities affecting war veterans. In 1988 President Reagan signed legislation creating a new federal Cabinet-level Department of Veterans Affairs to replace the Veterans Administration. The Veterans Health Administration (VHA) is the component that implements medical programs and draws its mission from Abraham Lincoln's eloquent Second Inaugural Address. It is a single-payer, government-run health care system operating 153 medical centers, over 200 Vet Centers, and 875 outpatient clinics.[2] Over 4 million veterans are enrolled in VHA and compared to age-matched Americans, these veterans are more medically complex and poorer. North Carolina has 4 VHA Medical Centers, 2 large outpatient clinics, 6 community-based outpatient clinics, and 5 Vet Centers. Sara Haigh describes the VHA system and resources more fully in her commentary.

For multiple years running, veterans have been more satisfied with their VHA health care than patients in the private sector. Despite caring for medically complex patients, VHA has won accolades for quality of care that meets or exceeds that seen in the private sector.[18] In a Rand Corporation study, VHA matched or exceeded private sector quality scores in virtually every category studied, despite spending substantially less per patient than the national average.[19] For example, the VHA's prescription accuracy rate is greater than 99.997% compared to 92% to 97% in the private sector. Prescription accuracy has been improved by the intelligent use of technology—barcoding every medication dispensed. Among chronic care patients, VHA patients received about 70% of recommended care compared with about 60% in the private sector. Preventive care is even better with VHA patients receiving about 65% of recommended care compared to 20% in the private sector. The greatest difference between VHA and the national sample were in areas where VHA actively measured performance. While other reasons for the outperformance are not completely known, a sophisticated electronic medical record system, strong leadership with decentralized decision making, and investments in systematic quality improvement and applied research are clearly a large part of the quality gains. As America enters an election year with health care near the top of the voters agenda, VHA successes deserve closer examination for possible applications to the private sector. Eugene Oddone and Seth Eisen describe the national VHA medical research effort and examples of local impact.

Conclusion

The nature of war and the composition of our fighting forces have changed in important ways over the past 100 years. Soldiers are surviving more severe injuries that require longer term rehabilitation. Many of these soldiers will want to complete rehabilitation close to home, and there may be an opportunity for North Carolina treatment facilities to support this need.

Greater capacity for rehabilitation services is consistent with the general need to expand longitudinal care services in the US medical system. The rates of mental illness are higher than reported in previous wars—possibly due to the nature of combat but also likely related to better detection in military and VHA health facilities. Fledgling efforts to improve detection of mental illness and integration of mental health and primary care services in North Carolina need to be supported.[20] This is likely to require changes in reimbursement policies to support care management activities. Finally, it's clear that the military and VHA investment in applied research is yielding actionable data that allows for improved health services. North Carolina has made large private and public investments in medical research. We should ensure that a significant proportion has a high return on investment through better planning of workforce, services, and quality improvement. Through carefully crafted polices, education of our clinical workforce, and intelligent research investments, North Carolina can excel in meeting its obligation to support the health needs of its citizen soldiers. **NCMJ**

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The Veterans Affairs Health Care System in North Carolina

Sara Haigh

The mission of the Veterans Health Administration, one of 3 divisions of the United States Department of Veterans Affairs, is to "honor America's veterans by delivering exceptional health care that improves their health and well-being." In North Carolina, that mission is carried out through an integrated network of hospitals and community-based clinics that are designed to maximize coordination and communication between sites of care. This article presents an overview of the Department of Veterans Affairs, followed by a description of services available at VA facilities in North Carolina; a brief explanation of eligibility, enrollment, and benefits; and a description of VA's integrated health care system. Special emphasis is placed on services available to veterans now returning to North Carolina from participation in Operations Enduring Freedom and Iraqi Freedom.

Department of Veterans Affairs

The Department of Veterans Affairs benefits system traces its roots back to 1636 when the Pilgrims of Plymouth Colony were at war with the Pequot Indians. The Pilgrims passed a law which stated that disabled soldiers would be supported by the colony. Since that time the system has evolved to include disability compensation, insurance, vocational rehabilitation, and education benefits. The establishment of the Veterans Administration came in 1930 when Congress authorized the President to "consolidate and coordinate Government activities affecting war veterans." World War II resulted in not only a vast increase in the veteran population but also in a large number of new benefits enacted by the Congress for veterans of the war. The World War II GI Bill, signed into law on June 22, 1944, is said to have had more impact on the American way of life than any law since the Homestead Act more than a century ago. Further educational assistance acts were passed for the benefit of veterans of the Korean Conflict, the Vietnam Era, Persian Gulf War, and the All-Volunteer Force. The Department of Veterans Affairs (VA) was established as a Cabinet-level position on March 15, 1989.[1]

> *"In North Carolina, VA has launched special efforts to provide a 'seamless transition' for those returning from service in Operations Enduring Freedom and Iraqi Freedom (OEF/OIF). Each VA medical facility has a point of contact to coordinate activities locally to help meet the needs of these returning combat service members and veterans."*

The Department of Veterans Affairs is the second largest of 15 Cabinet departments and operates nationwide programs for

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health care, financial assistance, and burial benefits. The Veterans Health Administration, Veterans Benefits Administration, and National Cemetery Administration are the 3 main branches of the department, with the Veterans Health Administration (VHA) handling health care services.

Veterans Health Administration Services

In North Carolina, a system of hospitals, community-based outpatient clinics, and Vet Centers deliver the majority of health services to veterans.

Veterans Affairs Medical Centers

The Charles George VA Medical Center (VAMC)[3] in Asheville consists of a 116-bed acute care hospital and a separate 120-bed extended care and rehabilitation center serving western North Carolina as well as portions of South Carolina, Georgia, and Tennessee. The Charles George VAMC is a tertiary care facility providing primary, tertiary, and long-term care in the areas of medicine, surgery, psychiatry, physical medicine and rehabilitation, neurology, oncology, dentistry, geriatrics, and extended care. The Asheville facility also operates a home-based primary care program and a substance abuse rehabilitation treatment program.[4]

The Durham VA Medical Center is a 154-bed tertiary referral hospital with a separate 120-bed extended care and rehabilitation center. The facility serves as a major referral center for North Carolina, southern Virginia, northern South Carolina, and eastern Tennessee for subspecialty treatment, radiation therapy, neurological disorders, therapeutic endoscopy, high-risk open-heart surgery, and other special procedures. Special programs at Durham include the comprehensive Women's Health Center, a home-based primary care program, the Geriatric Research, Education, and Clinical Center (GRECC), the VISN 6 Mental Illness, Research, Education, and Clinical Center (MIRECC), the Center for Health Services Research in Primary Care, and the Epidemiology Research and Information Center (ERIC).[5]

The Fayetteville VA Medical Center is a general medicine and surgery and mental health facility with 90 beds. It also maintains a 69-bed long-term care unit. The medical center serves veterans in 19 counties in southeastern North Carolina and 2 counties in northeastern South Carolina. Comprehensive health care is provided through primary and long-term care in areas of medicine, surgery, psychiatry, posttraumatic stress disorder, ophthalmology, podiatry, physical medicine and rehabilitation, neurology, dentistry, geriatrics, and extended care. Tertiary care is referred to Durham VA Medical Center.[6]

The W G (Bill) Hefner VA Medical Center in Salisbury provides primary and secondary inpatient health care to more than 287 000 veterans living in a 23-county area of the central Piedmont region of North Carolina. This includes the Charlotte area with over 100 000 veterans and the Winston-Salem area with 65 000 veterans. Inpatient services include acute medicine, cardiology, surgery, psychiatry, and physical medicine and rehabilitation, as well as subacute and extended care.[7]

Veterans Affairs Community-Based Outpatient Clinics

Community-based outpatient clinics are located in Charlotte, Winston-Salem, Jacksonville, Wilmington, Raleigh, Greenville, and Morehead City. Additional community-based outpatient clinics are scheduled to open in Hamlet, Hickory, and Franklin by late 2008. Community-based outpatient clinics provide primary care, mental health, and selected specialty services and were established to improve geographic access for veterans. Patients receive prescriptions via a mailout pharmacy. If they need specialty care or testing, such as a CT scan or cardiology consultation, they are referred to a main VA hospital. In some cases, patients are referred to private providers on a fee-for-service basis when VA services are not available or the patient is not able to travel to a facility that provides the needed service.

Veterans Affairs Vet Centers

Vet Centers in Charlotte, Greensboro, Raleigh, Fayetteville, and Greenville are part of VA's Readjustment Counseling Service. Vet Centers provide psychological counseling for war-related trauma, community outreach, case management, and referral activities plus supportive social services to veterans and family members. Vet Centers are open to any veteran who served in the military in a combat theater during wartime or anywhere during a period of armed hostilities. Vet Centers also provide trauma counseling to veterans who were sexually assaulted or harassed while on active duty and bereavement counseling to the families of service members who die on active duty.[2]

The 4 North Carolina VA Medical Centers and 7 community-based outpatient clinics are components of the VA Mid-Atlantic Health Care Network (VISN 6), headquartered in Durham. VISN 6 includes an additional 3 VA Medical Centers in Virginia and 1 in West Virginia and 5 outpatient clinics. In fiscal year 2007, some 307 959 veterans received care throughout the network service area.

Eligibility, Enrollment, and Benefits

Eligibility for most veterans' health care benefits is based solely on active military service in the Army, Navy, Air Force, Marines, or Coast Guard (or Merchant Marines during WW II), with a discharge under other than dishonorable conditions. Reservists and National Guard members who were called to active duty by a Federal Executive Order may qualify for VA health care benefits as well. Returning service members (including Reservists and National Guard members) who served on active duty in a theater of combat operations have special eligibility for hospital care, medical services, and nursing home care for 2 years following discharge from active duty.

The Department of Veterans Affairs maintains an annual enrollment system to manage the provision of quality hospital and outpatient medical care and treatment to all enrolled veterans. A priority system ensures that veterans with service-connected disabilities and those below the low-income threshold are able to be enrolled in VA's health care system. Some veterans are exempted from having to enroll. This includes veterans with a service-connected disability of 50% or more, veterans discharged from the military within one year but not yet rated for a VA disability benefit, and veterans seeking care for only a service-connected disability. Veterans with service-connected disabilities receive priority access to care for hospitalization and outpatient care.

The Department of Veteran Affairs' enrollment allows health care benefits to become portable throughout the entire VA system. Enrolled veterans who are traveling or who spend time away from their primary treatment facility may obtain care at any VA health care facility across the country without the worry of having to reapply.

The Department of Veterans Affairs provides a medical benefits package to enrolled veterans which includes the following types of services:

- Hospital, outpatient medical, dental, pharmacy, and prosthetic services
- Domiciliary, nursing home, and community-based residential care
- Sexual trauma counseling
- Specialized health care for women veterans
- Health and rehabilitation programs for homeless veterans
- Readjustment counseling
- Alcohol and drug dependency treatment
- Medical evaluation for disorders associated with military service in the Gulf War or for exposure to Agent Orange, radiation, and other environmental hazards[2]

Integrated Health Care System

A great strength of the VA health care system is the integrated nature of the clinical care network. All sites use a computerized patient record system to document all aspects of care including office visits, provider orders, diagnostic tests, specialty consultations, prescriptions, procedures, and hospitalizations. Paper documents from non-VA providers are scanned into the electronic record as needed. The system allows a physician in Durham to look up past treatment, medication, and testing information on a patient from Fayetteville with a few clicks of the computer mouse. Since all information is typed, legibility is not an issue. The prescription ordering interface includes a variety of patient safety features such as checks for drug allergies, drug-drug interactions, or inappropriate dosing. For inpatient care, a bar code medication administration system is used to match the computerized drug order, the medication, and the patient to ensure the patient receives the right drug at the right dose at the right time. A special system of clinical reminders is used to facilitate compliance with clinical practice guidelines. For example, the computer will flag a patient who is due for an annual mammogram or depression screening. It alerts providers to patients with out-of-range lab values or abnormal radiology results by sending an electronic notification.

Another way that VA ensures health care delivery is consistent across all sites of care is through an extensive performance management system. Clinical performance measures are used to assess key aspects of the care process such as diabetes control, management of hypertension or hyperlipidemia, screening for posttraumatic stress disorder or depression, and cancer prevention. Other measures assess the process of care delivery by looking at waiting times for appointments, patient satisfaction, and utilization of hospital beds. Data is collected at all VA sites of care and compared to VA and private sector benchmarks. The performance measure system is woven into performance plans and appraisal systems for VA managers and care providers with physician pay being linked to performance.

Post Conflict Care: The Department of Veterans Affairs Newest Wounded Warriors

In North Carolina, VA has launched special efforts to provide a "seamless transition" for those returning from service in Operations Enduring Freedom and Iraqi Freedom (OEF/OIF). Each VA medical facility has a point of contact to coordinate activities locally to help meet the needs of these returning combat service members and veterans. Special interdisciplinary care teams work with National Guard Units to provide onsite information about VA health care benefits to troops returning from deployment. They also perform health care screenings and enrollment to those wishing to access VA health care. In addition, VA has increased the staffing of benefits counselors at key military hospitals where severely wounded service members from Iraq and Afghanistan are frequently sent. Once home, recent Iraq and Afghan veterans have ready access to VA health care which is free of charge for 2 years following separation for any health problem possibly related to wartime service. According to the VA Mid-Atlantic Health Care Network Data Warehouse, over 14 300 active duty service members and veterans of the Global War on Terror have sought VA health care in North Carolina since September 11, 2001. Special polytrauma care units have been established at VA medical centers, and screenings for the possible presence of traumatic brain injury is provided to every OEF/OIF enrollee. President Bush's Commission on Wounded Warriors and the President's Task Force on Returning War on Terror Heroes have recently generated additional recommendations on how VA can provide speedier, fairer, and more efficient care to returning veterans of the Global War on Terror.[8]

Focus on the Future

This is a time of challenge for VA health care. It must meet the needs of its newest veterans by providing individualized case management services while also maintaining the historic commitment to providing the highest quality care to veterans of all eras. The ability to respond quickly to new needs is sometimes affected by the Congressional budget and capital project approval and funding processes which may create a lag between when new demands for care arise and when the facilities and resources are in place to meet those needs. The Department of Veterans Affairs has successfully responded to past challenges through the dedication of its staff and an ongoing commitment to its special mission. As the other articles in this issue show, the full attention of VA's clinical and research community is focused on meeting the health care needs of veterans by fulfilling the charge made by President Abraham Lincoln in his 1862 inaugural address: "To care for him who shall have borne the battle, and for his widow, and his orphan." **NCMJ**

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COMMENTARY

The Epidemiology of Health Problems in Returning Operation Iraqi Freedom and Operation Enduring Freedom Veterans

A National and North Carolina-Based Summary

Kenneth C. Goldberg, MD

As large numbers of veterans return from military service in Operation Iraqi Freedom and Operation Enduring Freedom (OIF/OEF), policy leaders will need to anticipate their health concerns and align resources to serve those needs. This population of recent veterans is younger, much more likely to be female, and has a unique set of medical and mental health needs that vary significantly from those of the majority of the veterans who obtain health care from the Veterans Health Administration (VHA). Although the care provided to these newest veterans is a small portion of the total care provided to veterans enrolled in VHA facilities, these veterans represent a rapidly growing proportion of the veterans being served.

As this is a diverse and mobile population, it is difficult to obtain definitive information about its health care needs. The following information is synthesized from multiple national, regional, and local data sources. Most data are provided by sources within VHA. This is the single most reliable and available source of information, and returning veterans are actively encouraged to seek assistance for health care needs at VHA facilities.

> *"the 3 most common health problems reported [by veterans of the wars in Afghanistan and Iraq] are musculoskeletal ailments (principally joint and back disorders), mental health disorders, and 'symptoms, signs, and ill-defined conditions.'"*

National Data

As a working definition, we consider service members discharged from the Armed Forces beginning in fiscal year 2002 as returning OIF/OEF veterans. This does not include veterans who served in the first Gulf War, but it may include veterans who served recently and did not see combat. As with any group this large, it is problematic to make generalizations about their experience or health care needs.

With those caveats, there are approximately 4.4 million veterans of the OIF/OEF conflicts, of whom 720 000 have become eligible to receive health care within VHA since the beginning of fiscal year 2002 after completing their military service.[1] Of these, 47% are former active duty troops, and the remainder served in the Reserve forces and with National Guard units. To date, approximately 252 000 (35%) eligible OIF/OEF veterans have sought care through the VHA system. This is a significantly higher percentage than the estimated 20% of the entire veteran population that receives health care through VHA. To place this number in perspective, however, the VHA system currently provides care to a total of approximately 5.5 million veterans. Therefore, although 35% of eligible OIF/OEF veterans have sought care, these newest veterans represent only 5% of the total number of veterans served by VHA.[2]

Of the care the OIF/OEF veterans have received through

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the VA Medical Centers (VAMC), 94% of the visits have been to outpatient clinics, and 4% of the encounters have occurred in an inpatient setting. When analyzed and grouped by diagnosis codes, the 3 most common health problems reported are musculoskeletal ailments (principally joint and back disorders), mental health disorders, and "symptoms, signs, and ill-defined conditions."[2]

Approximately 350 000 (48%) OIF/OEF veterans have been seen at least once at a Vet Center. These centers, of which there are currently 207 throughout the country, focus on issues specific to combat veterans and their families. They are based outside of major medical facilities and deliver counseling and outreach services.[1]

Almost 95 000 (38%) OIF/OEF veterans have received care for mental health-related problems through the VHA system. Table 1 lists the coded diagnoses assigned to those visits by category of mental health problem. Posttraumatic stress, substance abuse (which includes tobacco abuse), and depression are the most frequently coded diagnoses.[2]

Table 1.
Coded Mental-Health Diagnoses Attributed to 94 921 OIF/OEF Veterans Who Have Received Health Care Services at Veterans Affairs Medical Centers Nationwide.[2]

Psychiatric Diagnosis (ICD-9CM code)	Percent (%) of Total
PTSD (309.81)	26
Nondependent abuse of drugs (305)	21
Depressive disorders (311)	17
Neurotic disorders (300)	14
Affective psychoses (296)	9
Alcohol dependence syndrome (303)	4
Sexual deviations and disorders (302)	2
Special symptoms, not elsewhere classified (307)	2
Drug dependence (304)	2
Acute reaction to stress (308)	2

North Carolina Data

There are 4 Veterans Affairs Medical Centers in North Carolina. They are arranged into a larger organizational unit, The VA Mid-Atlantic Health Care Network, which also operates medical centers in Virginia and West Virginia. Together they provide comprehensive, integrated primary, specialty, and inpatient care. The location of these facilities in North Carolina is shown in Figure 1.

Of the 147 000 enrolled North Carolina veterans, approximately 12 000 (8%) are considered OIF/OEF veterans. This is a slightly higher percentage than that seen in the national veteran population, reflecting the large number of military bases in North Carolina. Table 2 describes the demographic characteristics of this group. Compared to the overall population of veterans served by the VA system, this group is younger and contains more women. Considering this is a group of recently discharged veterans, there is a surprising percentage of older veterans. More than one-third of this group deployed to a combat theater more than once. (M. Gentry, oral communication, November 2007.)

Table 2 also lists the service-connected ratings of current OIF/OEF veterans. A service-connected rating is essentially a disability score awarded by the Veterans Benefits Administration (which is separate from the Veterans Health Administration) for injuries or conditions either caused by or diagnosed during military service. Higher

Figure 1.
Locations of the Major Veterans Affairs Medical Centers in North Carolina as Well as Their Affiliated Satellite Facilities[3]

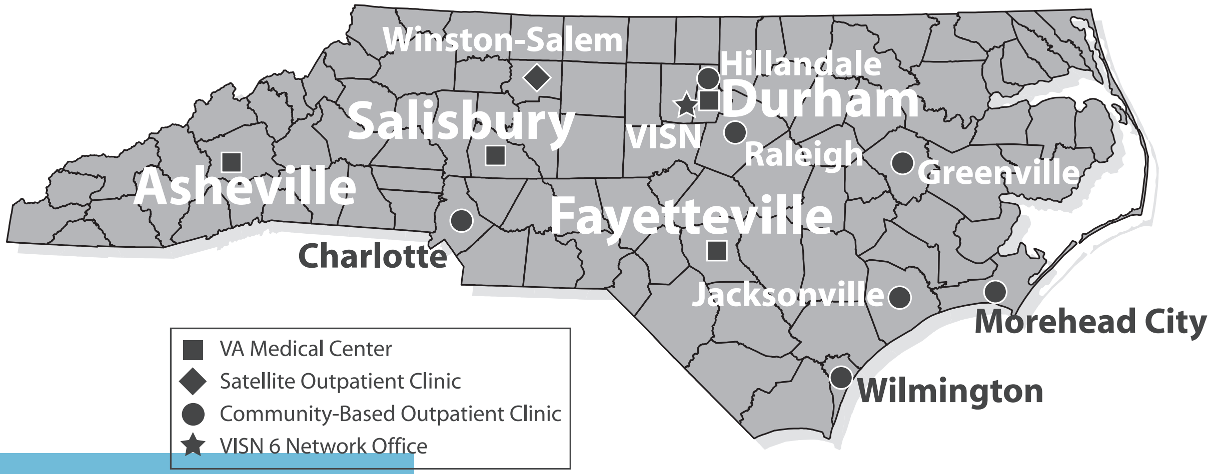

Table 2.
Demographic Breakdown of OIF/OEF Veterans Registered to Receive Care at North Carolina-Based Veterans Affairs Medical Centers

Variable	Category	Percent (%)
Service	Air Force	14
	Army	61
	Coast Guard	0.05
	Marine Corps	21
	Navy	4
Multiple deployments	Yes	37
	No	63
Marital status	Divorced	4
	Married	48
	Never married	46
Age (years)	<25	15
	25-29	32
	30-34	15
	35-39	11
	40-44	14
	>=45	14
Sex	Male	88
	Female	12
Race	Black	23
	White	68
	Hispanic	4
	Other	2
	Unknown	3
Service-connected status	None	64
	0%	25
	1%-49%	8
	>=50%	3

Source: M. Gentry, oral communication, November 2007.

ratings reflect greater disability, and ratings greater than 50% are designed to reflect severely disabling conditions. Compared to the general population of veterans followed by VHA, the OIF/OEF veterans are significantly less likely to have been assigned a service-connected disability. Veterans need to apply specifically to receive this rating, and many do not initially apply upon leaving the service. Once a veteran applies, the application process itself can take months or sometimes years to complete, and the percentage of veterans with a service-connected injury is expected to rise over time. The proportionally smaller number of OIF/OEF veterans with service-connected disabilities may also reflect the change from a prior policy of not allowing some veterans without service connection to enroll in the VA system and thereby selecting for veterans with service-connected disabilities. This service connection restriction does not apply to OIF/OEF veterans.

One particular disability that is associated with OIF/OEF service is traumatic brain injury. Limitations primarily in medical knowledge about the spectrum of this condition make the collection of data difficult. However, the VA has an aggressive system that attempts to identify veterans who may have suffered traumatic brain injuries. At the Durham VAMC, between April and September 2007, almost 3000 veterans were screened for traumatic brain injury (80% of them OIF/OEF veterans). (B. Capehart, oral communication, October 2007.)

Another high-profile injury from the recent conflict is "polytrauma," or severely injured veterans. These veterans have suffered significant injury that has affected multiple organ systems, often resulting in amputation and cognitive deficits. At this time the North Carolina VAMCs are currently managing fewer than 100 of these veterans (M. Gentry, oral communication, November 2007).

Table 3 summarizes care that OIF/OEF veterans have received through the North Carolina VAMCs in fiscal year 2007. The care provided to these veterans during that year is almost equal to the cumulative number of visits provided in fiscal years 2002 through 2006, showing that as more and more veterans of the recent conflict become eligible for VHA care, their use of the system is growing exponentially. Table 4 lists the most common types of outpatient visits from fiscal year 2007. Compared to veterans from other periods, OIF/OEF veterans are far more likely to be seen in a mental health clinic. Table 5 lists the primary treating specialties of the inpatient care received during the same period. Inpatient stays for

Table 3.
Geographic Breakdown of OIF/OEF Veterans Who Received Care at North Carolina-Based Veterans Affairs Medical Centers in Fiscal Year 2007

Visit Type	Facility	Visits by OIF/OEF Veterans	Percent (%) of Total
Inpatient	Durham	94	1.94
	Fayetteville	69	3.88
	Salisbury	86	3.69
	Asheville	51	1.54
	Total	300	2.45
Outpatient	Durham	1351	1.90
	Fayetteville	1861	2.89
	Salisbury	1652	1.81
	Asheville	405	0.90
	Total	5269	1.86

Source: M. Gentry, oral communication, November 2007.

Table 4.
Outpatient Visit Types by OIF/OEF Veterans, Fiscal Year 2007, All North Carolina Facilities

Clinic	Visits	Percent (%) of All Visits by OIF/OEF Veterans
Primary care	5589	11.0
Mental health	5062	10.0
Emergency department	1023	2.0
Physical therapy	783	1.5
Dental	624	1.2

Source: M. Gentry, oral communication, November 2007.

Table 5.
Inpatient Admission Types by OIF/OEF Veterans, Fiscal Year 2007, All North Carolina Facilities

Ward Type	Visits	Percent (%) of Inpatient Stays
Surgery	50	17
Medicine	71	24
Psychiatry	175	58

Source: M. Gentry, oral communication, November 2007.

recent veterans are far more likely to occur on a psychiatric ward, and somewhat more likely to occur on a surgical ward, than they are for veterans from other periods whose hospitalizations are more likely to occur on a medicine service.

Limitations

The preceding data are the best available to provide a synthesis of the objective health needs of North Carolina OIF/OEF veterans. Unfortunately, the majority (65%) of OIF/OEF veterans have not sought care through the VHA system. It is very possible that veterans who seek VHA care differ from those veterans who do not. At this time there is no systematic and accessible system that tracks the health needs of veterans not served by VHA, so analysis of VHA data remains the best and currently only method to estimate the health needs of the entire group.

It is also likely that the needs of OIF/OEF veterans will change over time. It has already been documented that screening tools used to identify posttraumatic stress among recently returning veterans likely underestimate the prevalence of this disease, and identified cases will increase over time.[4]

Furthermore, much of the data presented here derive from specialized queries performed explicitly for this manuscript and may not be completely reproducible. **NCMJ**

Acknowledgement

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COMMENTARY

Veterans Affairs Research and Development:
Using Science to Improve Health Care for Veterans

Eugene Z. Oddone, MD, MHSc; Seth Eisen, MD, MSc

The Veterans Affairs Office of Research & Development (ORD) is a congressionally mandated research program established in 1947 whose mission is to study all aspects of health and disease relevant to our nations' veterans. The Office of Research & Development consists of 4 research services including the Biomedical Laboratory, Clinical Science, Rehabilitation, and Health Services. The Biomedical Laboratory Research & Development Service conducts research that explores basic biological or physiological principles in humans or animals. The Clinical Science Research & Development Service (Clinical Science) conducts research that focuses on human subjects including interventional, clinical, epidemiological, and technological studies. Clinical Science houses the VA Cooperative Studies Program which has conducted landmark studies over the last 50 years that have established the effectiveness of new treatments for tuberculosis, hypertension, and coronary artery disease to name only a few. The Rehabilitation Research & Development Service conducts research exploring areas where technology can enhance or sustain veterans' independence. Lastly, the Health Services Research & Development Service pursues research at the interface of health care systems, patients, and health care outcomes. Its researchers examine all aspects of VA health care including access to care, adherence to quality of care standards, methods of improving quality of care and patient outcomes, the impact of health system organization on care, and cost of care. The Veterans Affairs Office of Research & Development is the only national research entity that is tied directly to a fully integrated health care system—the Veterans Health Administration. In fiscal year 2007 Congress appropriated $480 million in direct funding for ORD. VA Research is an intramural program that funds only eligible VA employees through a rigorous merit review process. The majority of funded VA researchers are also VA clinicians, and their research is conducted within VA. Veterans Affairs researchers are also very successful in obtaining non-VA, other federal, and foundation funds through competitive extramural grant programs. Veterans Affairs researchers also are faculty members at affiliated academic institutions.

> *"The Veterans Affairs Office of Research & Development is the only national research entity that is tied directly to a fully integrated health care system—the Veterans Health Administration."*

VA's primary research mission is to investigate health issues that are of primary relevance to veterans. However, because the diseases and conditions studied in VA are also prevalent in the general population, VA research is widely relevant to civilian health. As such, Congress requires a continuing review of relevance and applicability. The VA research mission has gained importance given the burden of disease and injury in veterans. Research on chronic medical illnesses has dominated the research program for the last two decades reflecting the prevalence and burden of cardiovascular, neurological, and pulmonary diseases as well as cancer in the aging veteran population. With the more recent conflicts in Afghanistan and Iraq, VA has seen an

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influx of younger patients with both physical and mental trauma as well as other complex and chronic conditions. There has been a surge of interest in research designed to diagnose and treat these conditions. Congressional 2007 appropriations included $32.5 million for research in areas of importance to these veterans including traumatic brain injury, sensory loss, spinal cord injury, and posttraumatic stress disorder.

Quality Enhancement Research Initiative

One unique feature of VA research is its close association with the health system. While most academic research programs are conducted by university-based independent investigators, VA researchers are tied more directly to the health care system and the patients they serve. As an example, in 1998 the VA Health Sciences R&D program launched the VA Quality Enhancement Research Initiative (QUERI).[1,2] The QUERI mission is to enhance the quality and outcomes of VA health care by systematically implementing clinical research findings and evidence-based recommendations into routine clinical practice. In evaluating quality of care, the QUERI process focuses on 3 elements: structure (provider and organizational characteristics), process (practitioners' clinical actions toward patients), and outcome (health status, economic impact, satisfaction). The Quality Enhancement Research Initiative is founded on the principle that practice needs determine the research agenda, and research results determine interventions that improve the quality of patient care. It is a comprehensive, data-driven, outcomes-based quality improvement program that utilizes a 6-step process to facilitate the implementation of research findings and evidence-based clinical practices to achieve better health care outcomes for veterans. Steps in the QUERI process are:

1. Identify high-risk/high-volume diseases or problems.
2. Identify best practices.
3. Define existing practice patterns and outcomes across VA and current variation from best practices.
4. Identify and implement interventions to promote best practices.
5. Document that best practices improve outcomes.
6. Document that outcomes are associated with improved health-related quality of life.

The Quality Enhancement Research Initiative focuses on 9 diseases and conditions that are prevalent among veterans. These include chronic heart failure, diabetes, HIV/hepatitis, ischemic heart disease, mental health problems, polytrauma and blast related injuries, spinal cord injury, stroke, and substance abuse. Functionally, there is a research coordinator and a clinical coordinator as well as a cadre of experts for each of the 9 QUERI areas. These 9 focused groups of experts develop strategic plans and form collaborations with VA central, regional, and health center-based facilities across the country to develop and conduct projects to improve quality of care to veterans.

Operation Iraqi Freedom/Operation Enduring Freedom

VA Research & Development has made working to address the health care needs of our military returning from conflicts in Iraq and Afghanistan a top research priority. VA investigators are working on developing new knowledge, effective tools, and innovative ways to evaluate and treat polytrauma, mental health issues such as depression and post traumatic stress disorder, spinal cord injury, traumatic brain injury, amputations and prosthetics, and burns.

Veterans Affairs Research in North Carolina

In North Carolina, the Durham VA Medical Center has one of the oldest and largest research programs in all of VA. From its founding date in 1953, all clinical faculty have been recruited to VA with dual academic appointments at Duke University, and key leadership positions in VA have been staffed by clinician scientists. Thus the clinical expertise of VA was tied closely to the research mission. Throughout its history Durham VA has provided significant basic, clinical, and health services research training opportunities for both PhD trained and clinician scientists in the form of fellowships and postdoctoral programs as well as career development and enhancement programs. The VA medical centers in Asheville and Salisbury, North Carolina maintain smaller research programs.

In 1981 the Health Services Research Program at Durham VA was funded as one of the initial national Field Programs in Health Services. It has grown into one of the largest Centers of Excellence in Health Services Research now focusing on issues relevant to access, quality, and outcomes of primary care for veterans. The Durham Epidemiology Research and Information Center was established in 1990 as 1 of 3 national epidemiology centers in VA. Its areas of expertise are in neuroepidemiology and genomics. There are several examples of clinically relevant research in North Carolina including amyotrophic lateral sclerosis, managing hypertension outside a clinic, and posttraumatic stress disorder.

Amyotrophic Lateral Sclerosis

Amyotrophic lateral sclerosis (ALS) is an adult-onset, fatal neuromuscular disease involving progressive degeneration of upper and lower motor neurons with clinical manifestations including muscular weakness, atrophy, and spasticity with exaggeration of tendon reflexes. Concern about potential environmental exposures in the context of military service in the 1990-1991 Gulf War was an important factor in the formulation of the ALS Gulf War study run by investigators at the Durham Veterans Affairs Medical Center (VAMC).[3,4] In an effort to stimulate both etiologic and therapeutic research on ALS in veterans, the VA Cooperative Studies Program developed a National Registry of Veterans with ALS.[5] The objectives of the registry are to identify living US military veterans with ALS, track their health status and disease progression over time, collect data (including DNA) that will be available for multiple epidemiologic studies of ALS, and provide a mechanism for informing veterans with ALS about clinical trials for which they may be eligible. This VA registry is the largest fully specified cohort of patients with ALS worldwide with over 2400 patients now enrolled, 1200 of whom have provided DNA samples for future research. Because ALS is a relatively rare disease, it is often difficult to identify sufficient numbers of patients for important epidemiologic and genetic studies. It is VA's hope that the resource created in the registry will lead to important discoveries for patients with this lethal disease. To date, over 20 different investigators (both VA and non-VA) have received access to this important resource.

Managing Hypertension Outside the Clinic

Hypertension is the most common reason for primary care clinic visits both at VA and nationally. Because a significant proportion of civilian and veteran patients remain above evidence-based targets for blood pressure control, researchers at Durham VA have designed and tested a multicomponent intervention that promotes patient self-management by establishing practices around adherence to best behaviors and medication management.[6-8] This multicomponent intervention uses a combination of telehealth blood pressure monitoring devices, scripted text delivered by nurses, and medication changes initiated and monitored centrally by physicians. The main goal of this research was to move the management of hypertension outside the context of a clinic visit and into the patient's home. A series of studies have established the safety of this method of care, and ongoing research is addressing its effectiveness. Elements of this system are being tested in a pilot project in North Carolina's Medicaid population.

Posttraumatic Stress Disorder

Posttraumatic stress disorder (PTSD) is a serious and prevalent problem in veterans. While PTSD has clearly been present in all wars and conflicts, our understanding of the long-term consequences of this illness did not emerge until after the Vietnam War. VA investigators have led the nation by conducting research designed to better understand the etiology, diagnosis, and treatment of PTSD. A recent study established that as many as one-third of veterans returning from conflicts in Iraq and Afghanistan experience some psychological problems, half of whom are diagnosed with PTSD.[9] While much of current treatment is focused on patients reexperiencing the traumatic event that precipitated the disorder, researchers at Durham VA are examining the potential benefits of a treatment called "guided imagery." In a novel study that compares the effectiveness of soothing music alone to the effectiveness of tailored audio instructions and soothing music treatment delivered in the veteran's home using a dedicated personal digital assistant (PDA), researchers will discover if guided imagery will allow veterans with this debilitating disorder to achieve symptom resolution and enhanced quality of life. If the intervention proves to be successful, it is likely to be a very cost-effective treatment modality for the growing number of veterans with PTSD.

Summary

VA has a rich tradition in supporting research in areas that span basic science to health system implementation. Its unique success is tied to the fact that researchers are focused on issues that arise from a unique population—our nation's veterans. Moreover, because VA is the largest integrated health system in the country and because the health system must manage an annual budget, there is a keen interest among VA health administrators to apply research that enhances quality and efficiency of care. Furthermore, because these findings overlap with the general population, VA Research & Development programs can be applicable on a much broader scale. **NCMJ**

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North Carolina
MEDICAL JOURNAL

COMMENTARY

Identifying and Treating Post Deployment Mental Health Problems Among New Combat Veterans

Harold Kudler, MD; Kristy Straits-Tröster, PhD

North Carolina is one of the nation's most military friendly states because it is home to more than 101 000 active-duty military personnel at Fort Bragg, Pope Air Force Base, Camp Lejeune Marine Corps Base, Seymour Johnson Air Force Base, the US Coast Guard Air Station at Elizabeth City, and Marine Corps Air Stations at New River and Cherry Point. In addition, North Carolina has 164 Army and Air National Guard units comprised of nearly 12 000 members as well as another 10 234 Army, Navy, Air Force, Marine, and Coast Guard reservists.[1] North Carolina-based military units have played an important role in the Global War on Terror including multiple deployments to Operation Enduring Freedom (OEF) in Afghanistan and Operation Iraqi Freedom (OIF). Many servicemen and women have families in the state and many choose to make North Carolina their home when they become veterans. The effects of war reverberate across our state and within each of our local communities.

> *"The stigma associated with seeing a mental health provider will often drive combat veterans and their family members to seek help in primary care settings, but primary care practices are not always well prepared to identify or treat such problems."*

Treating Post Deployment Mental Health Problems in Community Settings

While it might be natural to expect that any post deployment mental health problems of service members and veterans would be identified, assessed, and treated within the Department of Defense (DoD)/Department of Veterans Affairs (VA) medical care continuum, the available data suggest otherwise. Hoge and colleagues from the Walter Reed Army Institute of Research[2] found significant reticence to discuss post deployment mental health problems in military settings among service members who had served in OEF/OIF. The National Vietnam Veterans Readjustment Study[3] showed that only 20% of Vietnam veterans with a diagnosis of posttraumatic stress disorder sought VA care. Thus far, only about 1 out of every 3 OEF/OIF veterans eligible for VA care has applied for that care. Taken together, these findings indicate that many OEF/OIF veterans may seek care outside of DoD and VA. Their family members are also subject to significant deployment-related stress, and they too will be seeking help in the greater community. The stigma associated with seeing a mental health provider will often drive combat veterans and their family members to seek help in primary care settings, but primary care practices are not always well prepared to identify or treat such problems.[4] This

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article provides essential information on screening for, assessing, treating, and, when necessary, triaging disorders associated with military deployment.

Screening

Posttraumatic stress disorder (PTSD) is characterized by a constellation of symptoms that follow exposure to an extreme traumatic event which involves actual or threatened death or serious injury.[5] The response to the event must include intense fear, helplessness, or horror and symptoms that persist more than one month including (1) reexperiencing the traumatic event through intrusive recollections, dreams, or nightmares; (2) avoidance of trauma-associated stimuli such as people, situations, or noises; and (3) persistent symptoms of increased arousal which may include sleep disturbance, hypervigilance, irritability, or an exaggerated startle response. A PTSD diagnosis must also be accompanied by clinically significant distress and a decline or impairment in social, occupational, or other important areas of functioning.

A structured clinical interview such as the Clinician Administered PTSD Scale[6] (CAPS) is an optimal assessment for PTSD and has long been the gold standard for making that diagnosis in clinical studies. However, detecting possible PTSD at the population level or within a large cohort of returning combat veterans is best approached with a brief, optimally sensitive measure which minimizes false negatives while efficiently identifying those in need of further assessment.

Table 1.
The Primary Care Posttraumatic Stress Disorder Screen (PC-PTSD)

In your life, have you ever had any experience that was so frightening, horrible, or upsetting that, in the past month, you:

1. Have had nightmares about it or thought about it when you did not want to?
   YES / NO
2. Tried hard not to think about it or went out of your way to avoid situations that reminded you of it?
   YES / NO
3. Were constantly on guard, watchful, or easily startled?
   YES / NO
4. Felt numb or detached from others, activities, or your surroundings?
   YES / NO

Current research suggests that the results of the PC-PTSD should be considered “positive” if a patient answers “yes” to any 3 items.

The 4-item Primary Care PTSD screening tool (PC-PTSD)[7] has been adopted by both DoD and VA due to its brevity and sensitivity. It was developed specifically for application in primary care settings and has been incorporated into both DoD’s Post Deployment Health Assessment (PDHA), performed at the time of return from a combat area, and its Post Deployment Reassessment (PDHRA), performed 3 to 6 months after return. The Primary Care PTSD screening tool has also been incorporated into VA’s computerized medical record system as a pop-up reminder on all OEF/OIF veterans registered for VA health care. This valuable screening tool is in the public domain and can be a useful aid in medical practices outside of DoD and VA.

While a score of 3 positive answers or more is required to trigger further action in VA settings, we advise that any positive response to a Primary Care PTSD question should spur further follow up from health care providers even if only to ask basic questions about personal and family readjustment following deployment. Most service members and veterans will not meet diagnostic criteria for any mental disorder and yet all of them are dealing with significant readjustment stress (as are their families). The object of screening is not simply to rule in or rule out a diagnosis of PTSD: it is to learn more about other common post deployment medical problems (eg, substance abuse, major depression) and to identify significant functional problems including job stress, unemployment, family stress, and homelessness. Combat veterans may report anxiety, sadness, loss of interest in work or recreation, or inordinate fear for the safety of family members and friends. Psychological trauma may surface indirectly as an exacerbation of chronic physical ailments such as shortness of breath in an asthmatic or increased pain in a person with arthritis. It may be expressed in new somatic symptoms (eg, headaches, abdominal pain) or as new or exacerbated substance abuse. It may lie veiled behind vague complaints of poor energy or poor sleep. Problems with memory, concentration, emotional lability, or irritability may also suggest traumatic brain injury which might then trigger further screening such as the 3-Question Screening Tool developed by the Defense and Veterans Brain Injury Center.[8]

Perhaps the most basic and most important screening step is simply to ask patients, “Are you a veteran or are you the family member of a veteran?” This question may be key to understanding why this particular patient is coming to see you and why now.

If a patient scores a 3 or higher on the Primary Care PTSD screening tool, a good follow-up instrument for further assessment would be the PTSD Checklist, Civilian Version (PCL-C).[9] This 17-item self-report measure covers each of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) symptoms of PTSD. Patients are asked whether they were “bothered by that problem in the past month” and responses are scored on a 5-point scale ranging from 1 (“not at all”) to 5 (“extremely”). Available in several forms, the PTSD Checklist, Civilian Version is recommended for post deployment screening because, unlike the military version, it is not focused on any one specific traumatic event. This allows the respondent to make connections to a broad range of deployment experiences, any one of which might be the key stressor for that individual. The PTSD Checklist can be scored in different ways; a total score (range 17-85) can be obtained by summing the scores from each item or the responses can be reviewed to establish that DSM-IV criteria for PTSD have been met. Hoge et al[2] employed a cut-off score of 50 as a conservative indicator for a positive diagnosis of PTSD.

Treatment

A recent review of the evidence base for psychotherapies and psychopharmacological strategies in the treatment of PTSD among combat veterans by the Institute of Medicine of the National Academies[10] suggested that more research is needed before all but one of these can be recommended at the highest level of confidence (exposure therapy being that single exception). Having acknowledged that finding, a number of clinical practice guidelines exist to assist clinicians in learning about available treatments, reviewing their evidence base, and making practical, patient-specific choices among them.

Most relevant among these is the VA/DoD Clinical Practice Guideline for the Management of Posttraumatic Stress.[11] Created by a joint working group of VA and DoD clinicians and researchers, this comprehensive guideline provides clinical algorithms that walk clinicians through the necessary steps from screening and initial assessment through treatment and reassessment. Separate algorithms are defined for primary care providers and mental health professionals. Evidence tables are provided for each recommendation and a substantial literature review is included. This guideline is available on the Internet (http://www.oqp.med.va.gov/cpg/PTSD/PTSD_Base.htm.) and is in the public domain.

The American Psychiatric Association has published the Practice Guideline for the Treatment of Patients with Acute Stress Disorder and Posttraumatic Stress Disorder.[12] The International Society for Traumatic Stress Studies, the world's largest international multidisciplinary professional organization working in the field of psychological trauma, provided a comprehensive set of treatment guidelines in 2000[13] with a new edition expected in 2008. Both guidelines provide a thoughtful introduction to available therapies, significant background information, and evidence-based treatment recommendations.

A thorough review of these treatments is beyond the scope of this paper, but a brief summary statement of the most highly recommended modalities (based on the VA/DoD guidelines) may prove helpful. Among the psychotherapies, prolonged exposure therapies (based on behavioral principles including habituation and extinction), cognitive behavior therapies (focusing on correcting misattributions and maladaptive responses), and Eye Movement Desensitization and Reprocessing (believed to facilitate psychological and neurological processing of traumatic events) have the strongest evidence base. The use of psychodynamic psychotherapy (derived from psychoanalytic principles) is supported by at least one randomized control study but does not have as strong a research base. Little evidence exists to support the use of Critical Incident Debriefing in the prevention of PTSD, and there is some evidence suggesting that debriefing activities can actually increase the risk of PTSD by retraumatizing survivors who are not prepared to be reexposed to horrific memories.

Among the medications available for the treatment of PTSD, specific serotonin reuptake inhibitors and venlafaxine have the strongest evidence base. While many drugs from a wide range of classes have been studied in PTSD, there is little evidence to support their use except as adjunctive treatment. Available research suggests that prazosin reduces the frequency and intensity of posttraumatic nightmares and may be effective in managing other symptoms of PTSD, but it cannot yet be recommended as a stand-alone treatment. There is evidence that benzodiazepines are not effective as first line agents in the treatment of PTSD. Because of their potential for dependence and abuse, their use as single agents is strongly discouraged in the VA/DoD guidelines.

Accessing Additional Support

Clinical practice guidelines are of significant value in the management of PTSD. Similar guidelines for disorders that are frequently comorbid with PTSD are also available through their respective DoD/VA work groups and the American Psychiatric Association among other authoritative sources. As noted earlier, many of the problems faced by returning combat veterans and their families are not specifically clinical: they may best be conceptualized in functional terms (eg, work stress, unemployment, educational/training needs, housing needs, financial and/or legal problems), and family terms (eg, lack of social support, estrangement, family breakup). Veterans, their family members, and their practitioners may find it helpful to consult a unique service available in North Carolina: NCcareLINK.[14] NCcareLINK (http://www.nccarelink.gov) is a comprehensive health and human services Web site offering information services and bilingual support that connects patients and their care givers with over 10 000 agencies and services across our state. Administered by the North Carolina Department of Health and Human Services, NCcareLINK was developed in partnership with DoD, VA, and state and community entities following recommendations made by the North Carolina Governor's Focus on Returning Veterans and their Families.[15] People who are unable to access the Web-based service may call the toll-free telephone counterpart NC CARE-LINE (1-800-662-7030). Established in 2006, NC CARE-LINE will soon begin operating 24 hours per day 7 days per week.

North Carolina has a great stake in the post deployment health of military personnel, veterans, and their families. An impressive network of programs, services, and information systems stands ready to support these citizens and their health care providers in retaining and/or regaining their highest potential for health and function. Optimal health and function cannot, however, be attained unless key questions are asked throughout our entire health system. The first and most basic of these is "Are you a veteran or the family member of a veteran?" With this information in hand, effective work can begin. **NCMJ**

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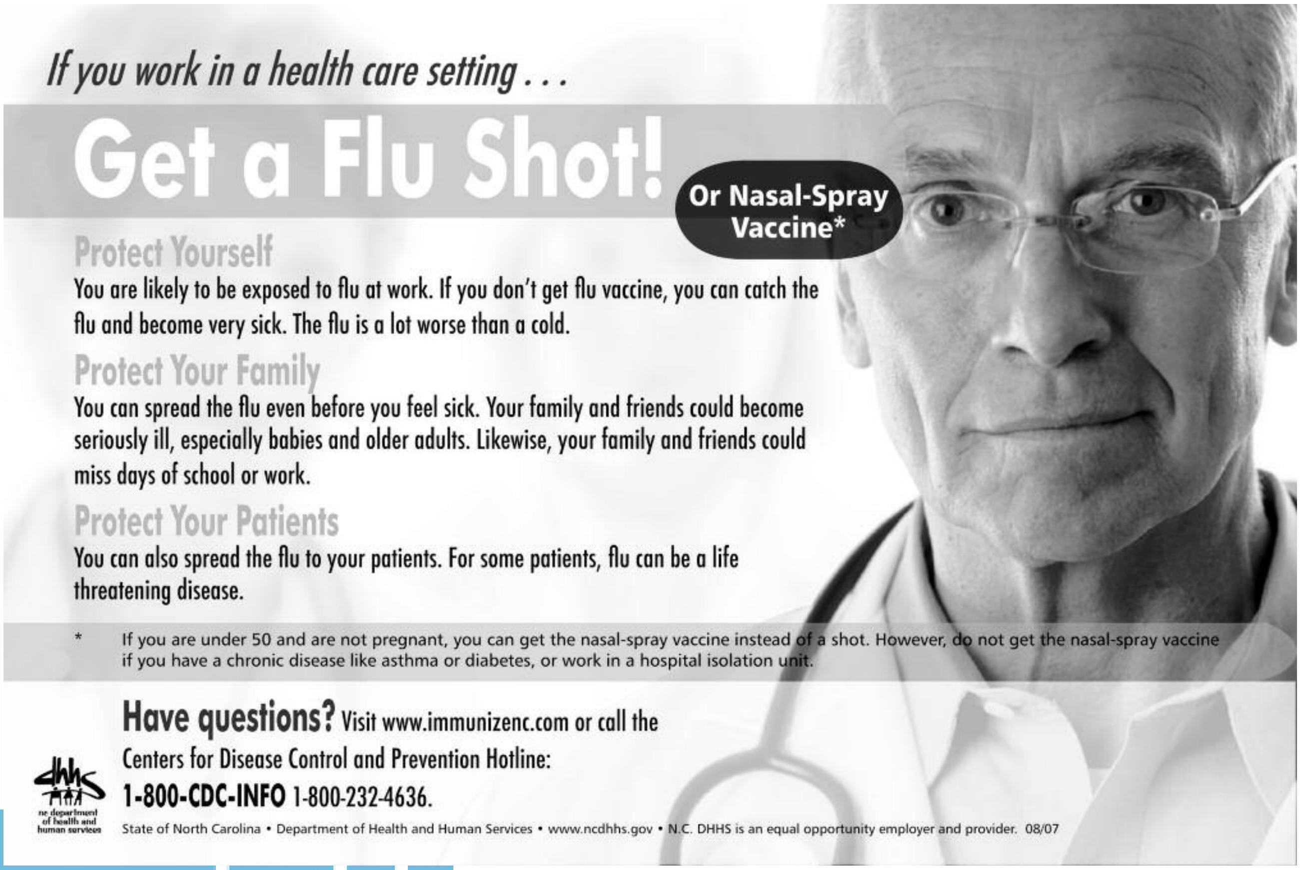

Detecting Traumatic Brain Injury Among Veterans of Operations Enduring and Iraqi Freedom

George L. Jackson, PhD, MHA; Natia S. Hamilton; Larry A. Tupler, PhD

Advances in battlefield medicine and protective devices used in Operation Enduring Freedom-Afghanistan (OEF), beginning in October 2001, and Operation Iraqi Freedom (OIF), beginning in March 2003, are saving the lives of many service members who would have died in other wars. While the mortality rate for injures was 30% in World War II and 24% in Vietnam, the rate in these recent wars has been constantly close to 10%.[1-3] The result is that many veterans who previously would have died are living with very serious injuries, and those who formerly would have had serious and apparent injuries now have conditions that significantly impact their lives but are not always obvious.

One of these conditions, traumatic brain injury (TBI), is considered the signature wound of the current conflicts.[4,5] It is estimated that almost 50% of soldiers injured in combat return with some form of TBI (mild, moderate, or severe).[6] This compares with 14% to 18% of combat casualties having a brain injury during the Vietnam War.[4]

What is Traumatic Brain Injury?

Traumatic brain injury is a form of brain damage resulting from a sudden jolt, blow, or penetrating head injury.[7,8] It most commonly occurs when the head is accelerated and then decelerated abruptly. The effect is that strain forces are applied to the axons (nerve fibers) in the brain. This type of closed TBI is broadly referred to as a diffuse axonal injury.[9,10] These injures may result from the head hitting an immovable object, being struck in the head, or waves of energy from an explosion. Penetrating objects such as bullets may also damage the brain. Traumatic brain injury can result in temporary to permanent cognitive, physical, or emotional dysfunction. The severity of the TBI depends on the symptoms that result from the injury, and outcomes can range from a complete recovery to permanent disability or death.[11-13] Table 1 lists common symptoms of TBI.[14-17]

> *"… traumatic brain injury (TBI) is considered the signature wound of the current conflicts. It is estimated that almost 50% of soldiers injured in combat return with some form of TBI (mild, moderate, or severe)."*

Traumatic Brain Injury Severity

In more serious cases, when blasts and other mechanisms of injury result in loss of consciousness producing a TBI, the injury may be defined as mild (≤ 30 minutes) [American

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Table 1.
Common Symptoms of Traumatic Brain Injury

General Symptoms of TBI	Symptoms of Moderate to Severe TBI
Headaches	Loss of consciousness (30 minutes or more)
Difficulty organizing daily tasks	Personality change
Mental confusion (easily confused, easily feeling overwhelmed)	Loss of coordination
Lightheadness or feeling dizzy	Weakness or numbness in the extremities
More sensitive to auditory stimuli, lights, or other distractions	Slurred speech
Behavior or mood changes (feeling sad, anxious, or listless)	Dilation of one or both pupils
Double vision, blurred vision, or tired eyes	Inability to awaken
Ringing in the ears	Seizures
Bad taste in the mouth	Repeated vomiting or nausea
Fatigue or lethargy (feeling tired all of the time)	A severe, persistent, or worsening headache
A change in sleep patterns	
Trouble with memory, concentration, or calculations	
Easily irritated or angered	
Impulsivity (lack of inhibition)	
Slowed movement, talking, reading, or thinking	
Sexual dysfunction	

TBI – traumatic brain injury

Sources: Centers for Disease Control and Prevention (May 2003);[14] DePalma et al (2005);[15] Kahn et al (2003);[16] Lew et al (2006)[17]

Congress of Rehabilitation Medicine definition], moderate (≤ 6 hours), or severe (> 6 hours).[18] Also accompanying TBI may be anterograde memory loss or posttraumatic amnesia, difficulty encoding new information following the injury. Posttraumatic amnesia may be mild (< 1 day), moderate (1 to 7 days), or severe (> 7 days).[16,19] Retrograde amnesia tends to follow the same or somewhat less of a time gradient as posttraumatic amnesia. Not all TBI victims suffer from loss of consciousness or amnesia, but those with more mild exposure to trauma may become dazed and confused, characterized by difficulties with orientation, perception, concentration, memory encoding and retrieval, and judgment.[14-16]

Table 2.
Common Criteria for Determining the Severity of Traumatic Brain Injury

	Loss of Consciousness	Brain Functioning	Posttraumatic Amnesia	Glasgow Coma Scale Score
Mild TBI	≤ 30 minutes	Normal MRI and CT	< 24 hours	13-15
Moderate TBI	≤ 6 hours	Abnormal MRI and CT	≤ 7 days	9-12
Severe TBI	> 6 hours	Abnormal MRI and CT	> 7 days	3-8

TBI – traumatic brain injury; MRI – magnetic resonance imaging; CT – computerized axial tomography scan

Sources: Coetzer et al (2002);[18] Kahn et al (2003);[16] Sternbach (2000)[19]

Because an estimated 80% of individuals sustaining TBI are classified as mild (mTBI), it is often a condition that is not readily apparent.[12] Most mTBI patients make a rapid recovery, suffer few postinjury complications, and, for these reasons, often bypass acute medical attention or hospitalization. Nevertheless, up to one-third of mTBI patients develop chronic symptoms, and delayed symptom onset is not uncommon.[11]

Postconcussive syndrome refers to an array of cognitive, physical, and emotional symptoms that can occur following mTBI.[20-22] Patients with postconcussive syndrome may complain of headaches, postural imbalance, insomnia, memory problems, fatigue, irritable or depressed mood, or interpersonal conflict.[17,23] Postconcussive syndrome is challenging to diagnose using a detailed physical exam or neuroimaging alone. It is often the case, unfortunately, that misattributions of underlying psychopathology prevent postconcussive syndrome patients from receiving appropriate care. The constellation of cognitive, behavioral, and social deficits common to TBI may impinge on interpersonal relationships and family support, thus complicating recovery.[24] Table 2 lists characteristics of mild, moderate, and severe TBI.[16,19]

Causes of Traumatic Brain Injury

Common causes of TBI, both civilian and military, include falls, motor-vehicle accidents, striking or being thrown against an object, or assault.[7] In the OEF and OIF war zones, however, the most common sources of TBI are explosives and blasts.[5,15,25,26] Traumatic brain injury accounts for approximately 60% of war injuries caused by blasts.[5]

Explosives can take the form of conventional bombs or enhanced-blast explosive devices.[15] Conventional bombs cause a blast wave that spreads out around its point of origin. It is initially a wave of high pressure which is followed by strong and forceful wind. Damage tends to increase as distance from the explosion decreases. Warfare in Iraq often uses explosive devices loaded with metal pieces which cause greater penetrating force, potentially causing penetrating injuries on top of closed injuries caused by blast waves. Enhanced blast-explosive devices can present greater damage than conventional bombs because the initial explosion triggers a secondary explosion, spreading out force that lasts longer.[15]

Four basic types of injuries are caused by blasts: (1) primary—over-pressurization of "blast wave"; (2) secondary—projectiles based on proximity of primary blast; (3) tertiary—effects due to wind, which may propel the victim into walls, the ground, or other objects; and (4) quaternary—burns, asphyxia, and exposure to toxic inhalants. (See Table 3.)[14,15,25,27]

Table 3.
Types of Blast Related Injuries

Category of Injury	Source of Injury	Implications of Injury
Primary blast injury	Overpressurization of blast wave	Tympanic membrane damage; lung damage; occipital rupture; concussion
Secondary blast injury	Projectiles based on proximity of primary blast	Penetration of extremities (including the head)
Tertiary blast injury	Blast related wind impacting the speed and force with which the body hits or is hit by objects	Fracture; amputation; closed or open brain injury
Quaternary blast injury	Random circumstances such as burns, asphyxia, and exposure to toxic inhalants	Burns; closed and open brain injury; breathing problems (eg, asthma; COPD); exacerbation of cardiovascular risk factors (eg, hypertension)

COPD – chronic obstructive pulmonary disease
Sources: Centers for Disease Control and Prevention (May 2003)[14] and (December 2006)[27]; DePalma (2005)[15]; Finkel (2006)[25]

Screening at the Time of Potential Traumatic Brain Injury

The most common initial screening tool is the Glasgow Coma Scale. It includes questions on motor responses (6 grades), verbal responses (5 grades), and eye-opening responses (4 grades). Lower scale scores indicate greater likelihood of more severe TBI.[28] Table 2 includes the scale cutoff scores for levels of TBI severity.[16,19] A copy of the Glasgow Coma Scale can be found on the Internet at http://www.strokecenter.org/trials/scales/glasgow_coma.pdf.[29]

The Defense and Veterans Brain Injury Center (DVBIC) at Walter Read Army Medical Center has developed a Military Acute Concussion Evaluation assessment procedure for use in warzones. The Military Acute Concussion Evaluation is based on the Standardized Assessment of Concussion[30] and includes more detailed assessments of the incident leading to potential TBI and current clinical status than occurs with administration of the Glasgow Coma Scale. While not yet validated, a description of this procedure is available on the DVBIC Web site at http://www.dvbic.org/.[31]

Course and Recovery of Traumatic Brain Injury

Recovery from brain injury varies significantly by severity group. Victims of moderate to severe TBI may suffer from residual neurocognitive deficits for the remainder of their lives. They can manifest amnesia, hyperdistractibility, and other attentional deficits, language impairment, motor slowing and incoordination, and changes in personality.[11]

Although most victims of mTBI suffering from PCS recover over a 3-month to 1-year time frame, many do not.[23] It has been argued that those who do not recover their function typically manifest psychiatric presentations predating the TBI or in response to the trauma.[22,32] However, more research is required to determine what post-TBI symptoms are due to mechanisms of brain injury versus functional psychiatric involvement either preceding or following the trauma

While extensive literature exists describing recovery from blunt-force trauma due to motor-vehicle accidents or falls,[7] data and studies describing blast injury are limited.[9] Whereas blunt force trauma may be somewhat more focal due to coup and contrecoup forces, blast injury may be more diffuse due to primary overpressurized waves pervasively affecting the entire brain; secondary and tertiary effects might furthermore create more multifocal effects.[15] There may also be an accumulation of effects secondary to repeated blasts. Veterans may have been exposed to multiple explosions, and while receiving only mild postconcussive effects from one blast, a second or third blast of equal force could result in more severe injury.[9]

Traumatic Brain Injury and Posttraumatic Stress Disorder Comorbidity

Posttraumatic stress disorder (PTSD) frequently follows exposure to blast and other TBI etiologies, and symptoms frequently overlap with those observed following TBI. Diagnostic discrimination between the two conditions may therefore be challenging and complicate treatment formulations. Furthermore, many brain areas typically affected in TBI such as frontal, temporal, and subcortical regions are the same as those putatively involved in PTSD symptom expression.[33]

Some authors have noted that the overlap between symptoms of PTSD and TBI calls into question current diagnostic tools for discriminating PTSD among TBI patients and thus requires the development of new measures that can differentiate the two. At a minimum, it is likely that symptoms from TBI compromise the ability to cope with the stress of PTSD (eg, through disinhibition of executive-control processes), and PTSD likewise compromises the ability to navigate the cognitive and other manifestations of TBI.[34] Those with TBI may also have more severe PTSD.[35]

Screening for Traumatic Brain Injury – Department of Defense

Because mTBI may not have obvious outward symptoms, and symptoms may overlap with other conditions,[36] extensive screening efforts are required. Starting in April 2003, all active duty, reserve, and National Guard service members and Department of Defense civilians deployed to a war zone have been required to complete an in-person post-deployment health assessment (PDHA) between 30 days before and 30 days after redeployment away from the war zone. This process includes a screening form (DD2796) that has 4 questions about potential TBI.[37] These address (1) experiences that could lead to TBI (eg, explosion); (2) condition following the event (eg, dazed, confused); (3) symptoms that began or got worse after the event (eg, memory problems); and (4) symptoms experienced in the last week. Patients indicating they were exposed to an event and have had symptoms are then referred for further evaluation.[38,39] The screening forms and specific questions mentioned in this section are available on the Department of Defense Deployment Health Clinical Center-PDHealth Web site at http://www.pdhealth.mil/.

Since March 2005, it is required that returning service members be offered a postdeployment health reassessment (PDHRA) 90-180 days (preferably 120-150 days) following redeployment. Individuals who were hospitalized must have a PDHRA 90-180 days after discharge. This includes form DD2900, which has the same 4 TBI questions described above.[40] Information from the PDHA and PDHRA, along with the predeployment health assessment form DD2795[41] (completed within 60 days prior to deployment), is maintained in the permanent medical record and Defense Medical Surveillance System.[38,42] A recent report summarizing results of the PDHRA indicated a higher rate of self-reported mental health concerns and referrals than that observed with the PDHA, suggesting increased morbidity over time following deployment.[42]

Screening for Traumatic Brain Injury – Veterans Health Administration

On April 2, 2007, a system-wide TBI Screening Clinical Reminder was introduced into the Veterans Health Administration (VHA). On April 13, VHA directive 2007-013, *Screening and Evaluation of Possible Traumatic Brain Injury in Operation Enduring Freedom (OEF) and Operation Iraqi Freedom (OIF) Veterans*, was released based on the deliberations of a dedicated task force.[43] In this directive, it was noted that "currently there are no validated [TBI] screening instruments accepted for use in clinical practice." The directive furthermore cautioned that screening can lead to positive results due to other postdeployment conditions (eg, PTSD).

The TBI Screening Clinical Reminder is part of the VA Computerized Patient Record System (CPRS) and is designed to be administered to all veteran VHA patients who separated from active duty after September 11, 2001. It embodies a branching pattern of inquiry that first determines whether a previous diagnosis of TBI has been established, and, if not, whether (1) a plausible etiology for a TBI exists (eg, being near an explosion); (2) posttraumatic neurological alterations followed the etiological event; (3) postconcussive symptoms followed the posttraumatic neurological alterations; and (4) postconcussive symptoms persisted into the week preceding the evaluation. Each of these branches (sections) of the clinical reminder is evaluated only if the branch preceding it is true. Positive findings for all 4 branches result in a positive screening result. If the outcome is positive, then follow-up ensues.

A TBI Second Level Evaluation format was recently implemented by VHA. Second-level screening probes in greater detail (a) etiological variables such as number of, types of, and parameters (eg, distance from blast) relating to events predicting TBI severity; (b) neurological sequelae such as number of loss of consciousness episodes, duration of longest loss of consciousness episode, and number of episodes; (c) nondeployment TBI; (d) pain documented as to location and degree of interference with life; and (e) physical exam and medication review. The practitioner signing the related progress note must be a physiatrist, physical medicine and rehabilitation physician, or neurologist who arrives at a final TBI diagnosis.

Traumatic Brain Injury Incidence Among Veterans of Afghanistan and Iraq

Precise numbers describing the burden of TBI among OEF and OIF veterans are not available. Estimates come from a variety of sources. As of September 30, 2007 the Pentagon listed 4471 TBI diagnoses from OEF and OIF.[44] However, this number excludes cases of TBI not initially considered battle injuries. According to the founder of the Congressional Brain Injury Task force, more than 150 000 TBI instances have occurred among approximately 1.5 million OEF/OIF participants.[44]

The rate of those who screened positive on the initial VA TBI Screening Clinical Reminder is 20%.[44] That does not mean all of these patients actually had a TBI. This figure represents those who screened positive for possible TBI, requiring further diagnostic workup which may or may not indicate a TBI. This rate is similar to that seen in at least one VA hospital in North Carolina.

Many TBI sufferers, especially if untreated, may endure medical, behavioral, and social consequences for many years—perhaps even a lifetime.[4,17,24,45,46] It is essential that health care providers in the Department of Defense, VA, and private sectors do their best to identify and appropriately treat TBI among OEF and OIF veterans. **NCMJ**

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Second, make a family communications plan. Make sure family members know how to contact each other in an emergency. It may be smart to have everyone call an out-of-state friend or relative. Keep a list of emergency numbers near the phone. Plan how you will evacuate if you are asked to do so.

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COMMENTARY

Veterans Health Administration Primary Care-Mental Health Integration Initiative

Edward P. Post, MD, PhD; William W. Van Stone, MD

The Veterans Health Administration has undertaken a large national initiative to integrate primary care and mental health services. A request for proposals was disseminated throughout the Veterans Affairs (VA) system inviting proposals for new programs to promote the effective treatment of common mental health and substance use disorders in the primary care environment. Both individual facilities and Veterans Integrated Service Networks (VISNs) were eligible to apply, and proposals could encompass activities at one or multiple VA facilities. Similarly, facilities within VISNs were free to use different evidence-based models for delivering integrated care. Program funding commenced during fiscal year 2007 (FY07).

The overarching rationale for the initiative is to integrate care for veterans' physical and mental health conditions, improve access and quality of care across the spectrum of illness severity, and allow treatment in mental health specialty settings to focus on persons with more severe mental illnesses.

The report of the President's New Freedom Commission on Mental Health emphasizes that mental health and physical health problems are interrelated components of overall health and are best treated in a coordinated care system.[1] That recognition also is embedded in the VA's Mental Health Strategic Plan and its goal to "[d]evelop a collaborative care model for mental health disorders that elevates mental health care to the same level of urgency/intervention as medical health care."[2]

The important context of integrated care recognizes several facts: primary care provides opportunities to screen for unrecognized disease; mental health and substance abuse conditions are common and are often treated by primary care practitioners; patients may prefer treatment in primary care settings; an established relationship with a primary care practitioner fosters engagement in and adherence to treatment; and health conditions do not always fall neatly into "physical" and "mental health" categories. As former Surgeon General David Satcher said, "Primary care practitioners are a critical link in identifying and addressing mental disorders… Opportunities are missed to improve mental health and general medical outcomes when a mental illness is under-recognized and under-treated in primary care settings."[3]

> *"The report of the President's New Freedom Commission on Mental Health emphasizes that mental health and physical health problems are interrelated components of overall health and are best treated in a coordinated care system."*

Approximately 20% of the 5 million veterans who received VA care in FY05 received mental health services. However, the number of veterans diagnosed with mental health disorders is even greater. While some have complex or severe conditions

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that require specialty services, others may benefit from receiving mental health treatment in the primary care setting, administered either by primary care practitioners who are given appropriate support or by mental health practitioners based in the primary care environment. Colocated collaborative treatment and care management are two evidence-based models for services that can promote patient engagement in and adherence to treatment and can avoid stigmatization and fragmentation of care. Furthermore, using these models allows providers to facilitate the coordination of care for mental health problems and other medical conditions which can translate into important patient outcomes. For example, one recent trial of an effective 2-year integrated care program for depression among older primary care patients demonstrated reduced all-cause mortality over a 5-year period.[4]

An example of the evidence base for integrated care models within VA is the Primary Care Research in Substance Abuse and Mental Health for Elderly (PRISM-E) study which VA and the Substance Abuse and Mental Health Services Administration (SAMHSA) of the US Department of Health and Human Services undertook to better understand what care delivery systems are effective for managing depression, anxiety disorders, and problem drinking in older primary care patients.[5-7] The PRISM-E randomized controlled trial demonstrated that patients were significantly more likely to engage in mental health services that were integrated with primary care than to follow through on referrals to specialty services. For example, depressed patients in integrated care were 2.86 times more likely to have at least one contact with a mental health specialist than those in referral care.[7] Findings like these led the President's New Freedom Commission to recommend important elements of integrated care such as expanded screening and collaborative care in primary care settings.

While much of the research evidence in this area has focused on depression, there also have been studies demonstrating the efficacy of an integrated approach for anxiety disorders[8-11] and problem drinking.[12-16] Although there is no current evidence demonstrating the effectiveness of this approach for managing patients with posttraumatic stress disorder (PTSD), research is in progress.

Three major categories of integrated care models are being implemented in the Primary Care-Mental Health Integration Initiative: (1) colocated collaborative care; (2) care management; and (3) blended models that incorporate features of the other two.

Colocated collaborative care entails both mental health and primary care practitioners being physically present in the primary care setting with shared responsibility for evaluation, treatment planning, and monitoring outcomes. Episodes of care in this model can vary depending on the needs of the patient, ranging from a referral with a "warm hand-off" to informal consultation with primary care practitioners. A particular example of colocated collaborative care in VA is the White River Model of open access mental health treatment in primary care. This model has demonstrated significant increases in both the proportion of depression screen-positive patients receiving any treatment as well as the proportion of patients receiving guideline-concordant treatment for depression.[17]

Care management models need not be physically located in the primary care setting, but care managers are actively involved in the process of delivering mental health treatment to primary care patients. Nurses constitute a core profession in care management, although social workers and psychologists perform the role of mental health care manager, too. Care managers interact directly with patients, facilitate ongoing evaluation, and maintain active communication that enables responsibility for mental health treatment to remain in the primary care setting. Two examples of care management models in VA are Translating Initiatives for Depression into Effective Solutions (TIDES) and the Behavioral Health Laboratory. The TIDES care management model uses registered nurses to provide guideline-based treatment support and has demonstrated high levels of treatment engagement among depressed primary care patients.[18] The Behavioral Health Laboratory uses a software-based structured assessment for initial evaluation as well as on demand follow-up in support of primary care-based mental health and substance abuse treatment. Its implementation in a primary care setting led to a significant increase in the proportion of patients screening positive for depression as well as identification of substantial numbers of cooccurring mental health disorders and substance misuse.[19]

Finally, blended models combine elements of both care management and colocated, collaborative care. In a blended model, the mental health practitioner evaluates patients and offers psychosocial treatment when preferred or needed while the care manager provides complementary services including education, ongoing assessment, monitoring of adherence, algorithm-based use of medication, and referral management when necessary.

Irrespective of the structural form of the integrated care model, there are standard minimum requirements for the scope and process of services provided under the initiative. Foremost among these is a focus on prevalent conditions in primary care, namely depression, alcohol misuse and abuse, and PTSD. This is in keeping with the overarching rationale of integrated care being a complement rather than a substitute for mental health specialty services. Integrated care programs have an existing foundation upon which to build in that VA already screens primary care patients for depression, alcohol misuse, and PTSD on an ongoing basis. Important required components of evaluation, treatment, and follow-up include the following: risk assessment and appropriate action for suicidality among patients that screen positive for depression and PTSD; watchful waiting for subsyndromal conditions; availability of evidence-based treatments in primary care including brief treatment for problem drinking and pharmacological treatment for major depression; access to evidence-based psychotherapies; and ongoing monitoring for treatment adherence, medication side effects, and clinical outcomes. The fundamental aim of these processes is to support the primary care practitioner in addressing prevalent mental health concerns in a manner that is flexible and convenient for patients as well as centered on a patient's need for disease education and preferences for treatment.

As mentioned previously, the VA Primary Care-Mental Health Integration Initiative is a large national implementation effort presently composed of 92 integrated care programs. The sites for these programs include VA Medical Centers (VAMCs), Community Based Outpatient Clinics (CBOCs), and VISN-level groups of facilities. These sites are implementing diverse models of care including 24 colocated collaborative programs, 19 Behavioral Health Lab programs, 25 care management programs including sites using the TIDES model, and 24 sites with blended models of care. Annualized funding in FY07 was $32 million representing 409 full-time equivalent positions. The program is continuing at a similar level of funding in FY08 and expansion of sites is anticipated in FY09.

In North Carolina there are 3 integrated care programs being funded through this initiative. A blended model consisting of colocated collaborative care and care management is being implemented at the Durham VAMC, the satellite Durham Clinic, and the Raleigh CBOC, which collectively represent a target population of 16 933 unique primary care patients. A similar blended model is also being implemented at primary care clinics in the Fayetteville VAMC serving a target population of 9600 veterans. Finally, the Salisbury VAMC is implementing a colocated collaborative model of integrated care in clinics serving 11 589 unique primary care patients.

The national program office for Primary Care-Mental Health Integration is undertaking a variety of activities in support of field implementation as well as evaluation of this important initiative. Program activities include national conferences attended by both primary care and mental health practitioners; monthly national educational teleconferences; policy development including procedures and tools for workload tracking, clinical utilization tracking, and performance measurement; collaboration on development and dissemination of automated decision supports; and training and technical assistance to field sites. An important example of these activities in FY07 was the development of new performance measures, processes, and tools surrounding evaluation and follow-up of positive screens for depression, PTSD, and alcohol misuse. In particular, performance measures are in place for FY08 to track whether practitioners are following up on PHQ-2 screening for depression with a PHQ-9, risk assessment for suicidality, and pertinent clinical evaluation and follow-up of these assessments; pertinent clinical evaluation and follow-up of PC-PTSD screening for posttraumatic stress disorder including risk assessment for suicidality; and follow-up of AUDIT-C screening for alcohol misuse and abuse with appropriate patient-specific counseling and follow-up.

Finally, the national program office is actively collaborating with the Serious Mental Illness Treatment Research and Evaluation Center at the Ann Arbor VAMC to develop ongoing program evaluation of primary care-mental health integration. The major goals of this evaluation are (1) to assess the extent to which integrated care programs have been implemented across the VA system; (2) to assess patient-level access to care, receipt of services, and disease-specific outcomes; and (3) to determine what factors contribute to differences in mental health-related access and quality of care including variation related to specific integrated care models, model fidelity, and other site-specific program characteristics. This evaluation effort includes so-called formative evaluation components that will enable targeting of specific areas for attention. Ongoing availability of information from the evaluation team will greatly assist the program office in its overall goal of continuous quality improvement for veterans with mental health conditions by maximizing the successful implementation of integrated care programs throughout the VA system. **NCMJ**

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COMMENTARY

Integrating Primary Care and Mental Health in the Army

Michael T. Latzka, MD, LTC, MC

Fifteen months ago, a family from the 82nd Airborne Division said their goodbyes from their North Carolina home at Fort Bragg. They weren't moving to another state, and they weren't moving together. Their goodbyes were to each other as one member of that family was going to war nearly halfway around the world. This was not just an isolated incident but a scene repeated thousands of times on military parade fields and in home front yards across the state of North Carolina. It has become a familiar scene in the years since September 11, 2001. Life has changed for everybody since that eventful day, but it has especially changed for the soldiers and families stationed at Fort Bragg, North Carolina.

Fort Bragg is one of the largest and busiest posts in the United States Army. Its lead position on the Global War on Terrorism has produced great sacrifice from the soldiers on the front lines and from the families at the home front. These sacrifices can be measured in dollar costs, time away, and in lives lost, but they can not be so easily measured by the numerous stressors on the families or the soldiers who have deployed to combat. Soldiers and families must cope with a wide variety of stressors which may manifest themselves in problematic behaviors. One study that did identify a response by soldiers to the stressors of combat showed a need for greater access to mental health resources within the military.[1] In response to this need, the Fort Bragg medical system has taken the lead to battle against these stressors by becoming a center of excellence for the recognition and treatment of depression and posttraumatic stress disorder (PTSD) in the military.

> *"Fort Bragg is one of the largest and busiest posts in the United States Army. Its lead position on the Global War on Terrorism has produced great sacrifice from the soldiers on the front lines and from the families at the home front."*

RESPECT-MIL (Re-engineering Systems of the Primary Care Treatment of Depression and PTSD in the Military) is a carefully-designed system that helps identify and treat soldiers who may have depression or PTSD. It was first developed for civilian practices with a primary care emphasis to better identify and treat depression.[2] The system uses a 3-component model (see Figure 1) and works when a well-prepared primary care practice teams up with a nurse care facilitator and a behavioral health professional. The nurse care facilitator and behavioral health professional facilitate the care of patients who have been identified with depression and are being treated by a primary care practitioner. Implementation begins when primary care and behavioral health champions lead a 3-hour training session for clinicians and administrative staff. Nurse care facilitators complete 2 days of training and then continue ongoing training as they interact with their initial patients. Champions use academic detailing and case-based "lunch and learns" to reinforce concepts. The core elements of the 3-component model are (1) routine screening for depression and PTSD; (2) diagnostic assessment with structured questionnaires for all those screening positive; (3) patient engagement, education, and eliciting treatment preferences; (4) proactive follow-up by the primary care clinician and RESPECT care facilitator; and (5) enhanced support by a mental health specialist through supervision of the

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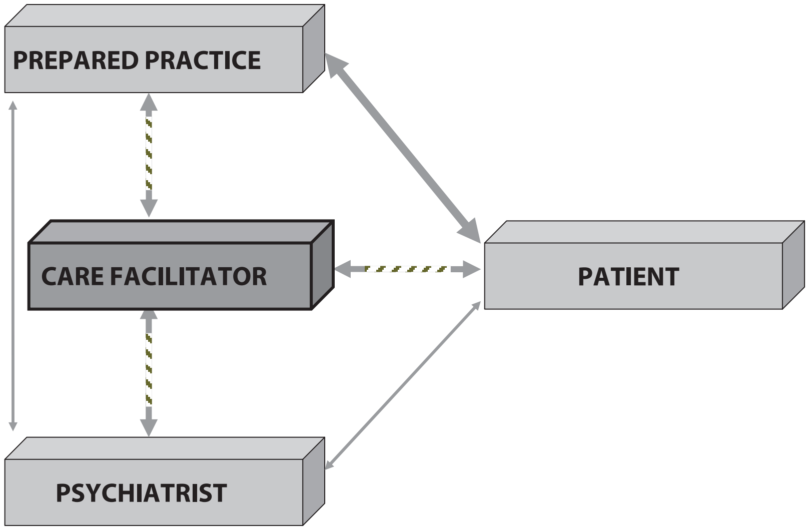
Figure 1.
Components of the RESPECT-Mil Model



care facilitator and availability for curbside consultation. (See Box 1.) Patients with complicated illnesses (eg, significant suicide risk) or who prefer specialty care are referred to mental health providers. For patients treated in primary care, the care facilitator reinforces the primary care clinician's treatment plan through telephone follow-up that addresses treatment adherence, self-management goals, and symptom response using structured questionnaires. The care manager is supervised by a psychiatrist and communicates any recommendations for management changes to the primary care clinician. This proactive treatment model increases the intensity of follow-up (see Figure 2) and has been demonstrated to increase guideline concordant care for depression and improve patient outcomes.[3] Because of its success in the civilian community, key leaders in the Army medical department put together a study at Fort Bragg to assess the model's feasibility within the military health care system.[4]

Box 1.
RESPECT-Mil Care Processes

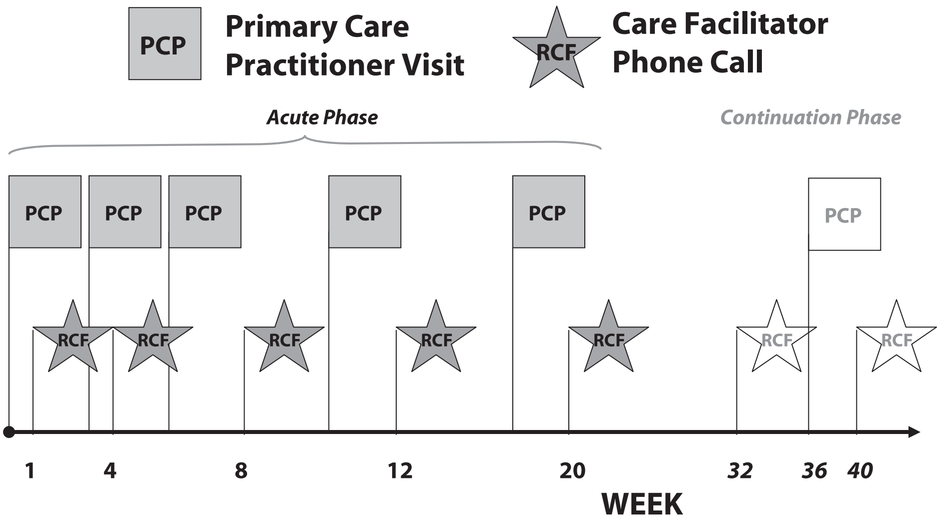
- Routine Screening
    - On arrival at sick call medic/nurse screens patient for depression and posttraumatic stress disorder as part of measuring vital signs
- Assessing Screen Positives
    - Screen positives complete PHQ-9 depression questionnaire and posttraumatic stress disorder checklist to guide diagnosis
    - Primary care providers score and complete diagnosis
- Treat Those With a Potential Diagnoses
    - Assess suicide risk
    - Elicit relevant history
    - Share diagnosis with patient, offer treatment and referral to care facilitator
- Systematic Follow-Up
    - Primary care continues to manage
    - Care facilitator provides additional telephone follow-up
    - Communication and treatment advice by team psychiatrist

The adaptation of the civilian model to one in the military included the addition of a screen for PTSD in response to the needs apparent in this important population. Another important modification was to mandate evaluation by a mental health specialist for any solider in treatment who had an upcoming deployment. This evaluation is an extra measure of safety for deploying soldiers.

In February of 2007, the first clinic at Fort Bragg began full implementation of RESPECT-MIL to include complete screening of all soldiers enrolled in General Roscoe Robinson Health Clinic, which serves soldiers and families of the 82nd Airborne Division. The soldier population for this one clinic alone is approximately 17 000. Since the beginning of February 2007, nearly three-quarters of all soldiers visiting the Robinson Health Clinic have been screened for depression and PTSD. Of the entire population of soldiers screened, just under 20% screened positive for either depression or PTSD. Of those soldiers who screened positive, roughly one-third were false positives and another one-third were already being treated for their depression or PTSD within the military behavioral health care system. The final one-third of those positive screens were newly identified depressive disorder or PTSD. About half of the soldiers chose to participate in RESPECT-MIL while the other half went to behavioral health. Only a small percentage chose no referral at all.

The RESPECT-MIL care model involves a paradigm shift from one clinician-one patient interactions to a team care model that features telephone follow-up and evaluation. It also requires a change in cultures from one where medical and mental health services are delivered relatively independently to one involving greater collaboration. Because these represent important changes in medical care delivery, we typically begin implementation with small-scale pilots (eg, the most highly motivated clinicians in a care site) and then gradually expand to involve more clinicians and more clinical sites at the base. These implementation challenges are quite similar to those seen in the private sector. Challenges that may be unique to the military include a highly mobile patient population, highly mobile clinical staff, and primary care services designed more for acute rather than longitudinal care. We have dealt with these later challenges

Figure 2.
Typical Frequency of Patient Contacts



in part by developing a greater capacity for ongoing training of new staff.

This initial experience to date has been very valuable. It has allowed for a process improvement within a military primary care clinic where a systematic approach to behavioral health needs is being addressed and is also becoming a part of the routine health care approach and culture of care at Robinson Health Clinic. It has also spread to 3 other clinics at Fort Bragg and beyond the state of North Carolina to other sites within the Army medical department as they begin to implement RESPECT-MIL. As part of this initial roll-out we plan to implement the program at 15 Army posts, including 3 in Europe. We have seen the valuable contribution of a nurse care facilitator expand the ability for primary care practitioners to treat depression and PTSD in such a way that more nurse care facilitators are being hired to meet the demand. Primary care practitioners initially concerned about the increased workload are now providing positive anecdotes about their improved ability to identify and care for depression and PTSD in soldiers. The result is that after 15 months of being in combat soldiers are returning home to their families in North Carolina, and they are also returning to a medical community that is improving its ability to help them deal with some of their health needs. In this way we can begin to address their needs and build a better military family right here at home. **NCMJ**

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COMMENTARY

The Citizen Soldier Support Program:
Building Bridges Between Communities and Military Families

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Citizen soldiers live across the nation, and they can be found in most local communities. In North Carolina, they are members of the North Carolina National Guard and the Military Reserves. The National Guard Armory has long been a local institution known to most citizens and readily recognized as a critical part of community structure. The needs of deployed Guard members and reservists and their families are unique and differ from those of active duty military forces. Active duty forces are primarily clustered around established military installations that usually house a wide variety of services and support networks for both the soldier and the affected family. Guard members or reservists often live far away from a military installation. Traditionally they train on selected weekends and on short tours of duty for extended training during the summer. As the concept and needs of the total military force have changed, these citizen soldiers are now being deployed for extended tours of duty, and the impact of their service upon themselves, their families, and their communities has dramatically changed.

Guard members and reservists are located in every North Carolina county, and families are routinely familiar with the short tours of duty required of Guard members or reservists in the past. When the citizen soldier is deployed, however, for an extended period of time, his or her family becomes an active military family. When faced with the active long-term deployment of a significant family member, the remaining family members must cope with a wide variety of new and unique circumstances that many had not planned for and which many may find quite daunting. Among these changes are issues affecting their health. Military families may have greater and very different health care needs compared to the general population. Nonetheless the families of Guard members and reservists still must largely acquire care in the local community. This may be challenging for both families and community providers who may not be ready to serve this population. Nonetheless the overall impact of having a deployed family member can dramatically impact the family's health.

Introduction to the Citizen-Soldier Support Program

The Citizen-Soldier Support Program is a federally-funded, national demonstration program whose mission is to mobilize and engage communities to support service members of the National Guard and Military Reserves and their families before, during, and after mobilization and deployment. The Citizen-Soldier Support Program is in its third year of operation and is rapidly moving toward implementing a variety of best practices and lessons learned in its first 2 years of operation.

As a demonstration project, the Citizen-Soldier Support Program and its products need to be readily reproducible across

> *"Community capacity is needed to adequately support citizen soldiers and their families in an effort to (1) strengthen them; (2) provide them with economic security; and (3) develop family-community connections."*

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North Carolina as well as in other states. Although the Citizen-Soldier Support Program in its early stages sought to develop direct community resources and show the impact there, it quickly became evident that these local models simply were economically unfeasible for real world duplication. In its current activities, the Citizen-Soldier Support Program is seeking to target its resources into larger models that impact systems and thus have a far greater potential benefit for communities and individual families.

With critical and targeted input from its National Advisory Committee, a strategic planning effort was undertaken, and the Citizen-Soldier Support Program is working to move forward on a number of targeted programs. Although these programs may impact a wide variety of family and community support activities, a number directly impact the health care status of citizen soldiers, their families, and their communities.

One area of health most dramatically impacted by deployment is mental health. Health concerns may be as subtle as the depression or anxiety of family members or as dramatic as the posttraumatic stress disorder (PTSD) or traumatic brain injury (TBI) of the returning soldier. The Governor's Focus on Returning Combat Veterans and Their Families is a statewide effort focusing on the mental health of returning soldiers. Building upon and cooperating with this effort, the Citizen-Soldier Support Program has brought together a number of varied specialists to form a steering committee to focus the joint efforts of all concerned stakeholders. The group includes representatives of the North Carolina National Guard and Military Reserves, Veterans Administration, state government, private medical practitioners, and a variety of other social support parties. Stakeholders hope to coordinate their efforts to address the mental health needs of returning combat veterans and their families. The group is intensely seeking to identify the geographic distribution of the state's mental health practitioners and then segment this population according to those who are in the TRICARE system (the Department of Defense managed health care program) and those who are not. Mental health problems may not be strictly managed through military health care, thus the continuum of mental health services including the Veterans Administration and the civilian sector are integral to serving the needs of returning soldiers and their families. A final comprehensive report on addressing this problem is forthcoming in early 2008.

Citizen Soldier Support Program Health Initiatives

The Citizen-Soldier Support Program has planned multiple initiatives. First, a training effort piloted through the Area Health Education Centers (AHEC) program seeks to provide targeted exposure to community-based medical practitioners on how to assess and treat specific problems experienced by citizen soldiers and where to refer them for additional care. Following the initial training and evaluation of this pilot project in the Coastal AHEC in January, similar efforts will be designed for other regions in the state. The goal is to export this model to similar practitioner training programs in other states as well. The Coastal AHEC training efforts target 2 groups of practitioners. An evening session targets primary care practitioners, especially family physicians, and focuses on the unique nature of the military experience and the impact of these experiences on mental health, especially PTSD. A full-day session targets the whole range of mental health professionals and presents the military perspective and its impact on mental health but also highlights aspects of assessment, clinical practice guidelines, and treatment interventions. Both programs provide attendees with a better understanding of TRICARE and how it can be used by practitioners to assist military health care coverage.

Second, a community-based health delivery model using mental health personnel in a largely rural area is being developed through the Mountain AHEC. The effort seeks to establish a real-world model that can be sustainable and effective where mental health practitioners are in short or limited supply. During the first year Haywood County will be provided psychiatric physician extenders to support community-based physicians in addressing mental health issues for the full range of military personnel, veterans, and their families. In addition to the services of psychiatric nurse practitioners and social workers, comprehensive medication management services also are being provided. The program will be expanded to Clay and Jackson counties over the next 2 years. It is hoped that the community-based effort will be effective in addressing the variety of military/veteran family community needs and can be made sustainable when properly implemented. When developed and evaluated, the exportable components of this effort will be publicly available.

Furthermore, expanded access to online AHEC resources will seek to increase the readily available information for both practitioners and concerned beneficiaries. Specific material related to military and mental health issues will be available through the AHEC Digital Library. The AHEC Digital Library provides access to military mental health information for practitioners[1] right in their own home communities. This freely available collection includes links to information on mental health aspects of amputation, deployment, depression, posttraumatic stress disorder, substance abuse, trauma, and traumatic brain injury as well as preformulated searches of the medical literature on pertinent topics, patient education materials, and information for practitioners who treat children.

Additionally, NC HealthInfo, a collection of links for health providers, services, and programs across the state, offers access to expanded information on health topics, military health care, veteran health care, and other related topics.[2] Individuals can access a series of medical and health topics and even locate local resources that provide these services. A special section devoted to military and family health concerns and issues was developed in collaboration with the Citizen-Soldier Support Program.[3] Soldiers and family members will find reliable information on amputation, deployment, traumatic brain disorder, and substance abuse. As a component of this effort, additional resources will help beneficiaries and practitioners understand TRICARE and increase their capability to enroll or utilize its services as well as navigate through the military health care system. The Citizen-Soldier Support Program Web site will also be expanding content to provide greater information on TRICARE for practitioners and streamlining practitioner enrollment in TRICARE.

Other Citizen-Soldier Support Program Initiatives

The Citizen-Soldier Support Program has undertaken several other community initiatives. It developed an Adopt-a-Soldier/Family model connecting reservists to a local faith/civic community organization. Working with the 108th Army Reserve Division in Charlotte as it expands its command responsibility from a regional to a national platform, our efforts will help to integrate adopt-a-soldier/family efforts into a comprehensive national Family Readiness Program for all Reserve members and their families.

In an effort to integrate its family support services across all active, Guard, and Reserve components and to ensure consistent delivery of quality services to all personnel regardless of component, the Citizen-Soldier Support Program was invited to develop a curriculum to train Army family service personnel in community engagement and capacity building. This will hopefully be utilized in a Chapel Hill-based national training institute which will provide this resource on an ongoing basis.

The Citizen-Soldier Support Program developed a statewide partnership to promote and deliver lower cost or pro bono legal services for Guard and Reserve families. Individuals from the North Carolina State Bar, military legal personnel, state law schools, and legal aid are working to develop mechanisms to provide needed support to citizen soldier families where deficiencies and needs exist.

Lastly, the Citizen-Soldier Support Program created community scorecards to assist communities in understanding how best to interact with citizen soldiers and to recognize those communities which are exceptional in this effort. Community capacity is needed to adequately support citizen soldiers and their families in an effort to (1) strengthen them; (2) provide them with economic security; and (3) develop family-community connections. The process will include developing critical community services (eg, child care, respite care, housing, economic stability services) and evaluating their effectiveness in the community. This effort will help communities understand both what works and what needs improvement. The ability to recognize communities who have done an outstanding effort in citizen soldier support also will be developed.

Conclusion

The Citizen-Soldier Support Program is a demonstration program and, as such, through a trial and evaluation process, we have established several efforts that can both be effective for those initially impacted as well as suitable for replication in other geographic locations. Within whatever continuum that impacts citizen soldiers, their families, and their communities, health care and its unique attributes are certainly critical. Local practitioners may experience problems adapting to this new community need, but understanding military health care is essential. Participating in the TRICARE delivery network may be new and daunting but also may be necessary. The geographical realities of widely dispersed individuals who often lack local peers experiencing the same situations, the challenges of blending existing health care and insurance within the TRICARE parameters, the lack of specialized medical practitioners in this widely dispersed geographical distribution, and the challenge of a new and changing social system that has direct impact upon the health of all involved—these are the challenges facing our citizen soldiers, their families, and our communities including our health care practitioners. The Citizen-Soldier Support Program stands ready to support this challenge and provide the coordination required to ensure that the difficult aspects of these challenges are minimized. **NCMJ**

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COMMENTARY

Military Families:
Opportunities and Challenges

Denisse Marion-Landais Ambler, MD

North Carolina is home to the fourth largest concentration of active duty military personnel (101 563) in the continental United States[1] as well as substantial numbers of National Guard and Reserve members. Of the active-duty component, 37% are married with children, and 6% are single parents. Of the reserve component, 34% are married with children, and 8% are single parents. There are an estimated 96 000 military children in North Carolina.[2] More than 12 000 of North Carolina's military personnel have been mobilized and over 3000 are actively deployed.[3] The mobilization and movement of so many spouses, fathers, and mothers has an enormous impact on the families they leave behind.

> *"Understanding the experiences of the injured veteran and his or her family is a critical component of healing."*

Military families have always faced unique challenges and opportunities. Answering the call to serve the greater interests of country require members of the military to sacrifice the personal duties to family. Military family members also make great sacrifices. For the active-duty family, frequent changes in duty station are a way of life that requires concomitant changes in schools, friends, and support systems. The Military Child Education Coalition™ reports that a military child moves an average of every 2.9 years which may be 3 times more than his or her civilian peers.[4] Parent-child separations are common as one or both active duty parents leave on tours of duty. For those in the reserve component, the traditional commitment of a monthly weekend with short-term annual training no longer prevails. The wars in Iraq and Afghanistan have brought new obligations for all service members. Prolonged separations have become the norm, and repeated tours of duty to combat zones have created unpredictability for the military family. Some families have seen a loved one leave for a third or fourth tour.

For as long as there has been war, there have been loved ones waiting for the warriors to return home. Military families, like all families, come in various shapes and sizes. Given that approximately 15% of service members are female,[5] it is not always the mother who is left to handle the homefront. Single parents and dual military couples must have Family Care Plans in place that indicate how dependents will be cared for in the case of deployment. Grandparents, extended family, and sometimes even nonbiological relatives become a part of the family as they assume care of children during parental deployments. Most military support systems for families on the home front are oriented toward "military dependents" and particularly female spouses and children; those not fitting this demographic can face additional isolation. Military dependents are defined as the spouse or servicemember's children who are unmarried and under 21 years or who are incapable of self-support due to physical or mental limitations, dependent parents, and similarly dependent brothers or sisters. Family members such as grandparents or aunts and uncles who are not captured under the definition of military dependent are less likely to be familiar with the resources available to them and thus less likely to use them.

Additionally, during deployment some families choose to move closer to other support systems such as extended family, which may entail a move to another city or even state. Such a move may mean a change in school, employment, and established health care resources. It may also separate the family further from the service member's home unit and his or her Family Readiness Group. A Family Readiness Group is the family's official communication network with other military families

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which offers them mutual support. Family Readiness Groups also provide opportunities to share lessons learned in regards to available community resources that may or may not be present in other areas.

Being part of a military family does have advantages. By definition, one family member is employed and has access to health care resources. If the service member is part of the active duty component, there may be additional advantages such as housing assistance through government housing or a basic allowance for housing. Schools and day care are often available on base as well as access to a health care system. However, for those in the reserve component, families often do not have such military services readily available to them. Reserve component families are more likely to use their local community services and supports, particularly if they live far from a base. Given that there are service members in all 100 North Carolina counties, most civilian health care practitioners are likely to have at least one military family in their practice. Spouses who move closer to extended family (and away from military installations) during a family member's deployment may face changes in their health care services. Changing between civilian health coverage and the TRICARE system can mean a change in providers and a disruption of continuity of care at an already stressful time.

Of the many challenges faced by military families, the most daunting and obvious is that a loved one is deployed to a war zone. Rentz et al[6] examined changes in the occurrence of child maltreatment in military families and the impact of deployment increases in the period 2000-2003. The rate of maltreatment in military families after the September 11, 2001 attacks was twice as high as in the period preceding that date. This article pointed to the stress of deployment and reintegration (and the risk thereof) as the likely culprit. Gibbs et al[7] also found greater rates of substantiated child maltreatment among families of enlisted (noncommissioned) soldiers in the US Army when the soldiers were on combat-related deployments. Junior enlisted families are often among the youngest families and those who commensurately receive the least compensation, factors that are known to place civilian families at risk for domestic violence. It is important to note that entry into the military maltreatment referral process tends to be more sensitive than entry into civilian child protective services. This is because families live on base among those with whom the service member works and this allows for multiple points of observation and identification of a domestic violence situation. These articles, however, did not explore the effects of deployment on the reserve population or nonspouse caretaker referrals, populations which may in fact have fewer formal supports during a deployment.

There is no denying that war itself is a stressor. The service member undergoes physical and mental changes that allow him or her to survive living in a war zone. These adaptations are vital to mission readiness. The service member's family goes through changes during deployment as well. The wars in Iraq and Afghanistan have brought both reminders of lessons learned in past conflicts as well as new understandings of these challenges. The knowledge gained from the Mental Health Advisory Team reports, real-time assessments of behavioral health benchmarks, and treatment in-theater is allowing real-time adjustments in combat stress treatment protocols. Advances in battlefield medicine are saving many from previously lethal injuries. However, some veterans will return with mental and physical injuries. Some will not return at all. All will have experienced some change. Their families have changed and grown in their absence as well.

Children as a whole are thought to be quite resilient when facing the deployment of a parent, but data from the present conflicts must be collected to evaluate their health and needs. Deployments cause stress on the entire family unit. Pediatricians and other primary care practitioners have the opportunity to explore the effects of deployment on the individual and family. The well-being of the parent who remains at home often directly impacts the response of the children. This observation appears to be particularly meaningful for the youngest children. Children of latency age have an increased verbal ability that allows for greater understanding and discussion of a parent's absence due to trainings and deployment. A wide range of reactionary behaviors may be seen from regressions in development (eg, bedwetting, resumption of thumb sucking) to attempts at mastery (eg, initiating a school project for veterans). Teenagers may display various responses as well, ranging from the young person who takes on many of the deployed parent's responsibilities to the adolescent who develops acting out behaviors. Maintaining routines helps to provide stability for children. Remaining connected to the deployed loved one is important also. The use of the Internet and text messaging has made this interaction more possible than ever before. The availability of these technologies also has added a new dimension because service members may feel more compelled to parent from the warzone in real time.[8] At the same time as technology allows for connections, it should be closely monitored as media exposure of war can add to families' anxieties.

Families also adapt as the deployed service member reintegrates into the family. Reestablishment of routines and parental and spousal roles can take time. Patience is always required. When a family member returns with injuries the reintegration into family life may be complicated. When a parent returns with psychiatric trauma the family, spouse and children, can also be profoundly affected. The loss of a parent is undoubtedly life-alerting. There is little research to date on these aspects of the wars in Iraq and Afghanistan, but the long-term effects on families and children of service members will perhaps be one of these conflicts' greatest legacies.

In recent years there has been an explosion of information and services, both nationally and in North Carolina, directed toward support of our military families. National efforts such as the SOFAR project and Zero to Five target children of deployed parents. The American Academy of Pediatrics has compiled a list of resources to help military families with special needs children find medical homes. Various other national and state by state programs are evolving to meet the needs of military families.

In North Carolina, the Citizen-Solider Support Program is an effort established by Congress and spearheaded by the

Odum Institute at the University of North Carolina at Chapel Hill (UNC-Chapel Hill). Created to build bridges between local community resources and military families, the program focuses especially on the needs of National Guard and other Reserve component members and their families. The Governor's Focus on Returning Combat Veterans and their Families is a partnership between the state and the federal government, community practitioners, and community programs that addresses the mental health and substance abuse needs of North Carolina's veterans and their families. This year, North Carolina also became host to the nation's first statewide "Living in the New Normal: Supporting Children Through Trauma and Loss" initiative, which brought together more than 100 representatives of government, business, education, health agencies, and faith-based organizations at a Public Engagement Workshop held in Raleigh as a part of the new statewide initiative created by the Military Child Education Coalition.™[2]

At this point, the abundance of information but lack of clear direction in locating available resources stymies many families. One effort designed to guide families through the system is NC Health Info (www.nchealthinfo.org), a special Internet portal based at the Health Sciences Library at UNC-Chapel Hill. NC Health Info contains a collection of consumer health information with an easy-to-use mental health information area for military members and their families. It also has a specific portal for professional primary care and mental health providers containing comprehensive coverage of military-related mental health topics and best practice information. NC Health Info was the first "Go Local" Web site which was created and developed by librarians at the UNC-Chapel Hill Health Sciences Library to provide access to information about local health services combined with reliable health information provided by MedlinePlus, the National Library of Medicine's consumer health site. It serves as a model for more than 25 other state and regional health-information sites.[9]

As our veterans return there will be numerous opportunities to assist them as they traverse the divide between civilian and military life. The biggest barrier to meeting the needs of military families is the shortage of civilian practitioners who have an understanding of the challenges facing military families. Knowing how deployment and reintegration affects families allows practitioners to identify when additional help is warranted. Understanding the experiences of the injured veteran and his or her family is a critical component of healing. The North Carolina AHEC Digital Library is a welcome resource for the practicing clinician interested in becoming more knowledgeable about the specific needs of military members and their loved ones. All North Carolina health professionals are eligible for membership in the AHEC Digital Library, a unique digital system that supports health professionals by providing a single, customized, web-based interface into health information resources and services. The AHEC Digital Library supports the delivery of quality, evidence-based health care across North Carolina and ensures that even in rural underserved areas of the state providers have access to the current information and resources necessary to provide quality care.[10]

Most military families wish only for an acknowledgement of their sacrifices. The call to duty has come for many of our neighbors here in North Carolina. Those of you who live near one of our military bases may be familiar with the sacrifices made by our country's service members and their families. Others may not realize that a neighbor gives service as part of the Reserve component. Sensitivity to the new stressors soldiers and families face during mobilization and deployment is important. Practical assistance is required for spouses adjusting to the functional roles as a single parent. Social and emotional needs of the children of deployed parents must be addressed. Military families often rely on civilian supports, particularly if the family is not located near a base and/or service members are on their initial deployments. North Carolina medical professionals have the opportunity to provide care for military family members right now. The challenge is to take the opportunity. **NCMJ**

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Pitt County Health Sciences Academy

Diane Poole; Randy Collier; Nettie Evans, RN, MSN; Janice Faulkner; Michael Priddy, PhD; and Janet Knox

In 2001 the University Health Systems of Eastern Carolina and its flagship 745-bed tertiary care center, Pitt County Memorial Hospital, were experiencing workforce shortages resulting in closed beds and subsequent service delays. Projections of a forthcoming health care workforce crisis propelled the health system to develop new strategies to address this issue. Workforce development became an organizational priority to assure that the 1.2 million citizens in its catchment area could have timely access to its tertiary care services.

A partnership was established that included University Health Systems of Eastern Carolina, East Carolina University and Brody School of Medicine, Pitt Community College, Eastern Area Health Education Center, Greenville-Pitt Chamber of Commerce, and Pitt County Schools. The partners shared a common belief that low student academic achievement was one of the largest barriers to resolving the health workforce shortage in eastern North Carolina. They agreed that investing in local students who desired to live and make a difference in the region could serve to promote economic development through increased opportunities for stable, good paying jobs while concurrently addressing the University Health Systems' workforce demands.

To respond to the needs and to take advantage of the resources available to the system, the Pitt County Health Sciences Academy was developed. With financial support from The Duke Endowment and the creative and committed leadership of this unique partnership, the Academy opened its virtual door to high school freshmen in the fall of 2003 and evolved as a broad-based, far-reaching strategy to create systemic change by improving students' academic strengths in math, science, and reading comprehension. The Academy is a high school enhanced curriculum, a school-within-a-school model, that provides 4-year health career pathways (academic and health sciences elective courses) for students pursuing health care-related careers after graduation. The Academy partners with Pitt Community College and East Carolina University's Brody School of Medicine to provide academic opportunities beyond the standard high school curriculum. Its goal was to produce students with increased academic knowledge and skills combined with an awareness of health career options. Emphasis was placed on the math, science, technology, reading, and critical thinking skills required for successful admission and completion of rigorous college or university health sciences coursework.

The first 4-year class of 51 students graduated in May 2007, and a total of 110 students have graduated since 2005. Thirty former high school participants have already entered the part-time workforce of Pitt County Memorial Hospital while pursuing health careers in colleges and universities. The program conducted 1- and 2-year follow-up studies of the graduates and found that 93% are pursuing health-related occupations.

The program has learned along the way that it can be more intensive and key modifications made to Pitt County Health Sciences Academy since its inception include opening its enhanced curriculum to all students, realigning its cohort to meet accountability standards, implementing an early college track, and enhancing early employment options such as internships and pharmacy technician certifications. In the future it plans to expand the early college option, consolidate the academy into a single facility, and explore aligning it with a regional math and science high school.

The partnership recognizes that the success of this endeavor can be expanded and continued. The program looks forward to continuing its task of expanding the academic achievement and interest in health careers of regional students.

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Spotlight on the Safety Net

A Community Collaboration

Kimberly M. Alexander-Bratcher, MPH

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The Veterans Health Administration (VHA) provides health care to servicemen and women honorably discharged from the military. Health care is provided on a priority system. Veterans with injuries related to the current conflicts receive first priority. Priority is next given to veterans based on the magnitude of their disabilities. The Veterans Health Administration also provides health care services for nonservice-related health issues based on availability and it offers a safety net program for low-income veterans. The safety net services are provided based on the available capacity of needed health services and on the patient's income. The VHA offers 5 specific safety net programs for low-income veterans: Home Based Primary Care, Care Coordination Home Telehealth, Contract Nursing Home, Compensated Work Therapy, and Health Care for Homeless Veterans. These programs are provided through the 4 Veterans Affairs Medical Centers (VAMCs) in North Carolina located in Asheville, Durham, Fayetteville, and Salisbury.

The Home Based Primary Care program provides a safety net for veterans between hospital discharge and Medicare coverage. A multidisciplinary team including the primary care physician, psychologist, social worker, nutritionist, dietician, and pharmacist provides care in the patient's home. The average patient is 77 years old and has some cognitive deficit. Many of the program's patients would be in nursing homes without the availability of the program. The length of stay in the program may be a few months, many years, or the remainder of a veteran's life. The program simply requires that the veteran be in need of home care and have a referral from a primary care provider in the VA system. The Durham VAMC provides this program to veterans within a 35-mile radius of the center. Other programs operate in Asheville and Salisbury with plans to expand to Fayetteville, Greenville, Morehead City, and Raleigh.

The Care Coordination Home Telehealth program provides distance care management for veterans with chronic progressive health problems including diabetes, hypertension, heart failure, and chronic obstructive pulmonary diseases (COPD). The program connects patients with a care coordinator to help them avoid emergency rooms visits and serves as the eyes and ears of the patient's physician. Monitors are placed in patients' homes that allow them to measure and input health data including heart rate, blood pressure, blood sugar, and oxygen saturation. The patients and their caregivers receive training on the monitors which ask a series of customized symptom questions. Patients may be connected directly to the measuring devices or patients or caregivers can input the data. The data are transmitted through telephone lines to the care coordinator and are then stratified by patient risk so that those with abnormal values are helped first.

Patients in the program are referred by their providers and must have a targeted condition, take 10 or more medications, have been hospitalized or visited an emergency room in the past 2 years, and be able to operate the monitor or have a caregiver who can operate the monitor. Patients range in age from 20 to 90 years in age. Since the program's inception in the Durham VAMC in August 2005, 550 veterans have been served. There are currently 356 active program participants. On a sample of program participants during a 7-month period, the program achieved a 65% reduction in days in a hospital bed, a 59% reduction in patient admissions, and a 54% reduction in patient visits. Future plans include expanding the program to include posttraumatic stress and substance abuse disorders.

The Contract Nursing Home program provides long-term care for veterans on the basis of need without regard to their priority status. Those with 70% to 100% disability receive paid nursing home care, long-term care, or home care programs. These home care programs include home health aids, adult day health care,

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and noninstitutional respite care. The Veterans Health Administration pays North Carolina's veterans' homes, located in Salisbury and Fayetteville, a stipend for each enrolled veteran. Veterans themselves may also receive payment in the form of compensation for military service-related conditions, pensions for conditions not related to military service, or Aid in Attendance funds for homebound veterans to receive care for daily living activities. Most of these veterans can receive care for free in a VAMC or satellite clinic. The program provides access to primary care, allied health, and other health care practitioners. The program has served more than 450 veterans since fiscal year 2006.

The Compensated Work Therapy program attempts to successfully reintegrate disabled veterans into the community through access to meaningful vocational opportunities aligned with the veteran's highest functional level. The program supports the idea that all veterans have potential for rehabilitation and focuses on recovery of a quality of life with which each veteran is comfortable. The program works with clinics and organizations across the Triangle including Duke University, the Employment Security Commission, the University of North Carolina (UNC) at Chapel Hill, North Carolina Vocational Rehabilitation, state agencies, and various private sector companies. It offers supported employment which specializes in working with veterans with severe mental illnesses, transitional work experience open to all veterans with any level of disability, and incentive therapy which caters to lower functioning veterans. A recently implemented program, Compensated Work Therapy served 45 veterans between August and November of 2007.

Health Care for Homeless Veterans provides health care (medical, mental, and dental), transitional housing, and special events for homeless veterans. The program helps homeless veterans establish a primary care home in a VAMC or satellite clinic. The program has a grant-in-per-diem program for transitional housing that will pay the community for transitional housing for up to 2 years. Currently, there is a partnership with Volunteers of America to build 24 housing units in Durham. Other facilities include Healing with Care, a 9-bed facility in Durham that will accept HIV-positive veterans: Servant Center in Greensboro for medically disabled and terminally ill homeless veterans; and Hospice. The UNC School of Dentistry is contracted to provide dental services for the program. In 1994 the Durham VAMC began community wide one-day events to connect homeless veterans with many services including employment, food, clothing, haircuts, financial counseling, and legal assistance in addition to mental health, posttraumatic stress disorder, and substance abuse services.

These 5 safety net programs administered by VHA provide significant services and opportunities that help bridge the gaps in care for low-income veterans across North Carolina.

Contributions from Bob Williamson, MSW, program coordinator, Health Care for Homeless Veterans; Tridell Morgan, MBA, program coordinator, Compensated Work Therapy; Ivey Chavis, MSW, coordinator, Contract Nursing Home; Peggy Becker, LCSW, program director, Home Based Primary Care; and Sue Kistler, lead care coordinator, Care Coordination Home Telehealth Program.

Readers' Forum

To the Editor:

There is no shortage of statistics about the obesity epidemic our nation faces. North Carolina is no stranger to this issue—just look around us as we shop at grocery stores or sit in doctors' offices to be treated for chronic conditions. Last year the Trust for America's Health ranked North Carolina as having the 17th highest rate of adult obesity and the 5th highest rate of overweight youths (ages 10-17) in the nation. We are taking personal risks by gaining excess weight, eating unhealthy foods, and not getting enough exercise. The costs to a person's life span are staggering, and that includes the high cost of health care needed to offset these lifestyle choices.

In response to this trend, Blue Cross and Blue Shield of North Carolina (BCBSNC) launched the Healthy Lifestyle Choices program [see also *North Carolina Medical Journal*, July/August 2006, pages 313-315]. This preventive health program began as a pilot program to help engage participants in regular exercise and nutritious eating. As part of our effort, participants received a personalized report on opportunities for lifestyle improvement, a diary to record food intake and physical activity, a step counter, a tape measure (to track waist circumference), a newsletter, and other educational materials. BCBSNC also provided physician toolkits for the treatment of obesity to 200 high-volume primary care practices. We acknowledged the critical role of the patient's physician by providing reimbursement for up to 4 office visits for the evaluation of obesity as a sole diagnosis.

Recently released results of a 2-year follow up study (2005-2006) compared the impact our Healthy Lifestyle Choices program had on the medical costs and behaviors of almost 1200 participants. Simple lifestyle changes added up to big savings—almost $200 annually per participating member in the Healthy Lifestyle Choices program. Savings over the 2-year period totaled close to $450 000. That translated into medical expenses that were one-third less than the average medical trend. The implication is that living a healthier lifestyle can save money.

Our findings are even more startling when you consider the significant impact our choices and habits have on the cost of health care. In fact, in 2004 BCBSNC found that members who are overweight cost the company 18% more than normal weight members in medical claims and expenses, and obese members cost 32% more. Preventive health programs offered by BCBSNC aim to curb that trend.

Results of the Healthy Lifestyle Choices program hit not only the bottom line, but also waistlines. Of those participants with a weight loss goal, 49% lost an average of 11.6 pounds. In addition, waist circumference decreased one-half inch for participants on average. Participating members also had real success in increasing the number of days exercised per week and in increasing consumption of fruits and vegetables to two or more times per day.

The success of the program led BCBSNC to expand its healthy living offerings into our comprehensive Member Health Partnerships program, which gives members access to a wide variety of health and disease management resources. Recently added benefits include one-on-one health coaching, where members can talk to a registered nurse about losing weight, chronic conditions, or other health issues. Most members who enroll also have access to 6 free nutritional visits. We believe these approaches are, along with physician advocacy, helping to drive changes in behavior.

The results have exceeded our expectations with the emphasis on long-term lifestyle changes to help people improve their health and manage their costs. It is encouraging to see that participants are making healthier lifestyle changes in both diet and exercise. Nutrition visits are growing quickly. We are on the right track, working with a full range of health care team members to help patients/members manage their weight and weight-related health issues.

While these results are encouraging, we have only scratched the surface of the problem. In order to inculcate true lifestyle changes we need to engage members/patients not only at home but at work and school. This is a family project in the broadest sense. In the meantime, BCBSNC will continue to offer members tools and resources to help them, working with their doctors, make the best choices for their own health. It's a marathon, not a sprint.

Don Bradley, MD
Chief Medical Officer and Senior Vice President
Blue Cross and Blue Shield of North Carolina

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Readers' Forum continued from page 67

To the Editor:

In your Readers' Forum section of the September/October 2007 *Journal* one of your readers commented on the shortage of family physicians in the United States. He was quite correct in this evaluation and suggested solutions. One very important point he did not mention is the role that physician assistants and nurse practitioners will play in the care of sick Americans. I strongly believe these professionals will play an extraordinary role in the new health reform in this country. It is very well-known that many minor illnesses can be taken care of by these practitioners; they listen to the patient, perform a physical examination, and diagnose and treat the illness. The successful results of the retail or minute clinics is the best proof of what the aforementioned practitioners can do to cut the cost of the increasing expenses of our health care. Of course this is only one factor in our broken system; the whole problem is more complex.

C. A. Ruiz, MD
Greensboro, North Carolina

Publishers of the *North Carolina Medical Journal*

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In 1983 the North Carolina General Assembly chartered the North Carolina Institute of Medicine as an independent, nonprofit organization to serve as a nonpolitical source of analysis and advice on issues of relevance to the health of North Carolina's population. The Institute is a convenor of persons and organizations with health-relevant expertise, a provider of carefully conducted studies of complex and often controversial health and health care issues, and a source of advice regarding available options for problem solution. The principal mode of addressing such issues is through the convening of task forces consisting of some of the state's leading professionals, policy makers, and interest group representatives to undertake detailed analyses of the various dimensions of such issues and to identify a range of possible options for addressing them.

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Running the Numbers

A Periodic Feature to Inform North Carolina Health Care Professionals
About Current Topics in Health Statistics

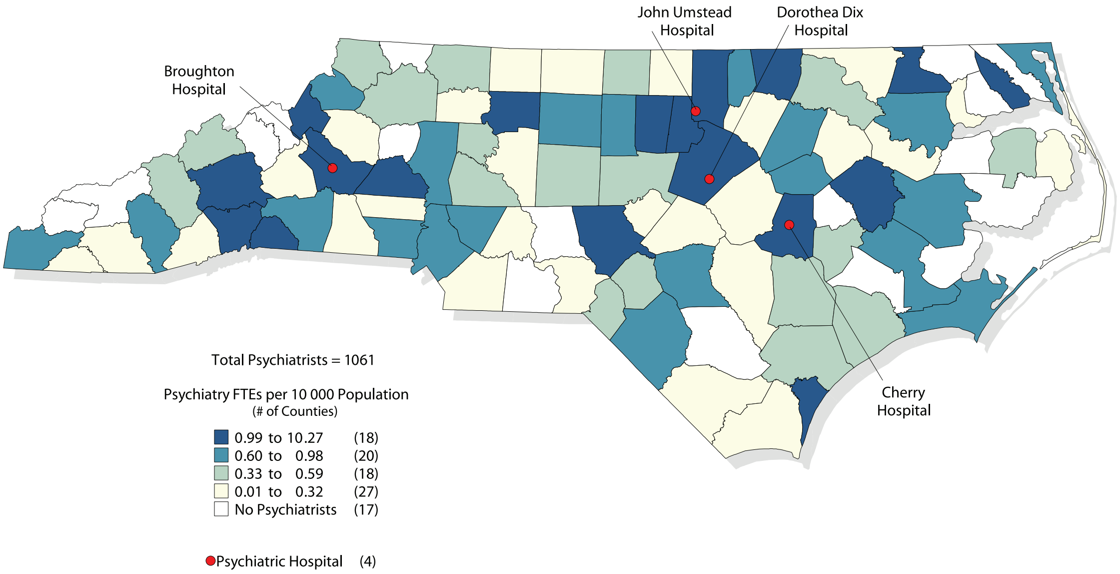
North Carolina Health Professions Data System
http://www.schsr.unc.edu/hp/index.html

Mental Health Professionals in North Carolina

Nearly one-third of nonelderly adults and one-sixth of children experience a mental health disorder in their lifetimes. Thirteen percent of Americans receive some form of mental health treatment each year including inpatient treatment (0.9%), outpatient treatment (7.9%), and behavioral medication (10%).

There are 3 broad classifications of mental health patients: (1) persons with developmentally disabilities, (2) persons with substance abuse disorders, and (3) persons with mental illnesses. Within this third group, there are numerous illnesses of varying severity. A severely mentally ill person who suffers from schizophrenia or bipolar disorder may have trouble functioning independently in society. People with moderate depression or posttraumatic stress disorder may be appropriately treated with medication. Within mental health there exists a wide range of health issues that may not require intense medical treatment but which may affect a patient's well-being.

Figure 1.
Psychiatrist Full-Time Equivalents per 10 000 Population North Carolina, 2004



Source: LINC, 2005; North Carolina Health Professions Data System, with data derived from the North Carolina Medical Board, 2004; NC DHHS, MHDDSAS, 2005.

Produced by: North Carolina Health Professions Data System, Cecil G. Sheps Center for Health Services Research, University of North Carolina at Chapel Hill.

*Psychiatrists include active (or unknown activity status), instate, nonfederal, nonresident-in-training physicians who indicate a primary specialty of psychiatry, child psychiatry, psychoanalysis, psychosomatic medicine, addiction/chemical dependency, forensic psychiatry, or geriatric psychiatry, and secondary specialties in child psychiatry and forensic psychiatry.

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Research estimates suggest there are 64 000 children and 49 000 adults with developmental disabilities in North Carolina. All together, research suggests 400 000 North Carolinians suffer from substance abuse disorders. Research also estimates there are 66 000 children and adolescents and 356 000 adults with serious mental illnesses within the state.

Among people with more moderate mental illnesses, depression is one of the most common ailments. According to the National Center on Drug Use and Health, 9% of North Carolina residents ages 12 to 17 years old suffered from at least one depressive episode in 2005. Among adults in the state, nearly 8% suffered at least one episode.

According to the Health Professions Data System at the University of North Carolina at Chapel Hill, 44 North Carolina counties qualified as Mental Health Professional Shortage Areas in 2004 because they had fewer than one-third of a psychiatrist for every 10 000 people. Between 1999 and 2004, 48 counties experienced a decline in psychiatrists relative to the change in population, 5 counties lost the psychiatrists they had, and 12 counties had none and gained none. In other words, during that 5-year period, nearly two-thirds of North Carolina counties either had no psychiatrists or experienced a decline in supply. The map in Figure 1 shows the uneven distribution of psychiatrists across counties and their density in relation to the state's major mental health facilities.

Compared to the rest of the nation, North Carolina ranks 20th in the density of psychiatrists. In 2005 North Carolina had 1091 psychiatrists in practice, or 1.2 per 10 000 population. Regardless of rank, North Carolina is well below the overall national average. In 2005 the United States had 41 958 psychiatrists in practice, or 1.42 per 10 000 population. For psychologists, North Carolina fell below the national average with 2.58 psychologists per 10 000 population compared to 3.35 for the nation. It is only in the social work profession where the state exceeds the national average with 17.9 per 10 000 compared to 15.8 per 10 000 population.

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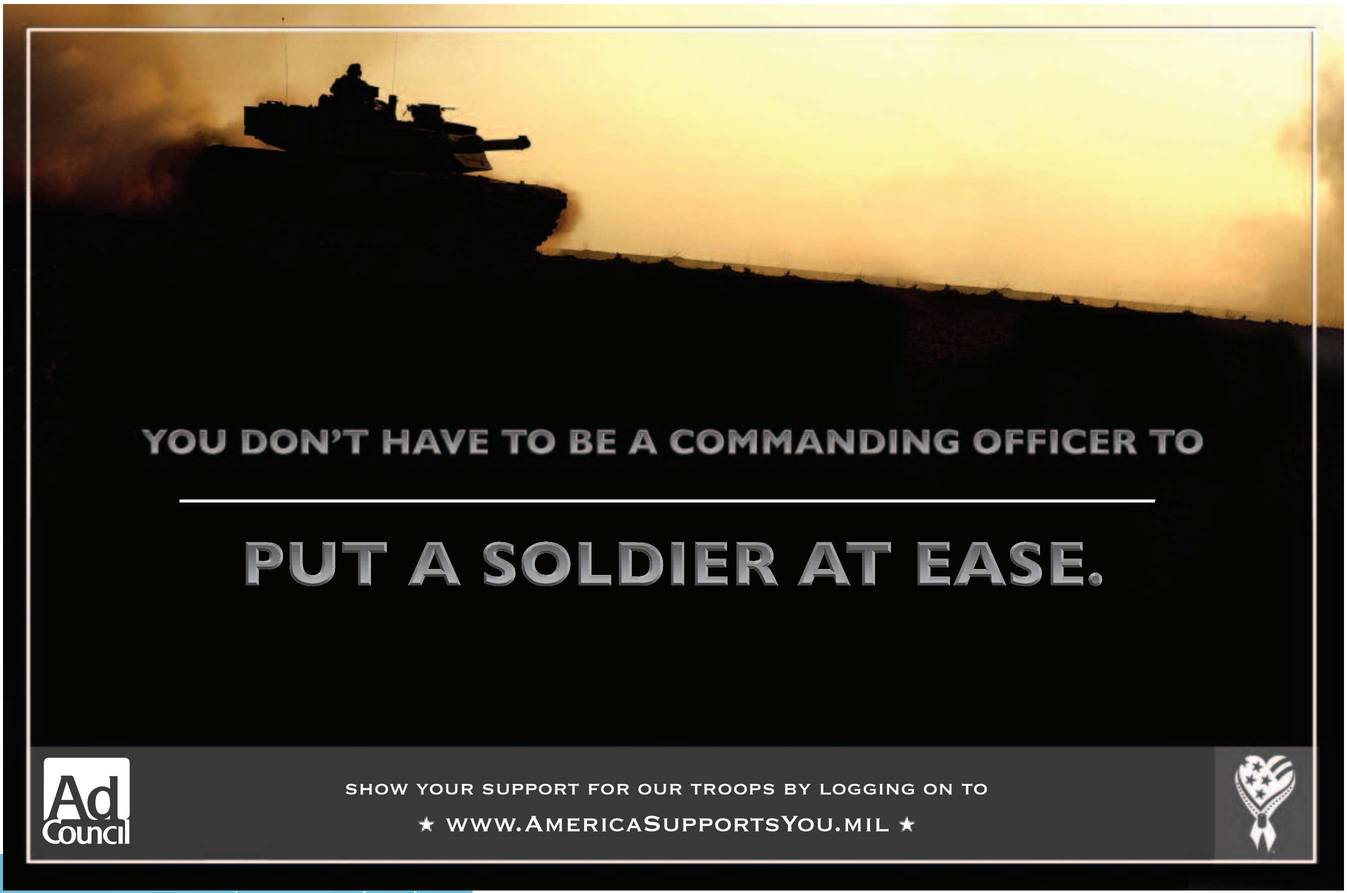

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Tarheel Footprints in Health Care

Recognizing unusual and often unsung contributions of individual citizens who have made health care for North Carolinians more accessible and of higher quality

Paul A. Buescher, PhD
Director, State Center for Health Statistics

North Carolina has a deserved reputation for excellence in collecting and reporting vital and health statistics. This is due in large part to the early development of a State Center for Health Statistics (SCHS) and the quality of individuals who have led that Center. The current director, Paul Buescher, is keeping alive the tradition of objectivity, responsiveness, and accuracy that has marked the SCHS since its beginning. Paul, in a sense, is one of our own at the *North Carolina Medical Journal* since he has edited a regular feature, *Running the Numbers*, for the past 7 years. We wish to recognize him, however, for his work at the Center. Paul has steadily and constructively made the State Center for Health Statistics a trusted and relevant participant in the health policy making process in North Carolina, and his willingness to bring the data of the Center into public forums sets him apart.

Paul became director of the State Center for Health Statistics in 2005 after serving in progressively responsible roles. He began work at the SCHS in 1980 as a statistician and gained a reputation as a productive contributor to its work. In 1993 he became head of the Statistical Services Unit. Having spent most of his career at the SCHS, Paul is intimately familiar with its programs and is highly committed to its ongoing success and improvement. Leah Devlin, state health director, notes that Paul "...is a master of turning data into meaningful information that is routinely used across North Carolina to identify health problems, define effective strategies, and evaluate outcomes. He is incredibly knowledgeable and dedicated —we all stand on his recommendations with absolute confidence."

Paul's role as a communicator is an important asset for both state and community leaders. Paul has been tasked to publicly explain positions that are often hard to grasp by a layperson, such as how an unusual number of cancer cases occurring in a community is unlikely to be due to a specific environmental cause but has a much greater probability of happening due to chance. These kinds of public discussions can become stressful and contentious, but Paul is able, through his calm demeanor and clear language, to make convincing arguments that rely on statistical facts and understanding—a skill that he has mastered.

An Eagle Scout who received his undergraduate degree in Sociology from Louisiana State University, Paul went on to receive a MA in Sociology and a PhD in Sociology/Demography from the University of North Carolina (UNC) at Chapel Hill. He has been an adjunct professor in the Department of Maternal and Child Health in the UNC Chapel Hill School of Public Health since 1991 and is a ready and willing mentor to students and faculty at the university.

Paul is an accomplished scholar and has published extensively in the medical and public health literature. He was the recipient of the national 2004 Maternal and Child Health (MCH) Epidemiology Effective Practice at the State Level Award from the Coalition for Excellence in MCH Epidemiology. The Effective Practice Award recognizes individuals who make significant contributions to MCH public health practice through the effective use of data and epidemiology. North Carolina is fortunate that Paul Buescher brings his knowledge and skills to the work of the State Center for Health Statistics.

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ARTICLE

The Economic Impacts of Medicaid in North Carolina

Christopher Dumas, PhD; William Hall, PhD; Patricia Garrett, PhD

Abstract

Objective: *The purpose of this study is to provide estimates of the economic impacts of Medicaid program expenditures in North Carolina in state fiscal year (SFY) 2003.*

Study Design: *The study uses input-output analysis to estimate the economic impacts of Medicaid expenditures.*

Data Sources /Study Setting: *The study uses North Carolina Medicaid program expenditure data for SFY 2003 as submitted by the North Carolina Division of Medical Assistance to the federal Centers for Medicare and Medicaid Services (CMS). Industry structure data from 2002 that are part of the IMPLAN input-output modeling software database are also used in the analysis.*

Principal Findings: *In SFY 2003 $6.307 billion in Medicaid program expenditures occurred within the state of North Carolina—$3.941 billion federal dollars, $2.014 billion state dollars, and $351 million in local government funds. Each dollar of state and local government expenditures brought $1.67 in federal Medicaid cost-share to the state. The economic impacts within North Carolina of the 2003 Medicaid expenditures included the following: 182 000 jobs supported (including both full-time and some part-time jobs); $6.1 billion in labor income (wages, salaries, sole proprietorship/partnership profits); and $1.9 billion in capital income (rents, interest payments, corporate dividend payments). If the Medicaid program were shut down and the funds returned to taxpayers who saved/spent the funds according to typical consumer expenditure patterns, employment in North Carolina would fall by an estimated 67 400 jobs, and labor income would fall by $2.83 billion, due to the labor-intensive nature of Medicaid expenditures.*

Limitations: *Medicaid expenditure and economic impact results do not capture the economic value of the improved health and well-being of Medicaid recipients. Furthermore, the results do not capture the savings to society from increased preventive care and reduced uncompensated care resulting from Medicaid.*

Conclusions: *State and local government expenditures do not fully capture the economic consequences of Medicaid in North Carolina. This study finds that Medicaid makes a large contribution to state and local economic activity by creating jobs, income, and profit in North Carolina. Any changes to the Medicaid program should be made with caution.*

Relevance: *The rising costs of health care and the appropriate role of government health insurance programs are the object of current policy debates. Informed discussion of these issues requires good information on the economic and health consequences of alternative policy choices. This is the first systematic study of the broader economic impacts of Medicaid expenditures in North Carolina.*

Medicaid is a health insurance program for certain low-income individuals and families. The program covers children in low-income households; the aged, blind, and/or disabled; and people who are eligible to receive federally-assisted income maintenance payments.[a] In North Carolina, Medicaid is jointly funded by federal, state, and county governments. (In October 2007 the state began a 3-year phaseout of county funding with this share being assumed by the state.) The North Carolina Division of Medical Assistance manages the Medicaid program.[1] Approximately 1 out of 6 North

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[a] For additional information on Medicaid, see http://www.cms.hhs.gov/.

Christopher Dumas, PhD, is an associate professor in the Department of Economics and Finance at the University of North Carolina Wilmington. He can be reached at 910-962-4026, dumasc (at) uncw.edu, or 601 South College Road, Wilmington, NC 28403.

William Hall, PhD, is a professor in the Department of Economics and Finance and director of the Center for Business and Economic Services at the University of North Carolina Wilmington.

Patricia Garrett, PhD, is a former project director at NC Covering Kids & Families for the North Carolina Pediatric Society Foundation in Raleigh, North Carolina.

Carolinians (1.4 million people) was eligible for Medicaid coverage at some time during state fiscal year (SFY) 2003. Although considerable information is available on Medicaid program services, recipients, and costs, relatively little information is available on the economic impacts of Medicaid expenditures, especially at the state or regional level. The purpose of this study is to estimate the economic impacts of Medicaid program expenditures in North Carolina in SFY 2003.

It is well-known that Medicaid program costs are large and growing.[2] In 2001 Medicaid financed $5.32 billion of the $31.6 billion spent on health care in North Carolina, or 17% of total health care spending in the state.[3] From 1978 to 2003, Medicaid expenditures in North Carolina increased from $307 million to $6.3 billion.[4,5] By 2003, average nationwide Medicaid costs (22.3% of state government expenditure) had displaced elementary and secondary education (21.4% of state government expenditure) as the largest state expenditure.[6] In North Carolina Medicaid is a large and growing proportion of the state budget—currently about 16%.[7] Moreover, because Medicaid is an entitlement program, state expenditures cannot be capped. This introduces unpredictability into the budgetary process, which is one factor that makes Medicaid a challenging program for states to administer.[6,8]

The individual and public health benefits of Medicaid are also well-known. Figure 1 provides a schematic summary of the health and economic benefits of Medicaid for individuals and communities. Health care professionals appropriately emphasize both the clinical benefits (see Figure 1.A) and public health benefits (see Figure 1.B) of the Medicaid program. By promoting access to timely and appropriate medical care, and with an emphasis on preventive care and best practice protocols, Medicaid improves health status and mitigates the possibility that chronic conditions will become disabilities. For example, a recent study finds that enrolling children in Medicaid before they get sick promotes the use of preventive care, reduces the need for hospitalization, and improves health.[9] In a recent review study of health insurance and access to prescription medicines, insurance coverage was found to be essential for access to prescription drugs with increased access consistently observed for insured compared to uninsured children.[10] In another recent study of automobile accident victims receiving hospital care, victims without health insurance were found to receive less care and suffer a substantially higher mortality rate compared to victims with health insurance.[11] In terms of public health effects, Medicaid expenditures support health care infrastructure used by the general public (eg, community hospitals), contain communicable diseases, and promote general public health through health awareness and wellness campaigns.

In addition to health benefits, Medicaid indirectly confers economic benefits to recipients (see Figure 1.C.1-2) and to other patients in the health care system (see Figure 1.C.2-3). By improving health, Medicaid improves labor participation—an individual's capacity to stay employed and work productively. By facilitating timely and preventive care, Medicaid reduces costly emergency care,[9] thus reducing the overall cost of health care to the individual and to the economy. Additionally, by reducing unpaid medical costs, Medicaid reduces cost-shifting. Cost-shifting occurs when unpaid medical costs are absorbed by hospitals, county health departments, or other safety net providers and/or passed on in the form of higher premiums to consumers with private health insurance. For example, a recent study by Families USA[12] finds that the uninsured cannot pay two-thirds of their health costs, and of this amount, two-thirds is passed on to those with private health insurance in the form of higher premiums. The Families USA study found that in 2005 the annual premium cost for a family health insurance policy provided by private employers was an average $922 higher due to the cost of care for the uninsured.

Figure 1.
Major Health and Economic Benefits of Medicaid Expenditures for Individuals and Communities

Benefits	**Beneficiaries**	
	Individual	***Community***
Health	**A.** *Clinical effects.* By promoting access to timely and appropriate medical care, and with an emphasis on preventive care and best practice protocols, Medicaid improves health status and mitigates the possibility that chronic conditions will become disabilities.	**B.** *Public health effects.* Medicaid expenditures support health care infrastructure used by the general public (eg, community hospitals), contain communicable diseases, and promote general public health through health awareness and wellness campaigns.
Economic	**C.** *1. Improved labor participation.* . By improving health Medicaid improves an individual's capacity to stay employed and work productively. *2. Reduced cost of care.* By facilitating timely and preventive care Medicaid reduces costly emergency care, reducing the overall cost of health care to the individual and the economy. *3. Reduced cost shifting.* By reducing unpaid medical costs Medicaid reduces health care provider write-offs that are passed on to the insured in the form of higher insurance premiums.	**D.** *Direct and multiplier effects.* Medicaid expenditures stimulate the local economy through supporting jobs, labor income (wages, salaries, and sole proprietorship/partnership income), capital income (rents, interest payments, and corporate dividend payments), and taxes.

What is less well-known is that Medicaid has substantial, positive impacts on state business activity (see Figure 1.D). Medicaid expenditures stimulate the local economy, supporting jobs, labor income, business income, and taxes. Recent studies nationwide have begun to assess these impacts at the state level.[13-31] For example, studies conducted in both Alaska[14] and Texas[15] found that Medicaid has substantial economic impacts in those states. The Alaska study found that Medicaid program expenditures supported over 9 000 jobs in the state and generated more than $346 million in personal income (wages, salaries, and business income). Each dollar of Alaska state funds invested in Medicaid resulted in $2.31 dollars of personal income to state residents due to the infusion of Medicaid cost share dollars from the federal government (ie, Alaska made money on Medicaid). As would be expected, the Medicaid program has larger impacts in states with larger economies and populations such as Texas. In Texas Medicaid supported 474 420 jobs and $20 billion in personal income. Unlike Alaska, Texas didn't make money on Medicaid—each dollar of Texas state funds invested in Medicaid returned 91 cents of personal income to Texans due to the vagaries of the federal cost sharing formula. However, it is critical to remember that these figures do not include the economic value of the improved health and well-being of Medicaid recipients or the medical cost savings resulting from preventive care funded by Medicaid.

This study provides estimates of the economic impacts of Medicaid program expenditures in North Carolina in SFY 2003 including estimates of economic impacts on employment; labor income (wages and salaries); capital income (rents, interest payments, and corporate dividends); and government tax revenues at the federal, state, and local levels. These estimates do not include the economic value of the improved health and well-being of Medicaid recipients or the medical cost savings resulting from preventive care funded by Medicaid. Hence, the goal of this study is to provide results for the direct and multiplier effects in the community (see Figure 1.D). In addition, our data set allows us to investigate Medicaid expenditures at the county level and to determine whether urban or more affluent counties receive disproportionately larger expenditures relative to rural or less affluent counties. We also report the results of a policy simulation experiment in which we determine the economic impacts of shutting down the Medicaid program, returning the money (federal, state, and local) to taxpayers, and allowing the taxpayers to spend the funds according to typical consumer expenditure patterns.

Data

The study relies on North Carolina Medicaid program expenditure data for SFY 2003 as submitted by the North Carolina Division of Medical Assistance to the federal Centers for Medicare and Medicaid Services (CMS). The data included all SFY 2003 North Carolina Medicaid program expenditures including the following associated programs: Baby Love; Community Alternatives; Dental Program; Health Check; Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) Services; Managed Care; Piedmont Behavioral Healthcare and Piedmont Innovations; and Transportation Program administration.[b] The analysis does not include NC Health Choice for Children (SCHIP) program expenditures.[c] The data used in this study are unique in that they provide Medicaid expenditures by county of health care provider location rather than by county of patient residency.

Methodology

This study uses input-output analysis to estimate the economic impacts of Medicaid.[32] Input-output analysis is commonly used by economists to estimate the full economic impacts of an initial change in spending in a regional economy. Input-output models are not perfect; they are approximations of spending patterns in regional economies. Nonetheless, they are widely used as good, first-order approximations of regional economies, and their use by economists to estimate economic impacts is standard operating procedure. IMPLAN Professional® Input-Output Analysis computer software was used in this study to conduct input-output analysis.[33] IMPLAN is a leading input-output modeling software package used by university researchers, government agencies, and consultants nationwide. In a review of the literature, we identified 19 studies[13-31] of the economic impacts of Medicaid at the state level, all of which used some form of input-output analysis to estimate economic impacts. Ten of the 19 studies used IMPLAN input-output modeling software. (Five studies used the RIMS II input-output model, which is fundamentally similar to IMPLAN, and the remaining studies used custom-built input-output models or did not report the type of input-output model used.) Carbaugh et al[34] reviewed 17 studies of the role of Medicaid in state economies. Of these, 11 used IMPLAN; 3 studies, including those of Families USA,[35,36] used RIMS II. IMPLAN has also been used to estimate the economic impacts of hospital closures.[37,38] Rickman and Schwer[39] compared benchmarked versions of IMPLAN, RIMS II, and a third leading input-output software package called REMI, and found that

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[b] For additional information on the distribution of Medicaid expenditures across program areas in North Carolina, see: http://www.dhhs.state.nc.us/dma/prog.htm.

[c] Unfortunately, this study is limited to the economic impacts of Medicaid because comparable information was not available for SCHIP dollars. Substantively, this has limited consequences because the Medicaid budget is much larger than the SCHIP budget. Nevertheless, because SCHIP dollars are targeted exclusively at children, their absence limits a nuanced appreciation of how public spending on children's health impacts the economy.

the economic impact multipliers of the benchmarked models do not differ significantly. Duncombe and Wong[40] provide a good introduction to the differences between input-output models and other methods of regional economic analysis.

Input-output models are interconnected systems of linear equations that track the flow of dollars between and among households, businesses, and government in a specified geographic region as small as a county or as large as the United States. The IMPLAN input-output modeling system consists of 2 parts: a mathematical computer model and a database. The IMPLAN modeling system contains equations for over 500 industry categories plus additional equations that model household and government spending. In essence, there is one equation for each *industry* in a regional economy. (The equation for a given industry can be different in different geographic areas.) Each industry equation specifies the dollar amounts of *input* goods and services required to produce the dollar amount of industry *output* in the region. The equations are linked together such that the output dollar amount produced by one industry is the total of all the input dollar amounts required by all of the other industries in the system. For example, the dollar value of electricity output produced by the electricity industry feeds into all of the other industry equations as the (dollar-valued) electricity inputs to those industries. (The electricity industry also uses some of its own electricity, which feeds back into its own equation.) In addition, some of the outputs leave the system as *exports* from the region, and some inputs enter the system as *imports* into the region. Furthermore, households (workers) and taxes are treated as inputs in the industry equations in the sense that industries pay for (send money to) workers and taxes. Households are treated as separate industries that receive their own inputs (eg, wages, salaries, rental income, dividend payments, government program payments) and produce their own outputs (eg, household expenditures for food, clothing, electricity, rent, mortgage payments, taxes). (In fact, there are multiple household industries, each corresponding to a different household income level, because households of different income levels have different patterns of inputs and outputs.) Each level of government (federal, state, and local) is treated as a separate industry in that it receives input tax receipts from households, businesses, and other levels of government, and it produces outputs (eg, expenditures on the military, highway construction, public schools, health care programs, payments to other levels of government).

The IMPLAN database is derived from federal and state employment and income data and government survey data of businesses and households.[33] The data are cleaned, organized, and transformed into consistent units. The industry equations, household receipts and expenditures, and government receipts and expenditures are all based on the employment, income, and survey data. The IMPLAN database is updated every few years as the government surveys are updated. The equations, receipts, and expenditures can be calculated at the national, state, or county level (or a collection of counties smaller than a state). When data are scarce for a particular industry in a particular geographic area, average results for that industry at the next level of aggregation are used (for example, if data are scarce for the widget production industry in a particular state, the average results for the nationwide widget industry might be used for that state). In addition, the database contains information on imports and exports for each geographic region.

When conducting economic impact analysis, IMPLAN is used to calculate changes in the economy relative to the baseline condition of the economy when local and system wide data were collected. The present study of Medicaid expenditures in 2003 relied on the 2002 IMPLAN database (ie, the 2002 IMPLAN structural matrix was used in the analysis). The initial change to the economy must be specified by the user. This initial change is called the direct impact. For example, if the state of North Carolina is the region of analysis then Medicaid dollars initially spent in the state constitute the *direct impact*. These initial expenditures purchase output from various health care industries. For example, in this study Medicaid dollars purchase output from the following list of IMPLAN health care industry sectors in North Carolina in 2003:

- Pharmaceutical and medicine manufacturing
- Surgical and medical instrument manufacturing
- Surgical appliance and supplies manufacturing
- Ophthalmic goods manufacturing (eg, eyeglasses)
- Home health care services
- Doctors, dentists, and other health care professionals
- Other ambulatory health care services
- Hospitals
- Nursing and residential care facilities
- Office administrative services (eg, program administration, tracking patient records)

In order to produce the purchased health care products and services, health care industries must, in turn, pay workers and purchase various goods and services from other industries. Next, the industries producing these goods and services must, in turn, purchase other goods and services, and so on. However, the process does not go on forever. At each round of purchasing, the dollar amount of purchases becomes smaller, eventually becoming negligible. The second and subsequent rounds of purchases constitute the *indirect impacts* of the initial Medicaid expenditures. At each round of purchasing, some of the dollars received by the producing industries go toward paying workers and owners of the firms. The workers and owners pay taxes on this income, save some of the income, and spend the rest. This spending by workers and owners initiates additional, attenuating rounds of purchasing called the *induced impacts* of the initial Medicaid expenditures. The indirect and induced impacts are collectively known as *multiplier effects*. The sum of the direct, indirect, and induced impacts is called the *total impact*.

The direct, indirect, and induced impacts of the Medicaid expenditures lead to changes in business sales (also known as business activity or business output), employment, labor income (eg, wages and salaries), capital income (eg, rents, interest and dividend income), and taxes paid to various levels of government. IMPLAN tracks the changes in business sales, employment, and other areas separately for the direct, indirect, and induced impacts and also cumulates them into total impacts.

Results

The Economic Impacts of Medicaid

In SFY 2003 $6.307 billion in initial Medicaid program expenditures occurred within the state of North Carolina—$3.941 billion federal dollars, $2.014 billion state dollars, and $351 million in local government funds. Each dollar of state and local government expenditures brought $1.67 federal cost-share Medicaid dollars to the state. Of the $6.307 billion in Medicaid expenditures, $1.63 billion or 25.8% was spent on children ages 0-18. The economic impacts of these Medicaid expenditures are both deep and broad. The estimated statewide total economic impacts (including economic multiplier effects) of the $6.307 billion in Medicaid expenditures within North Carolina in SFY 2003 are summarized in Table 1.

Table 1 provides impact estimates for 3 economic indicators of interest: employment (including full- and part-time jobs), labor income (including wages and salaries plus income from sole proprietorships or partnerships including many physicians' practices), and capital income (including rental income, interest income, and corporate dividend income). The economic impacts within North Carolina of the 2003 Medicaid expenditures in the state included 182 000 jobs supported (including both full-time and some part-time jobs), $6.1 billion in labor income (wages, salaries, and sole proprietorship/partnership profits), and $1.9 billion in capital income (rents, interest payments, and corporate dividend payments).

We find that Medicaid expenditures directly support 92 489 jobs (including both full- and part-time jobs) in North Carolina. An additional 89 634 jobs are supported by the indirect and induced multiplier effects of Medicaid spending for a total of 182 124 jobs statewide supported by Medicaid. Of these jobs, Medicaid directly supports the equivalent of approximately 85 000 health care industry jobs with multiplier effects supporting an additional 6 000 health care jobs for a

Table 1.
Economic Impacts of Medicaid Expenditures on Employment, Labor Income, and Capital Income: North Carolina State Fiscal Year 2003

	Economic Impacts of Federal Expenditures	Economic Impacts of State & Local Expenditures	Economic Impacts of Total Expenditures
Employment[1]			
Direct Impacts	57 738	34 751	92 489
Indirect Impacts	12 066	7 243	19 309
Induced Impacts	43 940	26 385	70 325
Total Impacts	**113 744 jobs**	**68 380 jobs**	**182 124 jobs**
Labor Income[2]			
Direct Impacts	$1 857 157 998	$1 115 689 427	$2 972 847 425
Indirect Impacts	$436 380 583	$262 417 396	$698 797 979
Induced Impacts	$1 524 323 030	$915 342 114	$2 439 665 144
Total Impacts	**$3 817 861 699**	**$2 292 842 764**	**$6 110 704 463**
Capital Income[3]			
Direct Impacts	$310 423 367	$186 369 112	$496 792 479
Indirect Impacts	$252 410 077	$151 467 201	$403 877 278
Induced Impacts	$619 650 077	$372 115 364	$991 765 441
Total Impacts	**$1 182 483 521**	**$709 951 650**	**$1 892 435 171**

SOURCE: Unless otherwise indicated all data reported in this article reflect the IMPLAN® analysis of data provided by the North Carolina Division of Medical Assistance for North Carolina State Fiscal Year 2003 as reported to the US Centers for Medicare and Medicaid Assistance.

NOTES:

1. Employment includes all jobs both full- and part-time.
2. Labor Income includes wages, salaries, sole proprietorship income, and partnership income. Values are 2003-year dollars.
3. Capital Income includes rental income, interest income, and corporate dividend income. Values are 2003-year dollars.

total of about 91 000 health care jobs supported. Estes[3] estimated that 395 000 individuals were employed in the North Carolina health care sector in 2001. Allowing for moderate growth (8% per year) in the total number of health care jobs in North Carolina between 2001 and 2003, Medicare conservatively supports at least 20% of all health care jobs in the state.

The direct impact of Medicaid spending on capital income is $497 million. The indirect and induced impacts of Medicaid spending on capital income are nearly 3 times larger than the direct effects. This means that the multiplier effects of Medicaid expenditures on capital income are very strong. It is not just the corporations in the health care industry that benefit from Medicaid; business quite broadly benefits as well.

The aggregate impact of Medicaid expenditures on labor income ($6.1 billion) is much larger than the impact on capital income ($1.9 billion). This is consistent with the fact that health care is a labor-intensive sector characterized at the service delivery level by many small firms with relatively high employment. While direct impacts occur predominantly in health care industries, Medicaid also produces substantial multiplier effects in nonhealth industries through business-to-business transactions (indirect impacts) and consumer purchasing (induced impacts). Industry-by-industry results produced by the IMPLAN model (not reported here for the sake of brevity) indicate that the construction, transportation, wholesale and warehousing, retail trade, finance and insurance, and hotel and restaurant industries in North Carolina each received over $100 million in wages and salaries due to the indirect and induced impacts of Medicaid expenditures in 2003.

How does Medicaid job creation compare to economic development efforts that offer firms incentives to open or expand activities in North Carolina? In a November 9, 2004 press release,[41] Governor Mike Easley announced that North Carolina offered Dell Computer an incentive package of $242.5 million over 20 years to create, directly and indirectly, 8 000 jobs within the state or $30 313 spending per job. By comparison North Carolina state and local governments invested $2.371 billion in Medicaid in 2003, which when leveraged with federal cost share dollars, supported 182 000 jobs or $13 000 in state/local spending per job. Although some Medicaid-supported health care jobs such as physician may pay higher salaries than the average Dell job, and other Medicaid-supported jobs such as hospital custodian may pay less, the average wage/salary of North Carolina health care workers in 2003 was $39 660—similar to the state-average median household income in 2004 of $40 863.[42] Furthermore, Medicaid-supported jobs are widely distributed geographically across the state, whereas the jobs created by specific industrial projects are typically concentrated in a relatively small geographic region.

Much of the labor income and capital income supported by Medicaid is taxable by federal, state, and local governments. The federal government collects personal income, corporate profit, and payroll taxes. There is a comparable set of taxes at the state level. In addition, households pay local property taxes plus state and local sales taxes.[d] Table 2 summarizes tax receipts by governmental entity.

Panel 1 of Table 2 shows that the federal government collected approximately $1.6 billion in taxes as a result of all Medicaid expenditures (by all levels of government) in North Carolina in 2003—most in the form of personal income taxes (53.6%) with another substantial proportion in payroll taxes (41%). Consequently, the federal government recouped approximately 42% of its $3.9 billion in North Carolina Medicaid expenditures. State and county governments contributed $2.365 billion in Medicaid expenditures and collected taxes of $567 million. Consequently, state and local governments recouped approximately 24% of their Medicaid expenditures in the form of tax collections supported by Medicaid expenditures. The larger share of taxes (60.5%) went to the state, principally in the form of personal income (44.6%) and sales taxes (38.6%). State and federal Medicaid funds flowing into each county do not appear directly as line items on the budgets of county governments; they appear only indirectly in the sales tax and property tax revenue lines. Counties and localities realized $224 million in sales and property tax receipts from Medicaid expenditures in 2003, which offset more than half (56%) of their $400 million in Medicaid contributions.

A Policy Experiment: "What if We Gave the Medicaid Money Back to Taxpayers?"

Although the economic impacts of Medicaid spending are large, the economic impacts of spending on this scale would likely be significant if the money were spent on something other than Medicaid. The opportunity cost to society of spending money on Medicaid is that society gives up the economic impacts of spending money in other ways. To investigate the opportunity cost of Medicaid spending, we conduct a policy simulation experiment in which we assume the Medicaid program is shut down, and the federal, state, and local taxes paid by North Carolina taxpayers to support Medicaid are returned to the taxpayers. The taxpayers save and spend the returned funds based on observed patterns in federal consumer expenditure survey data. The expenditure patterns vary by household income level (eg, higher income households save a larger proportion

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[d] In North Carolina separate sales taxes are levied by the state and local governments.[43] In SFY 2003 the North Carolina state sales tax rate was 4.5% on retail sales (or rental) of tangible personal property, room/lodging/hotel rentals, and laundering services with some exceptions. The North Carolina state sales tax does not apply to unprepared food (eg, groceries) but does apply to prepared food and other items (eg, restaurant meals, food purchased in the deli sections of grocery stores, alcohol, tobacco products). Nor does the North Carolina state tax apply to drugs or medical equipment sold with a prescription. The tax does not apply to insulin or prosthetic devices sold with or without a prescription. Every county may charge an additional 2.5% sales tax on all items subject to the North Carolina state 4.5% tax rate. In addition to general sales taxes, some counties levy additional sales taxes on particular items or activities, such as hotel occupancy taxes. Specific policies vary by county. Hence, the allocation of sales taxes in this table is a rough but realistic estimate.

Table 2.
Economic Impacts of Medicaid Expenditures on Federal, State, and County/Local Tax Receipts: North Carolina State Fiscal Year 2003

	Tax Receipts Supported By		
Government Entity	**Federal Medicaid Expenditures**	**State & Local Medicaid Expenditures**	**Total Medicaid Expenditures**
Federal Tax Receipts			
Personal Income	$547 681 505	$328 918 317	$876 599 822
Corporate Profit	$54 857 270	$32 931 277	$87 788 547
Payroll	$418 640 859	$251 423 317	$670 064 176
Total Receipts	$1 021 179 634	$613 274 911	$1 634 452 545
State Tax Receipts			
Personal Income	$95 705 675	$57 477 472	$153 183 147
Corporate Profits	$28 857 605	$17 323 462	$46 181 067
Payroll	$7 285 231	$4 375 321	$11 660 552
Estimated Sales[1]	$82 773 004	$49 694 615	$132 467 619
Total Receipts	$214 621 515	$128 870 870	$343 492 385
County/Local Tax Receipts			
Property	$93 337 918	$56 037 732	$149 375 650
Estimated Sales[1]	$46 559 814	$27 953 221	$74 513 035
Total Receipts	$139 897 732	$83 990 953	$223 888 685
All Entities	**$1 375 698 880**	**$826 134 734**	**$2 201 833 615**

SOURCE: IMPLAN model calculations.

NOTES: Because of the way data are reported estimates are necessary to apportion sales taxes between state and county governments. For the purposes of this exercise, we assume a state sales tax rate of 4.5% and a local sales tax rate of 2.5%. Under these assumptions the state receives 64% (4.5%/[4.5%+2.5%]=64%) of combined state and local sales tax revenues with counties/localities receiving the remaining 36%.

of each dollar returned). Because most Medicaid dollars are spent on labor-intensive, instate health care services rather than goods imported into the state, Medicaid spending has a relatively large instate economic multiplier effect. By contrast, a large proportion of the typical consumer's spending pays for goods imported into the state (eg, gasoline, food, clothing, entertainment, electronics). If the Medicaid program was shut down, funds returned to taxpayers, and taxpayers allowed to spend these monies according to typical consumer spending patterns, the instate economic impacts of these expenditures would be smaller than the instate economic impacts of Medicaid. In fact, our simulation indicated that employment in North Carolina would fall by an estimated 67 400 jobs and labor income would fall by $2.83 billion if Medicaid funds were returned to taxpayers. The reason for this perhaps surprising result is that most Medicaid dollars are spent on labor-intensive, instate health care services rather than goods imported into the state. In contrast, a far larger proportion of typical consumer spending buys goods and services imported into the state. In comparison to typical consumer spending, Medicaid dollars stay in the state, supporting employment and businesses within North Carolina.

The County Cost Share Issue

The rapid growth in Medicaid payments in recent years has put pressure on county government budgets in North Carolina, causing counties to lobby the state to assume the county portion of Medicaid payments. One issue of concern has been that some rural or less affluent counties may be more reliant on Medicaid and may be paying a disproportionate share of Medicaid costs. Another issue has been that Medicaid funds allocated to residents of a given county may not support businesses and tax collections in that county since residents travel across county lines to access health care services not available in the county of residence. As a temporary measure, the state government agreed in 2006 to cap county Medicaid expenditures.[44] On July 31, 2007, the governor of North Carolina signed into law a measure requiring the state to assume the county portion of Medicaid expenditures.[45] The transfer would be phased in over 3 years beginning October 1, 2007. In partial compensation, counties would be required to give up a portion of their sales tax revenues to the state.

To address the issue of whether some counties may be more reliant on Medicaid, we consider two measures of Medicaid reliance: county Medicaid expenditures[5] as a percentage of county budget[46] in 2003 and Medicaid eligibles[5] as a percentage of county population[46] in 2004. We regressed each of these measures on (1) per capita county income[46] ($1 000s) in 2003; (2) county population[46] (10 000s) in 2003; and (3) the United States Department of Agriculture Economic Research Service (USDA-ERS) Rural-Urban Continuum Codes,[47] 2003, an index of county rural character (larger code numbers indicate a more rural character). County Medicaid expenditures as a percentage of county budget in 2003 are negatively related to per capita county income at the 0.05 level of significance, indicating that wealthier counties spend a smaller percentage of the county budget on Medicaid. County population and USDA-ERS Rural-Urban Continuum Codes are not statistically significant determinants of county Medicaid expenditures as a percentage of county budget in 2003, indicating that rural/urban status does not appear to be a significant determinant of county Medicaid expenditures as a percentage of county budgets. Medicaid eligibles as a percentage of county population, 2004, is negatively related to per capita county income ($1 000s) in 2003 at the 0.05 level of significance. It is also positively related to both county population in 2003 and USDA-ERS Rural-Urban Continuum Codes at the 0.05 level of significance. Hence, wealthier counties tend to have fewer Medicaid eligibles as a percentage of county population while more populous counties and more rural counties have more Medicaid eligibles as a percentage of county population. We conclude that reliance on Medicaid does vary by county type with more affluent counties spending a smaller percentage of the county budget on Medicaid and having a smaller percentage of the population eligible for Medicaid, while more populous and more rural counties have a larger percentage of the population eligible for Medicaid.

To investigate the issue of whether Medicaid funds allocated to residents of a given county actually support businesses and tax collections in the county, we analyze the Medicaid expenditure data by county of health care provider location. The analysis shows that for every North Carolina county, the state and federal government cost share expenditures paid to health care providers located in the county were far greater than the county contribution to Medicaid. For example, relatively populous, urban, and affluent Wake County spent approximately $20 million in local government funds on Medicaid in SFY 2003, but the federal government paid over $200 million in Medicaid expenditures to health care providers located in Wake County. Similar results hold for rural, less populous, or less affluent counties. Even small Yancey County, which spent only $500 000 in local funds on Medicaid in 2003, received over $5 million in federal Medicaid expenditures paid to health care providers located in the county. (Results for all North Carolina counties are available on request from the authors.) One reason that Medicaid expenditures are significant even in rural locations is that a relatively large share of Medicaid expenditures in rural counties goes to nursing and residential care services that are provided in the rural counties themselves. We conclude that even after accounting for Medicaid expenditures that cross county lines, every county in North Carolina has far more state and federal Medicaid money spent in the county than the county itself collects and spends on Medicaid.

Discussion And Conclusions

The rising costs of health care and the appropriate role of government health insurance programs in the health care system are the source of current policy debates. Informed discussion of these issues requires good information on the economic as well as the health consequences of alternative policy choices. The purpose of this study is to estimate the economic impacts of Medicaid program expenditures in North Carolina in SFY 2003 (see Figure 1.D.). In SFY 2003 $6.307 billion in Medicaid program expenditures occurred within the state of North Carolina—$3.941 billion federal dollars, $2.014 billion state dollars, and $351 million in local government funds. Each dollar of state and local government expenditures brought $1.67 federal Medicaid cost-share dollars to the state. The total economic impacts (including direct, indirect, and induced impacts) in North Carolina of Medicaid expenditures in 2003 included (see Table 1):

- 182 000 jobs supported (including both full-time and some part-time jobs)
- $6.1 billion in wages, salaries, and sole proprietorship/partnership income
- $1.9 billion in rents, interest payments, and corporate dividend payments

State and local governments recouped approximately 24% of their Medicaid expenditures in the form of various tax collections on Medicaid expenditures and the economic ripple effects of Medicaid expenditures.

Our unique data set allows us to estimate Medicaid expenditures and economic impacts by health care provider location at the county level. Although we find that reliance on Medicaid does vary by rural/urban and rich/poor county type, the data also show that every North Carolina county received far more in state and federal government cost share expenditures paid to health care providers located in the county than they paid in county-share Medicaid expenditures.

Although Medicaid spending generates large economic impacts, it should be recognized that the Medicaid program diverts spending away from other potential uses that would have generated other economic impacts. In a policy simulation experiment we answer the question, "What would be the net economic impacts of giving the Medicaid money back to taxpayers?" In the experiment we assume that the Medicaid program is shut down, that federal, state and local taxes paid by North Carolina taxpayers to support Medicaid are returned to the taxpayers, and that the taxpayers save and spend the returned funds based on typical consumer expenditure patterns. We find that the instate economic impacts of these expenditures are substantially smaller than the instate economic impacts of Medicaid. In fact, our simulation indicates that employment in North Carolina would fall by an estimated 67 400 jobs and labor income would fall by $2.83 billion. The reason for this perhaps surprising result is that most Medicaid dollars are spent on labor-intensive, instate health care services rather than on goods imported into the state. In contrast, a far larger proportion of typical consumer spending buys goods and services imported into the state. In comparison to typical consumer spending, Medicaid dollars stay in the state, supporting employment and businesses within North Carolina.

It is important to keep in mind that the Medicaid expenditure and economic impact results do not capture the economic value of the improved health and well-being of Medicaid recipients. Furthermore, the results do not capture the savings to society in general of emphasizing preventive care and reducing uncompensated care nor the long-term benefits of promoting wellness. Health insurance like Medicaid provides access to routine medical care, thereby promoting preventive care and timely and appropriate medical interventions and minimizing the necessity of relying on costly emergency services. Medicaid also reduces uncompensated care, which in turn reduces health care providers' need to shift costs to patients with private insurance. Additionally, comprehensive Medicaid services may allow covered adults to obtain or return to employment more quickly. Medicaid services for children— especially Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) services—support both the typical child as well as children with special health care needs. This investment in human capital should improve the capacity of young Medicaid beneficiaries to become productive members of society in the future.

Another caveat is that Medicaid plays a role in supporting the health care infrastructure available to the general population. Medicaid cuts could threaten the financial health of key facilities such as hospitals, or at least shift a larger share of the infrastructure support costs to those with private insurance. Further, to the extent that health care facilities provide amenity effects—such as those associated with living near an ocean—that boost community property values, facility closures could reduce property values. Similarly, a factory may choose to relocate elsewhere if the only hospital in a community closes. These effects are not captured by standard economic impact analysis.

This article poses a basic question: "What are the economic impacts of Medicaid on the North Carolina economy?" Medicaid is a large program with complex implications for its beneficiaries and the communities in which they live. The program is important for the health of many North Carolina citizens. In addition, the economic impacts of the program are substantial and felt statewide from urban research hospitals to rural nursing home facilities. Budgetary costs do not fully capture the economic consequences of Medicaid in North Carolina. This study finds that Medicaid makes a large contribution to state and local economic activity by creating jobs, income, and profit in North Carolina. Any substantial changes to the Medicaid program should be made with caution. **NCMJ**

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ARTICLE

Accuracy of Self- and Parental Perception of Overweight Among Latino Preadolescents

Valentina Intagliata, MD; Edward H. Ip, PhD; Sabina B. Gesell, PhD; Shari L. Barkin, MD, MSHS

Abstract

Background: *This investigation examines self-perception and parental perception of child body size and factors associated with accurate parental perception of child body size.*

Methods: *Latino at-risk for overweight (AROW) and/or overweight preadolescent children (ages 8-11 years) along with their parents were recruited (N=123 dyads). Children's body mass index (BMI) was measured but not discussed before participants were shown pictures of body sizes and asked to select the image that represented the child's body.*

Results: *The correlation between the child's body size selection and the child's actual BMI was 0.117 (p=0.20) whereas the correlation between the parent's assessment of the child's body size and the child's actual BMI was 0.470 (p<0.001). Logistic regression revealed that only parental education level (≥college) was associated with a more accurate parental perception of their child's body size (OR: 0.11/ 95% CI: 0.01, 0.89) while child's sex, parental BMI, and parental health status were not associated with a perception that corresponded to the child's BMI.*

Limitations: *The sample was drawn from a single community clinic in Forsyth County which serves a large population of newer Latino immigrants in the county.*

Conclusions: *The results indicate that (1) Latino AROW/overweight preadolescent children do not have an accurate perception of their own body size; (2) Latino parents have a more accurate perception of their child's body size with a moderately sized correlation suggesting that their perception of their child's body size is frequently inaccurate; and (3) Latino parents with higher education perceive their child's body size more accurately than less educated parents.*

Keywords: *Weight perception; body mass index; ideal body size; Hispanic Americans; body image*

Accuracy of Self- and Parental Perception of Overweight Among Latino Preadolescents

Interventions for childhood obesity have, at times, been shown to be successful if they include parents.[1,2] But for parents to choose to actively participate in obesity prevention efforts with their children, they must first be aware of overweight in their children and must be concerned about the possible consequences. Erroneous perception of body size may have important health and behavioral implications.

Latino adults have been found to be inaccurate in their perceptions of their own overweight.[3] In a study of low-income Latinas and their children aged 5-7 years, all of the women selected a relatively thin body image as the most desirable and healthy for themselves but preferred a plumper figure for their children.[4] Several studies using multiethnic samples but not breaking results out by ethnicity have shown that parents often fail to identify their children as overweight.[5,6] These findings indicate that Latina mothers may have a more favorable view of childhood obesity and may fail to perceive overweight in their children as problematic. We examined the research question, "Do Latino preadolescents and their parents have similar interpretations of overweight as do medical providers who utilize Body Mass Index (BMI) to make this determination?"

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PATIENTS AND METHODS

Participants

Hispanic-American at-risk for overweight (AROW) (BMI ≥85% and ≥95%) and overweight (BMI >95%) preadolescent children (ages 8-11 years) along with one of their parents were recruited from a clinic that serves the greatest number of Latino families in Forsyth County, North Carolina. All patients who met the eligibility criteria (child's BMI ≥85%, child's age 8-11 years, self-identified as Latino, and parent willing to participate with child in the study) were invited to participate. Of the 210 families contacted, 159 families agreed to participate on the telephone, and 123 families provided data.

Measures

We obtained approval for this study from the Institutional Review Board of Wake Forest University Health Sciences. We present baseline data collected at the community-based health center in Winston-Salem, North Carolina prior to any discussion between the patient family and the health care provider. Children's and parents' BMI were measured[7] but not discussed before participants (both adults and children, separate from one another) were shown pictures of child body sizes and asked to select the image that most looked like the child's body. Body size perception was gathered from a picture scale ranging from 1-7 for children where 1-2 was considered by health care providers to be underweight, 3-4 was considered by health care providers to be the ideal body size, 5 was considered to be AROW, and 6-7 was considered to be overweight.[8] This scale is significantly and highly correlated with measured percentage overweight (r=0.79).[8] Additional variables that were collected include the following: (1) educational level of parent (using Census 2000 format);[9] (2) health status of parent (using questions from the Service Utilization Assessment);[10] and (3) parental acculturation (using questions from Marin's short acculturation scale for Hispanics).[11]

Statistical Methods

To assess how accurately Latino preadolescents perceive their body image compared to their parents, we calculated two correlations using Pearson's correlation coefficient: (1) between the child's assessment of his or her body size and the child's BMI, and (2) between the parent's assessment of the child's body size and the child's BMI.

To assess which factors are associated with a more accurate parental perception of body size, we created the variable AGREE. This was calculated by applying a cutoff point of 95% to the measured BMI percentile and classifying those above as overweight. We grouped the parental evaluation scores of 6 and 7 and defined this category as parents perceiving their child as overweight. When the parent's perception matched with the measured classification, the variable AGREE was coded 1; otherwise, it was coded 0. In a logistic regression, AGREE was used as the dependent variable with the sex of the child, education level of the parent (college degree versus no college degree), and self-reported health status of the parent included as independent variables.

RESULTS

In our sample of participating parents, 88% were mothers and 73% were from Mexico (other participants came from Guatemala, El Salvador, Dominican Republic, Columbia, Venezuela, and Nicaragua). Ninety-nine percent of our sample of parents reported that Spanish was spoken at home and with their friends. Moreover, 99% of these adults chose to complete surveys in Spanish. Forty-five percent (45%) of the adults had an education of 8th grade or less; 16% had education up to the 12th grade but not including graduation; 22% graduated from high school; 5% reported some college; 4% reported an a associates degree/technical school; and 8% reported a college degree or higher. Average adult age was 35 years (SD 7.4) and average adult BMI was 33.4 (SD 7.8). Only 17% of adults rated their health as "very good" or "excellent;" 38% reported "good" health; and 45% reported "fair" or "poor" health. Average child age was 9.3 years (SD 1.3). The distribution of female and male children was approximately equal. Average study child's BMI was 25.9 (SD 5.5) indicating that 30% were AROW and more than 60% were overweight.

The correlation between the child's body size selection and the child's actual BMI was 0.117 (p=0.20) whereas the correlation between the parent's assessment of the child's body size and the child's actual BMI was 0.470 (p<0.001). The two correlations were statistically different (p=0.001), suggesting that parents had a more accurate assessment of the child's body size than did the child. While the correlation between parental perception and child's true BMI is statistically significant, we note it is only moderate in magnitude and thus conclude that parental perception of body size is frequently inaccurate.

Table 1 shows the results of the logistic regression. Parent's education was significantly associated with a more accurate perception of the identified obese child (OR: 0.11, 95% CI: 0.01, 0.89, comparing parents with less than a college education to parents with a college education or higher).

Table 1.
Factors Associated with Accurate Perceptions of Child Obesity (N=123 Parent-Child Dyads)

	Odds ratio estimate	95% CI
Child's Sex[1]	0.68	0.30, 1.52
Parent's Education[2]	0.11	0.01, 0.89
Parent's BMI	0.97	0.92, 1.02
Parent's Health Status	1.04	0.67, 1.61

An estimate of higher than 1.0 in the odds ratio indicates an increased odds of agreement between perceived and actual overweight.

1 Reference category: Female

2 Reference category: With college degree

DISCUSSION

In this study, we found that Latino preadolescent overweight children perceived their body size inaccurately while their parents perceived their child's body size more accurately (but still with only a moderately sized correlation, suggesting frequent inaccuracy). Accuracy of parental perception was associated with higher parental educational levels, greater than or equal to a college level education.

Prior work from Killion et al demonstrated that African-American and Hispanic mothers' perceptions of their children's body sizes are often inaccurate for children with BMI > 95%.[12] However, that study only focused on young children aged 3-5 years. Likewise, Olvera et al demonstrated that less acculturated children and mothers identified thinner body sizes than the BMI would indicate.[13] A third of their sample of children were overweight or at-risk for overweight as indicated by the BMI. In our sample of only at-risk for overweight and overweight preadolescents, children were inaccurate in their body size identification, but parents were more accurate in identifying the correct body size for their child. Accuracy of perception was not affected by child's sex as it was in the study by Olvera et al.

The potential factors that create only a moderately-sized correlation between parental perception of their child's body size and actual BMI could be due to many reasons. Among low-income mothers in general, it has been shown that Latino parents do not believe growth charts are useful in defining a child's weight but that physical activity and good appetite are more important markers of health status.[14] Studies of Latino families in particular indicate that these individuals may have different standards for what constitutes a healthy child when compared to the standards of physicians or other ethnic groups.[15] One analysis demonstrated that Mexican-American mothers of obese children selected a "chubby baby" as ideal significantly more often than Mexican-American mothers of non-obese children.[16] From this report, one can infer that Latina mothers may strive to have overweight babies since it is perceived as an ideal body size. Mendoza et al proposes that the discrepancies in perception of a child's health between mother and physician, as revealed in the Hispanic Health and Nutrition Examination Survey (HHANES), may be due to an alternate view of what constitutes good health status in children, "one that is not fully appreciated by traditional measures."[15] In Mendoza's family-community health promotion model, he suggests that Latinos understand good health as the absence of problems that limit functional ability to perform everyday activities.[15]

Health professionals should not assume that defining overweight according to BMI has meaning for all parents. Furthermore, even if a group of people is able to assess body size accurately enough to appropriately apply the term "overweight," there still remains the issue of engendering an understanding that overweight/obesity is an unhealthy state.

Where should we focus future interventions? Jain et al believes that although a discrepancy exists between the views of parents and health professionals regarding the definition of overweight in children, both parties share a general belief that children should be physically active and eat healthy diets.[14] Future interventions should consider that it may be more valuable to focus on these common goals in our efforts towards decreasing the epidemic of childhood obesity.[14]

Limitations

The study was limited due to a sample that was drawn from a single clinic in Forsyth County; therefore, generalizeability may be limited. However, this clinic is one of the predominant clinics providing health care to Latino immigrant families in the county and might offer a glimpse into the less acculturated Latino family. The study involved mostly Latina mothers; it would be interesting to determine whether Latino fathers share similar degrees of body image perceptions for their children. Lastly, future research on Latino families should investigate other factors that enable parents to more accurately perceive their child's body size such as acculturation of the parent and child.

Relevance

Erroneous perception of body size may have important health and behavioral implications. Understanding the mutable factors that reinforce parental ability to see their child's body size accurately is a necessary first step to developing effective pediatric obesity interventions. Consistent with the Health Belief Model,[17] perceived severity of a problem impacts the likelihood that individuals are willing to change their behaviors. In this case, connecting an accurate perception of an overweight child to poor health would be an important first step for Latino parents to promote behavior change to address obesity in their overweight children. **NCMJ**

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SPECIAL ARTICLE

Newborn Screening in North Carolina:

The Evolution of Policy and Practice

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Abstract

Newborn screening policies in North Carolina are due to the efforts of skilled and knowledgeable state officials, clinicians, and scientists who are able to develop effective newborn screening procedures. A newborn screening that was developed in North Carolina is the first automated method for diagnosing phenylketonuria. This process was later adopted in many other states. The use of tandem mass spectrometry in newborn screening was also pioneered in North Carolina, and it is being used in an increasing number of states. Newborn screening is more than testing, however; follow-up and specialized care are essential. State-level policies should recognize the multiple links necessary to make newborn screening effective and efficient.

In 1934 Norwegian physician Asbjørn Fölling reported a pair of siblings with a disease we now call phenylketonuria or PKU. Left untreated, PKU usually affects brain development and leads to mental retardation.[1] The disease was soon recognized as an autosomal recessive disorder in which each sibling of an affected child has a 25% chance of being born with the condition. By the early 1960s an infant formula low in phenylalanine was marketed and showed promise, when begun early, of preventing mental retardation. In 1963 Robert Guthrie, a microbiologist at the State University of New York at Buffalo, published a blood test for detecting the disorder in infants soon after birth.[2] The test utilized blood spotted onto filter paper. A punch of the blood-spotted filter paper was placed on agar containing the bacterium *Bacillus subtilis* and a substance that made the bacteria dependent on phenylalanine for growth. Affected infants had a greater zone of bacterial growth around their paper disk than did unaffected infants.

Early Days

Along with concerned parents, Dr Guthrie lobbied the legislatures of various states to mandate the testing of all newborn infants for phenylketonuria. Many states passed the mandate in the 1960s and subsequent events justified the early detection of PKU through newborn screening. At that time, North Carolina was fortunate to have Dr Theodore D. Scurletis as chief of the Maternal and Child Health Section of the State Board of Health. With input from Dr James B. Sidbury, Jr of Duke University; Drs George Summer, John Hill, and Harrie Chamberlin of the University of North Carolina at Chapel Hill; and others, Dr Scurletis urged the governor and legislators to go beyond a mandate and authorize adequate funds for a state newborn screening laboratory in Raleigh. Governor Terry Sanford appropriated $52 000 toward the laboratory in 1964, and the legislature approved continued funding. The laboratory became what is now the Newborn Screening Laboratory in the North Carolina State Laboratory of Public Health. Before testing was mandated in North Carolina, Dr Scurletis recognized the value of informing medical personnel about the importance of screening, and in 1965 he undertook an educational campaign for physicians, nurses, and health department staff. As a result, North Carolina's compliance rate reached 97%, exceeding rates in some states with compulsory testing.

Legislative action benefited North Carolina's newborn screening initiative by providing additional funds that were seriously needed at the time. Funding in North Carolina is influenced by the fact that the Newborn Screening Laboratory has an all-volunteer advisory committee made up of physicians and scientists who are experts in the various disorders being screened and who are from the different North Carolina medical teaching centers. The committee, which includes the parents of affected children and a representative of the North Carolina Pediatric Society, meets several times a year. The practicing physician representative can relay concerns about problems

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with newborn screening as well as practice-related details about newborn screening.

North Carolina as a Leader in Newborn Screening Methods

In addition to proposing funding, Dr Scurletis encouraged the use of an automated test[3] for detecting elevated concentrations of phenylalanine rather than Guthrie's bacterial method. The automated test was developed in the early years of automated analysis—an approach now commonly used in laboratory medicine—and seemed more advanced and accurate than the Guthrie test. North Carolina physician-scientists Drs John Hill and George Summer of the University of North Carolina at Chapel Hill created the test. In the early years North Carolina was the only state using this test. It was later adopted by many other states as well as by regions of Canada.

The second major breakthrough in newborn screening also had its origin in North Carolina. In the late 1980s investigators at Duke University, principally Dr David S. Millington and Dr Steve Kahler, began using powerful tandem mass spectrometry (MS/MS) to study blood spots of newborns and to screen for amino acid disorders. Dr Mohamed Rashed of Saudi Arabia developed an electrospray method[4] that allowed samples to be processed more rapidly with MS/MS. After the feasibility of newborn screening with MS/MS was reported,[5] the procedure began to gain general use.[6-8] The International Society of Neonatal Screening awarded their 2006 Guthrie prize to Drs Millington and Rashed. The MS/MS method superseded the automated fluorometric method and is now being used in an increasing number of other states. Since MS/MS screening is a major component of so-called "expanded" newborn screening,[9] North Carolina was once again at the forefront. The MS/MS method can detect a wide variety of inborn errors of metabolism, some of which are so rare they are found in North Carolina infants only once every few years. (See Table 1.) Of the disorders detected by MS/MS in North Carolina, only those having an incidence of 0.5 in 100 000 or higher are individually listed in Table 1. While some disorders are too rare to justify screening for them individually, MS/MS detects them with little additional effort, raising ethical and legal questions about omitting them from screening.[10]

The Issue of Priority

In many states parents vigorously lobby state legislators to authorize screening for a disorder affecting their own child. Such action, while understandable, can result in testing with insufficient regard to cost or benefit. Hypothyroid screening in North Carolina came about in part because a distinguished pediatric endocrinologist, the late Dr Judson Van Wyk, explained the need for hypothyroid screening to his local state representative in 1978. The origin of state funding for galactosemia screening is not clear. But one story is that a bill was introduced by a state legislator after he read an article on the subject while waiting for a haircut. Congenital adrenal hyperplasia can take the potentially lethal salt-wasting form or the less severe virilizing form. Screening for the disorder in North Carolina was initiated by a laboratory manager who had successfully established a screening protocol in a previous position.

The 2006 Newborn Screening Fact Sheets[11,a] from the American Academy of Pediatrics briefly describe the disorders listed in Table 1 (and certain others) and include information on incidence and screening. In North Carolina, as in other states, the introduction of a test has not necessarily correlated with the prevalence of the disorder. Congenital hypothyroidism is over 10 times as common as PKU, also causes preventable mental retardation, and is easier to treat than PKU; however, testing for it was introduced after the PKU test. (See Table 1.) Screening for hemoglobinopathies was limited to infants of African American descent when introduced in 1987, although hemoglobinopathies can be present in other infants. Universal screening did not begin until 1994. Detection and treatment of galactosemia soon after birth can prevent cataracts, liver damage, and death but does little to prevent the moderate developmental disorders that occur. Screening for hearing impairment, which appears to be the most prevalent disorder, is on the basis that early intervention allows the affected infant to develop nearly normal speech, but this claim needs to be confirmed.[11] Figures for North Carolina are not yet known, but national surveys for this test indicate that the false positive rate is high and the follow-up rate is low.[11] For tracking of tests results to occur, a very serious need exists nationally[11] as well as in North Carolina for funding and policies that allow integration of hearing screening with ongoing programs of newborn screening and follow-up.

Prioritizing can be more complex than might be appreciated. As shown in Table I, biotinidase deficiency is rare, yet the extremely low cost of treating this potentially debilitating condition offsets its rarity. Congenital hypothyroidism and PKU have two features in common: both produce mental retardation if untreated in childhood, and both require management through adulthood. Considerations of the vulnerability of the developing brain led to the possibility that the costly phenylalanine-restricted diet of the child with PKU might be discontinued at age 4.[12] Subsequent experience revealed that discontinuing the diet caused the patient with PKU to have irritability, mood disorders, and a risk for seizures. Moreover, it is important for the woman with PKU to have her diet closely regulated during each pregnancy. Since high blood phenylalanine concentrations interfere with development of the brain in children with PKU, it is easy to understand why the same will occur with the brain of a fetus of a women who has a high blood phenylalanine concentrations (even though the infant of a woman with PKU usually will not actually have PKU). Without treatment of pregnant women

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[a] Fact sheets are available with updates, at http://www.pediatrics.org/cgi/content/full/118/e934.

Table 1.
Disorders for Which Newborn Screening is Provided in North Carolina in 2007

Disorder	Date testing started in NC	Confirmed cases per 100 000 newborns*
PKU	1966	See MS/MS
Congenital hypothyroidism	1979	49.7[a]
Hemoglobinopathies	1987 & 1994	83.4[a]
Galactosemia, classical	1988	1.6[a]
Galactosemia, variant	1988	3.4[a]
Congenital adrenal hyperplasia	1989	4.3[a]
Hearing impairment	2001	146[b]
Biotinidase deficiency	2004	0.5[c]
Detected by MS-MS	1999	25.6[d]
Amino acidopathies		
PKU		3.7
Hyperphenylalaninemia, not classical PKU		2.3
Citrullinemia		0.6
Organic acidemias		
3-methylcrotonyl-CoA carboxylase deficiency (3-MCC def)		2.9
Glutaric academia type 1		1.1
Methyl malonic acidemia		1.0
Isovaleric acidemia		0.6
Fatty acid oxidation defects		
Medium chain acyl-CoA dehydrogenase deficiency (MCADD)		7.6
Very long-chain acyl-CoA dehydrogenase deficiency (VLCADD)		1.4
Short-chain acyl-CoA dehydrogenase deficiency (SCADD)		1.0
Disorders (12 such) with incidence less than 0.5 per 100,000		3.4

*The following numbers of newborns screened and inclusive dates are from the North Carolina Newborn Screening Laboratory.

a 609,101 and 2002-2006.

b 363,974 and 2004-2006.

c 371,148 and 2004-2006.

d 930,321 and May 1999-December 2006. Of the infants in these MS/MS results, 81% are in the recent report[8] of Frazier, et al

with PKU, the frequency of mental retardation (from maternal PKU) would equal the frequency of mental retardation in people with PKU before newborn screening and treatment was initiated.[13] Thus, the total cost of managing PKU would seem to make it prohibitively expensive, yet the lifetime expense of the diet is less than the high cost of lifetime management of mental retardation or the costs associated with becoming unemployable.

Finally, early detection will not stop the ultimate progression of certain diseases but will provide opportunity to intervene and delay the onset of complications. Early detection also means the expense of unnecessary hospitalization and studies can be avoided. Examples of such diseases include sickle cell disease and cystic fibrosis. Newborn screening for the latter occurs in some states and is under consideration in North Carolina.

State or Commercial Laboratory?

The campaign of Dr Guthrie and concerned parents for mandated PKU testing probably encouraged the screening of newborns to be conducted in state laboratories rather than private laboratories since the bacterial methods required by the original test are used there. In most states this served to prevent the privatization of newborn screening. Private laboratories made an effort in the late 1990s to introduce bills in various state legislatures that would close state newborn screening laboratories and turn the activity over to commercial labs. At the same time the slowness with which many states adopt new screening methods prompted a discussion of the need for a national policy.[14] Directors of state laboratories cannot act independently to regularly update methods and equipment but are often dependent on legislative appropriation and are slowed by bureaucratic red tape. The breakup of communist governments in Europe in the 1990s revealed the inefficiency of government operated services and made a case for privatization. In North Carolina some physicians and parents, unaware of the 1999 incorporation of MS/MS into the state program, sent samples to a private laboratory in another state.

The director of one private laboratory based in another state lobbied the North Carolina Pediatric Society to recommend closing the state laboratory and allowing his lab to do testing (including MS/MS screening) on a broader range of disorders. Members of the Society were unaware that this director had earlier visited Duke University to learn that MS/MS could be used in newborn screening. More critically, his suggested tests included detection of glucose-6-phosphate dehydrogenase deficiency, a disorder for which testing on newborn infants had been found inadvisable 35 years earlier, as was recognized by a member of the Newborn Screening Advisory Committee (appointed by the Newborn Screening Lab directors) who had authored over 20 articles on this subject. It must be conceded, however, that this private laboratory provided 20 months of MS/MS screening under contract during development and confirmation of the MS/MS method in the state laboratory.

Remaining to be proven is whether privatizing newborn screening would result in lower costs. Many states now charge fees to support their state laboratories. In 1991 the North Carolina General Assembly authorized the North Carolina Department of Environment and Natural Resources to charge hospitals for testing. The charge was $10 per initial test in 2002 and $14 in 2005. The funds remain in the department to be used to support the Newborn Screening Program.

Screening and Follow-Up

Since the early days of newborn screening, the Newborn Screening Quality Assurance Program of the Centers for Disease Control and Prevention has been responsible for checking the accuracy of newborn screening laboratories in the United States. In North Carolina the extremely low rate of cases missed through laboratory error is due to the high quality of leadership within the Newborn Screening Laboratory. During many of the earlier years, the laboratory was under the capable direction of Maxine Matheson. As newborn screening became more technically complex, it was apparent the laboratory should be directed by someone board-certified in clinical chemistry, as has been the case for over 20 years.

The importance of an aggressive follow-up program became apparent in the early years of screening when 33 of 37 North Carolina infants detected as having PKU were promptly started on the low-phenylalanine diet. The 4 infants who were not placed on a phenylalanine-restricted diet developed retardation,[15] and several lawsuits were filed against physicians. None of these cases was the result of a laboratory error; all resulted from a breakdown in follow-up. This is in contrast to a national survey that revealed missed cases of PKU and hypothyroidism were more often the result of laboratory error than of failure to follow up.[16]

A system had evolved by 1974 for tracking abnormal results in North Carolina infants and seeing that each infant was either retested or referred for confirmation and treatment. That system was monitored by Elizabeth Moore, Genetic Program Manager of the Division of Maternal and Child Health. In the 1980s, during the period when MS/MS screening was contracted to a private laboratory, it became apparent that difficulty in coordinating follow-up was a potential problem. Another factor contributing to failed follow-up is a change in the physician of record when an infant is discharged from the hospital. A policy was finally established in North Carolina for laboratory staff to directly contact parents if repeat testing had not been obtained. This caused initial and understandable resentment among physicians until missed cases were documented. Despite the great importance of an effective follow-up program, the follow-up component is easily overlooked in funding of newborn screening programs.

The Issue of Who Will Manage Each Disorder

After an abnormal result from newborn screening, the confirmation and management of congenital hypothyroidism and the hemoglobinopathies (eg, sickle cell disease) may occur in many North Carolina medical teaching centers. In sharp contrast, the management of inborn errors of metabolism often requires specialized expertise. The dietary management of pregnant women with PKU, for example, is complicated by the nausea of early pregnancy and the changing metabolism of the pregnant woman. This situation is even more complex than that of the growing infant or child with PKU. Dietary management of many inborn errors of metabolism requires the expertise of a dietitian who has specific training and experience in managing such cases. Underrestriction can result in mental retardation or brain damage; overrestriction can result in death. Moreover, management of maple syrup urine disease, for example, requires regulating blood levels of three amino acids simultaneously.

In North Carolina, all PKU cases, approximately 90% of disorders detected by MS/MS, and certain inborn errors of metabolism are managed at the University of North Carolina at Chapel Hill by a dietitian who has a doctorate degree in biochemistry. This model of centralization also includes Duke University where confirmation and management of certain other inborn errors of metabolism occurs. This centralization is due to the difficulty of obtaining specialized skills in many locations. The disadvantage of centralization is the travel required of patients living elsewhere in the state. To offset this disadvantage, maximum use is made of mailed samples and telephone consultations. Although the Guthrie bacterial test is now seldom used, the method of collecting blood on filter paper (the Guthrie card) is ingenious and is widely used.

Guthrie cards have made newborn screening practical and have allowed North Carolina parents of infants and children with certain inborn errors of metabolism such as PKU to obtain samples for dietary monitoring and to inexpensively mail them to a laboratory. However, the cost of making available to needy families the expensive dietary formula and specialized care they require is a second area that is easily overlooked in funding newborn screening programs. The Guthrie card, incidentally, should not be called a "PKU card;" it is used to test for many more disorders than PKU. Until Dr W. Harry Hannon of the Centers for Disease Control and Prevention intervened in 1996, postal policies to prevent the transmission of HIV could have essentially put an end to newborn screening and subsequent dietary monitoring.

Current and Future Policies

Numerous considerations must be examined in developing policy on newborn screening. Little justification exists for screening for conditions that require no treatment until much later in life. It may be argued that the condition might be later missed, but such failure in later detection is a problem that must be addressed separately. The detection of some disorders must await technical advances that make screening reliable and relatively inexpensive. As newborn screening is extended to detecting more rare or less treatable conditions, testing becomes difficult to defend financially. Perhaps a standard should be applied that is unknown to newborn screening but familiar to other areas of public health. Will the dollars expended for the new screening prevent more grief and suffering than the same amount spent in other ways? Would funds be better directed to immunizations and accident prevention?

About 20% of current test samples need to be repeated because of an inadequate sample or borderline result. The introduction of screening for each new disorder inevitably leads to an increase in the total proportion of false positives, some of which can cause harm. A false positive for hypothyroidism or PKU is not as disturbing as one for galactosemia, which requires an immediate appraisal of whether the infant has septicemia, an early feature of untreated galactosemia. False negatives are still worse. Thyroid deficiency is not necessarily excluded by results soon after birth. Some infants have enough thyroid function to carry them through early infancy but then later become thyroid deficient (especially infants with birth weights under 1 500 g). With extensive transfusions, a condition can be missed when the test is dependent on a blood protein (eg, biotinidase deficiency and the hemoglobinopathies). Physicians can decrease the number of false negatives by considering how the tests are done. High levels of metabolites in the affected infant occur largely after birth. With mothers and babies being discharged very early, a blood sample should always be obtained at discharge with an additional sample obtained by 1 week of age if discharge was before 24 hours. Infants on soy formula or total intravenous feedings cannot be diagnosed as having galactosemia from an elevated blood galactose and therefore require an additional assay.

Present techniques in DNA analysis are unlikely to simplify newborn screening since each disorder often results from any of many mutations. Moreover, the most common type of congenital hypothyroidism does not have a genetic basis. Of very great importance in newborn screening is the changing effectiveness of treatment particularly when early treatment is essential. It is possible that future bone marrow or stem cell replacements, for example, will make additional disorders appropriate for newborn screening. Krabbe disease[17] and severe combined immunodeficiency[18] are two disorders presently approaching this point.

Future policy should reserve decisions about future tests within the staff of the Newborn Screening Laboratory and their consultants. Printed policies for newborn screening can be obtained by calling the Newborn Screening Clinical Chemistry Unit at (919) 733-3937. **NCMJ**

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North Carolina
MEDICAL JOURNAL

The Governor's Initiative to Improve Health Care:
Taking Measure of Medical Care in North Carolina

Charles Willson, MD

Most physicians I know are working longer hours and seeing more patients each day in order to meet the increasing demand for services and to make financial ends meet. We are practicing, as we were trained, to evaluate and treat each patient as an individual with unique complexities and needs. Much of the time, we deliver care that is timely, effective, and highly valued by our patients.

After the last patient of the day has been seen and the billing and paperwork is complete, we often put our feet up on the desk and read our journals and newspapers. Then we hear the drum beats of critics who say that medical care in America is not accessible to all Americans, often falls short of best practice, and sometimes is unsafe. Certainly, with our citizens' health status measuring below many third world countries and our per capita health care spending almost double that of the next most costly country (Switzerland), the question of value is most appropriate.

> *"…I believe that the act of measuring our processes and outcomes will be seen as the pivotal change that led to a safer, higher quality, and more affordable health care system."*

Payers for medical services, employers, insurers, and government are talking about mandating physician reporting of quality measures and outcomes of their care. There is talk of practice profiles, community ratings, and "pay for performance." Implementing best guidelines and generating these reports will require new office resources. Having practiced in a busy pediatric office for 19 years, often seeing more than 40 patients a day, I know how difficult it is to change how we care for patients. My analogy is that changing office processes while seeing your patients is like trying to change your pants while riding a bicycle.

As a leader of the North Carolina Medical Society, I have been privileged to participate in discussions at many venues of how we can improve and document the quality of care we physicians in North Carolina are delivering every day. I am totally committed to the proposition that it is no longer enough to say that our quality is good because we are well-trained, dedicated, and hardworking. However, I see a bicycle wreck coming down the road if physicians are required to report their compliance with best practices to each payer, in different formats and measuring different parameters.

Why not build on the data reporting primary care physicians already do for Community Care of North Carolina, our unique and highly successful case management program for NC Medicaid? Let's develop a system where one report on a care initiative meets the requirements of all insurers in North Carolina (and hopefully the federal Centers for Medicaid and Medicare Services)? Let's give our physicians the knowledge and resources necessary to measure the care they deliver to certain populations of patients within their practices. To meet this vision, a group of stakeholders, led by Governor Mike Easley, has developed a new initiative aimed at improving the quality of health care delivered to all North Carolinians.

For nearly two years, leaders from North Carolina government (the Governor's office), health care providers (the NC Medical Society, the NC Hospital Association), organizations helping practices document and improve their quality (NC Area Health Educations Centers Program, Community Care of North Carolina, the Improving Performance in Practice program), and

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insurers (Blue Cross and Blue Shield of North Carolina, the NC State Health Plan, Medicaid) have been meeting to see if we could agree on an approach that would support practice-based physicians in the implementation and measurement of best practices and produce data reports that would be accepted by the payers' *quality* programs. Generous funding from a variety of organizations, including Blue Cross and Blue Shield of North Carolina, NC Medicaid, the NC Health and Wellness Trust Fund, the Center for Health Care Strategies, and the National Governors Associations, has enabled this group to develop the plan and infrastructure necessary for this ambitious objective.

Fortunately, through a grant from the Robert Wood Johnson Foundation, the Improving Performance in Practice (IPIP) program in the Department of Family Medicine at the University of North Carolina at Chapel Hill School of Medicine has been rolled out to selected practices in eastern and western North Carolina. Using agreed upon best practices and hands-on office system analysis by field agents, IPIP provides a model for how this initiative might be implemented throughout our state without disruption of patient care or financial hardship to the practices.

In October 2006, the North Carolina Medical Society House of Delegates adopted a series of recommendations on quality reporting that parallels the American Medical Association policy on pay for performance. These programs must be voluntary, evidence-based, nonpunitive, and transparent and must provide the financial and technological resources needed to support them. A group of physicians in the state of Washington has sued an insurer for using quality data to unfairly channel patients to certain practices. We need safeguards that ensure the data generated by the initiative will not be used by insurers to direct patients to practices based on lower cost rather than higher quality.

As medical historians write about the crisis we face today in American health care, I believe that the act of measuring our processes and outcomes will be seen as the pivotal change that led to a safer, higher quality, and more affordable health care system. Every physician I know wants to practice the highest quality of care, but time and financial resources are limiting barriers. The first step is to measure what we do today. With that knowledge, we can integrate a continuous quality improvement culture within our practices.

In North Carolina, I believe that we are uniquely positioned to develop an honest statewide quality of care reporting program that will be the model for our country. By participating, North Carolina physicians will not only be measuring our care, we will be taking measure of our profession. The result will support my opinion that our physicians truly are the best in the world. **NCMJ**

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North Carolina MEDICAL JOURNAL

POLICY FORUM

Data and Health Policy

COMMENTARIES

> *"Wherever health policy is determined and by whomever it is made, the goal is to strive for policy decisions that are based on sound North Carolina data because these policies will have greater credence and acceptability."*

INTRODUCTION

Policy Forum:
Data and Health Policy

North Carolina is fortunate to have many rich sources of data that provide a solid foundation for making good policy and practice decisions to improve health and health care. Relevant, timely data and high quality analyses and interpretations provide justification for the development of evidence-based medicine, public health practice, and health policy to improve health in North Carolina.

Recently the role of evidence-based health care has been expanded with the announcement of a new, data-driven initiative from Governor Mike Easley. In April, Governor Easley announced a groundbreaking health care initiative in which insurers, organizations working to improve physician practices, providers, and others will collaborate to ensure North Carolinians receive optimal health care. Clinical as well as claims data are at the very core of the initiative. The goal is to extract information from these data, and the information will be used in innovative ways to promote optimal care through performance feedback and encouragement of best practices.

Despite the wealth of health data in the state, significant health information needs remain. For example, due to small samples, some data characterizing ethnic and racial groups yield imprecise estimates, and data pertaining to patient-practitioner interactions are also needed. Likewise, data representative of small geographic areas and subsets of the population—especially those at risk—are needed so that interventions and limited resources can be best targeted. Relatively new technologies such as electronic health records and geographic information systems are filling these gaps and providing researchers with access to much-needed data.

The issue brief by Sandra Greene, DrPH, discusses the relationship between health policy and data and provides an excellent backdrop for the commentaries. The commentary on the North Carolina Health Professions Data System (HPDS) highlights a prime example of data providing useful information to spur policy action and guide state health planning. Thanks to HPDS data, areas with health professional shortages have been identified and a possible future decline in the ratio of health providers to residents has been detected. As a result, medical schools in the state are expanding their programs, incentives are being offered to increase the number of medical school graduates, and physician retention is being encouraged.

In the run up to the fall 2008 elections, data and information systems are also at the heart of several proposals to improve health care quality and reduce the rapid growth of health care costs. North Carolina has explored the development of coordinated electronic data systems for over 15 years starting with data and information committees that were part of the Health Planning Commission and its successor, the Health Reform Commission. The Planning Commission issued a report in 1996 that formed the basis for a strategic plan for the adoption of statewide standards and systems for electronic medical records and information exchanges. The North Carolina Health Information and Communications Alliance (NCHICA) was subsequently formed to help move that plan forward. The time is now right for taking specific tactical steps toward implementation of a comprehensive health information strategy.

This issue of the *Journal* highlights the work of many organizations and individuals committed to collecting, analyzing, interpreting, and using data to improve health within the state. We hope this issue provides readers a broad understanding of the existing data resources in our state and provokes thoughtful discussion about how to enhance existing data resources, recognize possible synergy among datasets, and identify needs and potential solutions.

Thomas C. Ricketts III, PhD, MPH
Editor-in-Chief

Jennifer Hastings, MS, MPH
Interim Managing Editor

Data and Health Policy:

Do We Do Our Best?

Sandra B. Greene, DrPH

Health care policy has emerged among the general public as a priority issue for the November 2008 presidential election. Second only to the war in Iraq, health care and the economy are the domestic issues foremost on the minds of Republicans, Democrats, and Independents polled by the Kaiser Family Foundation.[1] Specific issues of greatest concern are the intertwined problems of cost and the availability of health insurance to provide financial access to care. While some candidates propose sweeping change to address the nation's health care ills,[2] historically the health care system has evolved incrementally through moderate policy reform.

Health care policy positions are formulated at the national, state, and local levels. In the state of North Carolina there are many stakeholders responsible for decision making, ranging from departments and divisions of state and local governments to public and private institutions. Collectively, health care policies impact who is eligible to receive health care, what types of care are available and provided, where facilities and services are located, and who pays the bill. In sum, health policy provides the direction, specifications, and building blocks that define our health care system.

Sources of Data for Health Policy

Data useful for health policy decision making in North Carolina originate from numerous sources. This issue of the *North Carolina Medical Journal* describes what these data are and where they come from and explains how they are or can be used. While some data are collected in a one-time study or survey, the most commonly used sources are collected on an ongoing basis, either mandated by state or federal law or by voluntary submission. The range of data sources includes population-based surveys, patient registries focused on specific diseases or conditions, vital records of births and deaths, workforce databases, electronic medical records, and insurance billing records.

The Behavioral Risk Factor Surveillance System (BRFSS), an example of a population-based survey, was originally developed by the Centers for Disease Control and Prevention to measure health behaviors and use of health care services.[3] It is now in use in all states and the District of Columbia and in this state is conducted by the North Carolina State Center for Health Statistics (SCHS). Paul Buescher discusses this survey and other data collection projects in an accompanying commentary. A sample of North Carolina households is randomly contacted by telephone, and adults in the household are interviewed. Questions cover topics including perceived health status, self-reported health care conditions, availability of health insurance, and respondent's use of health care services including screening. Results are reported on a statewide basis and for individual counties with large populations. Core questions are repeated each year, allowing analysis of trends. Additionally, selected questions are added annually as new policy interests emerge. While the BRFSS focuses on North Carolina adults, a companion survey was recently implemented to gather health characteristics of children. Data collection for the Child Health Assessment and Monitoring Program (CHAMP) began in January 2005.[4]

> *"Assuring that health policy decisions made for the citizens of our state are the best they can be calls for nothing less than data-driven decisions."*

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The North Carolina State Center for Health Statistics also administers patient registries which focus on specific at-risk populations. The Birth Defects Monitoring Program (BDMP) collects and analyzes information on infants born with serious congenital anomalies.[5] These data are aggregated from multiple sources including hospital medical records, hospital billing data, and vital records. A second registry, described in a commentary by Karen Knight, Paul Buescher, and Walter Shepherd, tracks cancer cases in the state, reporting that is required by law. These data are gleaned from hospital records, death certificates, and in cases where the patient is not hospitalized, by physician report.[6] Another source of health care data collected by the National Center for Health Statistics (NCHS) is vital records. Also mandated by law, these databases include registrations of all births and deaths occurring in the state.[7]

The North Carolina Trauma Registry (NCTR) has collected data since 1987 from state EMS agencies, acute care hospitals, and other providers in an effort to provide quality care for injured patients throughout North Carolina. Michael Thomason writes about NCTR and its coordinated data system in his commentary.

Data on the state's healthcare workforce can be found in the North Carolina Health Professions Data System (HPDS), housed at the Cecil G. Sheps Center for Health Services Research.[8] This system is a collaborative effort with the Area Health Education Centers Program and the independent licensing boards of each participating health profession. Included in the database are over 2 decades of demographic and employment history on physicians, nurses, dentists, chiropractors, and other types of health care professionals. Jennifer King and Mark Holmes speak to the importance of these databases and their uses.

Insurance billing records, also referred to as administrative records, provide a rich source of data for use in health policy decisions. These data originate from 2 primary billing forms: the Uniform Billing-92 (UB-04 after June 1, 2007) used for billing institutional charges and the Health Care Financing Administration (HCFA) 1500 used for billing professional charges.[9,10] Information from these records contain patient-level detail on health care services provided to a covered population including physician and clinic visits, emergency room care, hospitalizations, outpatient prescription drugs, and the charges and payments for those services. These databases also contain information on patients' diagnoses, tests, and procedures. Grouping an individual's claims into episodes illuminates patterns of care that when aggregated across population groups provides a picture of how illnesses are treated and how health care services are utilized.

Insurance billing records are maintained by insurance companies or, in the case of publicly funded programs such as Medicaid and Health Choice, a system administrator. The largest database of this type in North Carolina is maintained by Blue Cross and Blue Shield of North Carolina. The Division of Medical Assistance maintains the second largest insurance billing database which contains claims on all Medicaid eligible recipients. Databases such as these housed by private and public insurers are proprietary, and data from them are generally only available for analysis and use in health policy considerations on an ad hoc basis.

The most detailed information documenting patient care is contained in medical records. These are patient-specific files kept in every health care facility. They contain information on all care provided to the patient including patient symptoms and presenting complaints, information that is not contained on billing records. Medical records also contain results from laboratory tests, screening, and outcomes of treatments and procedures. While medical records have traditionally been handwritten, limiting their usefulness for analysis across population groups, the electronic medical record affords significant opportunities for data aggregation and population-based study. Xiaoming Zeng addresses this potential in his commentary.

The articles in this issue of the *Journal* focus on some specific data sets and their policy context. One data set in particular, the hospital discharge and ambulatory surgery data set, has a history that illustrates how policy can be shaped both by the information extracted from the data and by the data themselves, and how the data used can be shaped by the policy process.

History of the Medical Database Commission

As medical costs rose rapidly in the early 1980s, many legislators, employers, and health policy analysts recognized a need for public information on cost and utilization of health care services. Insurance billing records were viewed as a valuable potential data source. In 1985 the General Assembly created the North Carolina Medical Database Commission with the charge "to establish an information base to be used to improve the appropriate and efficient usage of medical care services, while at the same time maintaining an acceptable quality of health care services in this State. This is to be accomplished by compiling a uniform set of data and disseminating aggregate data, including but not limited to price and utilization data."[11] The Commission began its work in 1986, and 3 years later the first data reports, based on electronic copies of UB-92 records, were released. The reports contained summary information on all discharges from North Carolina acute care hospitals. For the first time, North Carolina had information on hospital discharge diagnoses, procedures, and associated facility charges for the entire population.

Through the early 1990s the North Carolina Medical Database Commission continued to expand its efforts to make health care data available to the public. In addition to enhanced hospital discharge data reports with comparisons of charges among providers and analyses of where patients travel to receive care, it also expanded into ambulatory surgery reporting. All licensed free standing ambulatory surgery centers submitted copies of UB-92 billing forms to the Commission's data processor. Annual reports were developed and released. By 1995 both hospital and ambulatory surgery utilization and charge information were available and widely disseminated.

Not all stakeholders were comfortable with the public availability of the Commission's data. In the 1995 session of the

General Assembly, the North Carolina Medical Database Commission was abruptly eliminated. In its place, the Medical Care Data Act was passed establishing the authority of a state data processor, with oversight of the Division of Facility Services [now the Division of Health Service Regulation (DHSR)], to assume responsibility for the collection and reporting of data.[12] The state data processor chosen for this role was Solucient (now Thomson Solucient). Under the direction of DHSR, a copy of the state databases is housed at SCHS for use by the state medical director, and a second copy is maintained at the Cecil G. Sheps Center for Health Services Research for use in state health planning. During the transition from the Medical Database Commission to the state data processor, 1995 data were not collected. Data collection resumed in 1996 and continues today with ongoing reporting by hospitals and freestanding ambulatory surgery centers. However, the public reporting function that existed under the Medical Database Commission no longer exists.

In 2004 statewide collection of health care data expanded with the collection of data from hospital emergency departments. Mandated by law, all emergency departments are required to report an electronic record of each visit.[13] Reporting is to occur daily. The purpose of this data collection effort is to provide data for public health surveillance and to enable an early warning system of bioterrorism or other public health crisis resulting in patients presenting for emergency care. The North Carolina Hospital Surveillance System, a collaborative project between the North Carolina Division of Public Health, the North Carolina Hospital Association, and the University of North Carolina at Chapel Hill School of Medicine, collects and processes the data from all North Carolina hospitals.[14]

How Do We Use Data for Health Policy?

The policy relevant data sources available in this state are used in a multitude of ways to identify new policy directions, support or change existing policy, or to illuminate health problems that if addressed would improve the public's health. Dianne Enright writes about how data provided by geographic information systems help determine allocation of limited public health resources. David Murday and Elizabeth Corley discuss how philanthropic foundations use health data to identify communities whose needs are aligned with a philanthropy's priorities. Christopher Manfield and James Wilson explore how data are used at the local level by citizens, providers, organizations, and policy makers to improve community health. Mark Massing and Anna Schenck discuss how data are used at The Carolinas Center for Medical Excellence to inform consumers, assist providers, and develop information to improve health policy at the federal and state levels.

BRFSS survey results provide relevant examples of how data sources are used to develop and direct policy. General population prevalence estimates of chronic conditions such as arthritis, asthma, and diabetes are calculated from the survey results. The North Carolina Division of Public Health develops programs to provide technical assistance, resources, and care management tips to reduce illness burden for these conditions.[15-17] Behavioral Risk Factor Surveillance System estimates also are used to measure levels of personal behavior that negatively impact health including smoking, alcohol use, and seatbelt use. Programs are then developed to address these behaviors.[18,19] The continuous data gathering of the BRFSS allows program administrators to evaluate their success in reducing negative behaviors by reviewing subsequent survey results.

In a similar fashion to the population estimates from the BRFSS survey, data from the state's vital records and condition-specific registries are used to develop and monitor health care programs. Infant death rates, for example, are closely monitored as a key indicator of the quality of our health care system. North Carolina's high rate of 8.5 infant deaths per 1000 live births in 2004,[20] compared to 6.8 in the US,[21] directs attention to programs that improve access to and use of prenatal care. Overall population death rates also provide rich opportunities to identify and address health care challenges. County and regional death rates, along with disease specific rates, illuminate program opportunities to reduce disease risk and improve the provision of care for those impacted by disease. An advantage of the ongoing availability of these data sources is that it allows continued monitoring and evaluation of program effectiveness.

Information from the state's workforce database, the Health Professions Data System, is used in a wide array of program and policy development activities. These data show where health professionals are employed and the relative availability of the workforce by county and region. It helps track trends in workforce use and identifies shortages in supply. It also enables determination of the age distribution of those working, allowing estimates of how retirements will impact future workforce availability. All of this information is essential for understanding employment needs and drives policy decisions on training programs required to assure a continued supply of the right discipline and number of health care professionals.[22]

The health planning process in this state is largely data driven as reflected in the annual state medical facilities plan developed by the Division of Health Service Regulation (DHSR) under the direction of the North Carolina State Health Coordinating Council.[23] This plan provides need projections for health care facilities and services as specified in GS § 131E-177 including hospital beds, rehabilitation beds, skilled nursing beds, operating rooms, technology, and medical equipment. Much of the data used in health planning are derived from the annual license renewal application form. These forms are required by DHSR for a facility to renew its operating license. Facilities currently complete a handwritten copy and submit it by mail to DHSR. Plans for electronic submission are underway. The form asks for counts of services provided at the institution with instruction on how services should be defined and counted. It is a lengthy form requiring considerable time and effort to complete. Facilities are generally diligent and conscientious in completing these forms. However, there is no audit function to determine the accuracy of the data submitted, and reporting categories are subject to individual interpretation by the facility completing the form.

Other sources of data used to support health planning are the hospital and ambulatory surgery databases collected by Thomson Solucient under the Medical Care Data Act. The State Health Coordinating Council committees that oversee the development and refinement of methodologies for determining needed facilities and services use these databases to understand how services are currently utilized and to project future use. As an illustration, to determine when additional acute care hospital beds are needed, 4 years of historical hospital discharge data are analyzed. An average annual historical rate of change is calculated for those 4 years. Using this rate of change, coupled with a projection of population growth or decline, a calculation is made to determine how many beds will be needed in a service area 6 years into the future. A comparison of the number of existing beds to the number projected to be needed determines if additional beds should be built. Starting with data on current utilization rates and reflecting recent changes in those rates provides a sound basis for future planning. The advantage of using the Thomson Solucient databases to determine utilization rates, rather than a self-reported number of cases from the provider, is more assurance that each facility is treated fairly by counting past utilization consistently.

Emergency room data collected by the North Carolina Hospital Surveillance System are used by the public health community for surveillance and planning. These data are submitted to the North Carolina Disease Event Tracking and Epidemiologic Collection Tool (NC DETECT) which is a tool for categorizing, analyzing, and reporting the data.[24] These data on nearly 3.5 million emergency department visits annually are available to approved users for population-based studies.[25]

What Additional Data Do We Need?

While there is always the desire for more and better data for policy and decision making, collecting additional data has significant ramifications, particularly if it is new information that would place administrative burden on providers to report. While expanding data collection is a worthy goal, we should carefully choose areas of expansion where the expense and effort can be justified. William Kalsbeek's commentary describes an effort underway at the University of North Carolina to identify gaps in public health information. We should also seek opportunities to make optimal use of the data we have. In this spirit the State Health Coordinating Council recently acted to transition to the use of the Thomson Solucient databases for determining operating room need in North Carolina. The current methodology utilizes self-reported aggregated data on the license renewal application form. Using administrative data will enable counts of individual procedures that are consistent for each provider. This change in methodology will take a number of years to accomplish but will improve the accuracy of the need projections and advance the credibility of the process.

Another initiative designed to make better use of the data we have is the North Carolina Comprehensive Assessment for Tracking Community Health (NC-CATCH). James Studnicki, John Fisher, and Christopher Eichelberger describe the development of this Web-based portal for community surveillance in their commentary.

The Thomson Solucient hospital discharge databases provide comprehensive data for care provided in the state's inpatient facilities. However, the Thomson Solucient ambulatory surgery database contains some gaps, with not all freestanding ambulatory surgery centers reporting as required. There has also been a void in data and information on services provided in hospital emergency departments. The new North Carolina Hospital Surveillance System data may serve to fill this gap if the data are made available to planners and policy analysts.

The biggest gap in available data, however, is in records for care provided in physician offices, clinics, and hospital outpatient departments. While approximately 12 in every 100 persons experience a hospitalization during the year and discharge records are available for these events, each person averages between 3 and 4 outpatient visits per year, and we have no database chronicling these events.[26] Outpatient settings are where most contacts with the health care system occur. If we are to adequately understand what care is provided, where it is provided, to whom it is provided, and for what conditions, there is a need to have data on these visits contained in publicly available databases that can be used for a wide range of planning and policy functions.

Another significant gap in publicly available data is information contained in medical records. To fully understand the care process, it is important to know more than diagnoses and procedures. It is necessary to understand patients' presenting complaints, signs, symptoms, and test results. These data are critical for determining the quality and appropriateness of provided care, for assessing patient outcomes, and for measuring and reducing racial and ethnic disparities in treatment patterns. As more medical records are converted to an electronic status, access to these data will become feasible. However, the challenges to the use of electronic medical records are significant. First, there is no standard acceptable format for a medical record like the standard UB-04 and CMS 1500 forms. Combining multiple formats can be difficult and costly. The second major challenge is finding a vehicle for pulling together medical records from multiple sites including physician offices, clinics, and hospitals. Yet this is necessary to aggregate data for population groups. Overcoming these obstacles would provide rich data for surveillance, research, and health policy.

What prevents us from collecting more expansive data and making it available for use in health planning and policy? Cost is perhaps the most significant deterrent, though there must also be the political will. It is costly to collect large amounts of new data. Extracting data that has already been collected for another purpose is less costly, as electronic processing and data storage costs have declined. Expansion of data collection is not viable, however, on a voluntary basis. Mandated reporting by providers, achieved through legislation, is critical to assure complete reporting.

Where Do We Go From Here?

To improve our ability to make data driven decisions in health policy, we should continually look for additional data sources and make publicly accessible those data sources that already exist for other purposes. In this spirit, the Carolina Cost and Quality Initiative (CCQI) was created. The Carolina Cost and Quality Initiative is a collaborative partnership between the University of North Carolina School of Public Health and the Sheps Center to build, maintain, and oversee the use of administrative databases on health care services provided to North Carolina population groups.[27] The purpose of this project is to promote population-based research on the incidence and prevalence of disease in insured populations, to study patterns of health care utilization and cost of care, and to provide information for informed policy decisions on issues impacting our population's health.

Owners of administrative databases in North Carolina have been invited to partner with the University of North Carolina in this project and to share their data. Two are currently participating, and we expect more to join. The Carolina Cost and Quality Initiative project now houses databases contributed by the North Carolina State Employees Health Plan (SEHP) and the North Carolina Division of Medical Assistance (DMA). As the data owners, SEHP and DMA share data through contractual agreements with the university. Each database contains 5 years of historical claims data, and the data owners have agreed to provide periodic updates to keep the databases as current as possible. University faculty and research staffs are invited to submit project proposals for use of the data. Each project request is reviewed by an oversight committee consisting of representatives of the data owner and of the university; upon approval, data are prepared by CCQI staff for the researcher's use.

The Carolina Cost and Quality Initiative databases include insurance claims for hospitalizations, doctor visits, outpatient surgery and treatments, emergency room use, and outpatient prescription drugs. Patient identifiers are encrypted to protect patient confidentiality and to allow the researcher to track all treatments provided to the same individual. The 2 databases combined represent all health care services provided to approximately 1.5 million persons who are geographically dispersed throughout the state. Such a rich set of data for this large population group provides a significant opportunity for research that can favorably impact health policy decisions in the state. We invite project requests and encourage these databases to be used in this way.

Administrative databases, as useful as they are, do not contain information on the results of tests and procedures. To add this additional level of detail, we must also strive to find ways to use electronic medical records for large population groups. Such an undertaking will require combining files of medical records across providers and facilities and encrypting identifying information to protect confidentiality in the process. Holt Anderson and Gary Bowers discuss health care information exchange across provider groups in their commentary. The resulting databases will be extremely large for a population group, but the advantages from this type of data aggregation in informing policy makers and researchers would be significant.

The potential rewards from increasing data collection and availability will be diminished if we do not simultaneously prepare researchers, planners, and policy makers to use available data sources. Elizabeth Layman, and Debbie Travers and Lawrence Mandelkehr, address these issues in their respective commentaries. We must put a greater focus on data and analytics in university curriculum in the courses and programs that are training our next generation of health care leaders. Health care researchers should be trained in the use of claims data analysis and electronic medical records. Those who are preparing for leadership roles should be trained in data literacy to ask for and expect quantitative assessment of health policy issues in their workplace.

All of us in the health care field must look for ways to work collaboratively towards increased availability and use of appropriate data. Assuring that health policy decisions made for the citizens of our state are the best they can be calls for nothing less than data-driven decisions. And as Marcus Plescia and Jeffrey Engel point out in their commentary, future public health data needs must reflect the foreseen and unforeseen changes in our state. Wherever health policy is determined and by whomever it is made, the goal is to strive for policy decisions that are based on sound North Carolina data because these policies will have greater credence and acceptability. **NCMJ**

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COMMENTARY

Electronic Records in Health Care

Xiaoming Zeng, MD, PhD

Health care can be studied from many viewpoints. Using information as the primary way to examine our health care system has lately been on the agenda of national health care policy. Physicians need to process large amounts of data into information to make clinical decisions. Public health practitioners need to aggregate heterogeneous data at population levels to prevent and detect epidemics. Health care policy makers need to use a variety of secondary databases as evidence for policy making. How can we ensure the right health care information is accessible to the right person at the right point in a timely manner? At this moment, the only solution to the question is to digitalize the information and share it on a secure, networked information system. Electronic health records (EHRs) offer one such solution by providing a platform for acquisition, storage, access, analysis, and presentation of health data. Electronic health records systems are touted as one of the keys to a new health care system that provides quality and cost-effective care.[1-6] President George W. Bush set a goal of making the use of electronic health records universal by 2014.[7] Various initiatives have been implemented across the health care spectrum from federal to community-level programs.[8,9] Studies demonstrate the promising effects of EHRs on controlling cost, enhancing quality, and reducing medical errors.[5,10-13]

> *"Electronic health records systems are touted as one of the keys to a new health care system that provides quality and cost-effective care."*

We are currently in a transition period in that many health care facilities are upgrading their paper-based record systems to electronic health records systems. Among the many functions of health records, documenting patient care over time is the most essential. To deliver quality care, providers need timely and accurate data on a patient's current and past medical history which may include findings from physical examinations, laboratory results, insurance, and other sources. This situation is made more complex due to increased life expectancy and the shift of the disease delivery model from acute care to chronic care. More data and information are created in the process of caring for a patient with complex, often multiple, diagnoses. Patients with chronic diseases often visit multiple providers and take multiple medications. It is cumbersome for doctors to go through the process of acquiring data from various sources in order to make the right diagnosis, perform the right procedures, and prevent medical errors. Even if practitioners obtain all of the data, they need enormous logistical and technical assistance in order to link it together.

Data in health care, especially patient-based clinical data, have long been entered and stored on paper. Paper records usually allow practitioners to record information in a semi-structured, free-text format. One weakness of paper records is that the information recorded there can be accessed by only one person at a time at one location. Sharing paper records is cumbersome and cost-inefficient. More importantly, it presents a challenge to aggregate all the data from different sources in order to find patterns which are often used in health policy analysis.

A consensus national priority is to establish a networked EHR system that shares the integrated information of each individual at the point of care. To achieve this goal, a totally automated EHR system is needed at each health care institution. More importantly, these institutions should have the capacity to share information with others. This commentary offers more detailed information about EHRs and their value as a data source for health policy, as depicted by Greene in the issue brief of this journal.

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Definitions

Historically, many terms have been used for the concept of an EHR system.[14] The electronic medical record (EMR) is a term often used interchangeably with EHR. The key conceptual difference between EMR and EHR is the owner and location of the record. Electronic medical records are usually included in a local clinical data repository used to support clinical operations. They are usually owned by an individual health care provider and are often accessible to the patients who are the customers of the health care provider. Electronic health records refer more to an overarching system based on information shared by individual care practitioners regardless of practitioner specialty, type of care (eg, inpatient, ambulatory), or location of care. Electronic medical records are often practitioner-oriented while the EHR is patient-centric and supports coordinated care. More importantly, the concept of EHR goes beyond episodic care in health care facilities by providing not only a comprehensive medical history (when patients interact with practitioners) but including patients' own records of their health status (when patients don't interact with practitioners). So, even an EMR system in an integrated delivery system is not equivalent to an EHR system because it does not contain the entire picture of a patient's health status.

Electronic medical records and EHRs are interrelated. Successful EHRs rely on EMRs as the data providers to construct different segments of the individual's health history. The key for the success of patient-centric EHR systems is for each EMR system to have the capability to share data in an automated and error proof way. Because a patient may have different records located in different EMRs, accurately and efficiently linking all the records together is a challenge because there is no existing centralized patient index. Such sharing is called health information exchange.[15]

To undertake the task of health information exchange, two solutions are being implemented by the Office of the National Coordinator of Health Information Technology. One is to build a national health information network which enables providers to access needed patient-related information. The US government is currently promoting a bottom-up, market-oriented approach by advocating regional health information organizations (RHIOs) as the foundation of a national health information network. Stakeholders within each RHIO will share data with their own selection of network and information architecture. The North Carolina Healthcare Information and Communications Alliance (NCHICA) is coordinating an effort to create a regional health information organization in North Carolina. Sharing data among regional health information organizations will complete the national health information network.

Fully functional regional health information organizations and national health information networks rely on information interoperability, which has a long way to go.[16] The other solution to health information exchange is to let patients manage their own personal health information using tools like personal health records. The American Health Information Management Association defines personal health records as "a collection of important information about your health or the health of someone you are caring for (such as a parent or child) that you actively maintain and update. The information comes from your healthcare provider and from you."[17] It is not necessary to have only the encounter data stored in the personal health record. Ideally, patients also would record data related to their health status such as weight, diet, and exercise routines. A successful personal health record system should have interfaces to all the EMR systems in which patients have data footprints.[18,19] Microsoft recently started a Web-based personal health record that allows consumers to store their health records online and share them with their designated providers.[20]

Electronic Health Records and Health Policy

The advocates of EHRs believe they are integral to controlling the cost, improving the quality, and increasing the efficiency of health care. These benefits are largely at the direct patient care level. There also are important benefits to health policy makers at a system level. As Sandra Greene defined in her issue brief, "health policy provides the direction, specifications, and building blocks that define our health care system." As such, EHRs could systematically be used for quick data collection and policy dissemination in health care.

Electronic Health Records As a Data Source for Health Policy

The EHR has primary and secondary usages. Examples of primary usage of EHRs include informing and supporting direct patient care, management support, financial and administrative processes, and patient self-management. Secondary usages of EHRs include education, regulation, research, public health policy, homeland security, and policy support.

The medical or clinical encounter record, whether in paper or electronic format, is the primary data source in health care because it contains specific data pertaining to a specific patient. Primary data sources, after de-identification and aggregation, are the raw inputs to the secondary data sources that are used in health care policy making. For example, a cancer registry is a secondary data source that collects data related to cancer diagnosis and uses it for monitoring patterns of cancer cases in the US. After a patient is diagnosed with cancer, demographic data, occupational history, and administrative and pathological data will be recorded into a facility's cancer registry. The information is then sent to state and national registries. The process of data collection historically relied on manual chart review and reporting due to the paper-based record environment. In an EHR system, data collection is simplified by querying a well-structured database. Moreover, it accelerates the data transmission from an individual facility to a state or national registry. The National Program of Cancer Registries' Modeling Electronic Reporting Project (NPCR-MERP) is an effort at the Centers for Disease Control and Prevention to enable cancer registries to obtain most cancer data electronically and to produce more complete, timely, and accurate cancer surveillance data.[22]

Electronic health records may not necessarily reduce the burden of data entry; however, they will largely facilitate data retrieval and analysis. For example, drug recalls in the past required nurses to manually review patient charts at one facility to find all patients who had the drug on their medication list. In the electronic health record environment, it would take a fraction of the time to query a database in order to identify these same patients.[23] Because EHR and personal health records systems are patient-centric and health-oriented, they make it easy to collect data that would be hard to collect from paper records. For example, the Behavioral Risk Factor Surveillance System (BRFSS) collects data from telephone surveys. If the BRFSS survey is implemented as data elements in an EHR or personal health records system, the data can be easily collected electronically. Ball and Gold[24] proposed a Health Record Bank model that provided patients the power to share their health data with researchers. This would expand the scope of health policy data collection from clinical care to health status.

Electronic Health Records as a Distribution Vehicle of Health Policy

The other implication of EHR for health policy is that health care providers can be informed of important policy by integrating health policy with EHR systems. The Institute of Medicine of the National Academies defined 8 core functions of EHRs in *Key Capabilities of An Electronic Health Record System: Letter Report:* (1) health information and data; (2) results management; (3) order entry/management; (4) decision support; (5) electronic communication and connectivity; (6) patient support; (7) administrative process; and (8) reporting and managing population health.[25] The functions of administrative process and reporting and of managing population health could be used as the leverage points for implementing health policy at the practitioner's level.

Improvements in health care, once verified, need to be disseminated quickly to individual practitioners to be effective, especially at the point of care. This could consist of reminders generated from guidelines related to preventive public health interventions. Many studies have demonstrated that relevant, integrated reminders in EHR could increase the level of compliance with accepted health care guidelines or policies. Alerts could include important information about disease outbreaks or important medication updates. When available, information could be extended to providers on applicable public health interventions, preventive medicine, or disease management.

In the event of a health event affecting a large population, a key activity of health policy is to notify practitioners and patients about available actions to prevent a disease or reduce its impact at the individual and the community levels. Electronic health records can facilitate such intervention in several ways. First, they can provide decision support that enables the implementation of a public health intervention directed to the patient at the point of care. Additionally, they can be a means to inform clinicians of health policy updates. Ultimately, they can provide necessary education to both practitioners and patients.

As mentioned above, EHRs also offer the opportunity to improve policy compliance by incorporating policies, or rules, into the EHR system. Because each EHR system should have decision support capability, transforming health policies—particularly those for disease prevention and management—to unambiguous knowledge representation modules will systematically standardize treatment of consumers at the point of care. For example, the use of reminders in an EHR system increased the number of mammograms, glycosylated hemoglobin tests, and varicella and influenza immunizations for persons with diabetes.[26]

Many barriers remain on the way to having a universal electronic health records system by year 2014—notably lack of initial financial support, misaligned incentives, and missing business models for sustainable health information exchange.[17,27] The US Department of Health and Human Services has recently started a 5-year project to encourage small and medium-size medical practices to adopt EHR systems by providing bonuses to participating practices that adopt certified electronic health records.[28] There is still a long way to go to before there is an EHR system that can store the entire health history of a patient and provide instant access to those who need the information. Until then, the benefit of electronic health records to health policy will not be fully realized. **NCMJ**

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COMMENTARY

Public Health Surveillance Data in North Carolina

Paul A. Buescher, PhD

Data from a variety of sources comprise the public health surveillance system for North Carolina today. The purposes of public health surveillance go far beyond collecting data. Effective public health surveillance ensures that the data are used by health policy makers, state and local public health agencies, and health program managers for effective public health planning, resource allocation, and program evaluation. Surveillance is a core public health function. A number of the 10 national essential public health services involve using data and include the following: monitor health status to identify community health problems; diagnose health problems and health hazards in the community; inform and educate people about health issues; evaluate the effectiveness, accessibility, and quality of personal and population-based health services; and conduct research for new insights and innovative solutions to health problems.

> *"Effective public health surveillance ensures that the data are used by health policy makers, state and local public health agencies, and health program managers…"*

The purpose of this article is to describe the major public health surveillance databases available in North Carolina and present some examples of how these data have been used for education, policy, planning, and evaluation. A number of these databases are housed in the State Center for Health Statistics (SCHS), which is located organizationally in the Chronic Disease and Injury Section of the North Carolina Division of Public Health. Until 1980, the SCHS was named the Public Health Statistics Branch and dealt mainly with vital records data such as births and deaths. It was renamed the State Center for Health Statistics, and its mandate was broadened to include responsibility for a wider range of databases. Even when the SCHS does not produce and house the data, it is responsible for accessing health data from a variety of sources and making it available for health policy and program planning. A number of these "outside" data sets are included in this inventory.

The State Center for Health Statistics consists of about 65 employees organized into the following 5 major work units: Statistical Services, Birth Defects Monitoring Program, Central Cancer Registry, Health and Spatial Analysis, and Operations/Quality Management. The State Center for Health Statistics serves the entire Division of Public Health and also some agencies in other areas of the North Carolina Department of Health and Human Services. In addition to providing data and technical support to health and human services programs, the SCHS produces a comprehensive set of health-related publications and answers thousands of requests for data from a variety of individuals from across the state and the nation. More information about the SCHS and its data products, publications, and services can be found at its Web site at http://www.schs.state.nc.us/SCHS.

The State Center for Health Statistics has a Health Data Query System (http://www.schs.state.nc.us/SCHS/data/query.html) that allows the user to generate custom designed, detailed data reports for deaths, births, birth defects, pregnancies, and population data. In addition, public use data files with individual birth, death, fetal death, and matched birth/infant records for the years 1968-2006 (with complete data file documentation) can be downloaded from the Odum Institute for Research in Social Science Web site (http://www.irss.unc.edu/odum/jsp/content_node.jsp?nodeid=10).

This article is not intended to provide a comprehensive inventory of health data available in North Carolina. We include databases that are (1) used extensively by public health programs for surveillance purposes; (2) statewide in coverage;

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and (3) regularly produced or updated as opposed to special or one-time data collection efforts. In general, we do not include health program databases that contain mainly patient and medical encounter information.

Some of the databases described here can be used only for statewide estimates (this includes most of the sample-based surveys) while many will support production of data at the county level. County-level data are used extensively for community health assessment and other local planning and evaluation efforts. (For information about the North Carolina Community Health Assessment Initiative, go to http://www.schs.state.nc.us/SCHS/about/chai.html.) Usually, data are tabulated by county of residence (regardless of the location of the event) so population-based rates can be produced. Even where the data represent a complete count of events (such as deaths), there may be substantial random error in rates based on small numbers of events. (See "Problems with Rates Based on Small Numbers" at http://www.schs.state.nc.us/SCHS/pdf/primer12.pdf.) Combining several years of data before producing rates or aggregating counties will stabilize the rates by reducing random variability due to small numbers.

MORTALITY DATA

Death Certificate Data

Vital records have been core data for public health surveillance since complete registration began for North Carolina in about 1918. North Carolina law requires that a death certificate be filed for each death that occurs in North Carolina. In addition, there is an interstate vital records exchange agreement where we receive death certificates for all North Carolina residents who died in other states. We combine these data to produce complete mortality data by county of residence. For most chronic diseases and for injuries, we do not have comprehensive morbidity data so death rates are often used to portray rates of chronic disease and injury in the state. *The Leading Causes of Death* publication of the SCHS shows numbers of deaths, unadjusted death rates, and age-adjusted death rates for 20 causes of death by county of residence.[1] For details about the rationale for and calculation of age-adjusted death rates, visit http://www.schs.state.nc.us/SCHS/pdf/primer13.pdf.

Medical Examiner Data

The Office of the Chief Medical Examiner (OCME) investigates all deaths due to injury and violence, those from suspicious or undetermined causes, and deaths not attended by a physician. The OCME collects additional information that is not available from the death certificate data system including alcohol and other toxicology test results and more detailed information on gun type for deaths involving firearms. Approximately 9000 of the 75 000 deaths in North Carolina each year are investigated by medical examiners. Limited medical examiner data can be found on the SCHS web site at http://www.schs.state.nc.us/SCHS/data/medexam. For additional information or further data, contact the OCME at (919) 966-2253.

North Carolina Violent Death Reporting System

The North Carolina Violent Death Reporting System (NC-VDRS) began collecting data in January 2004. The NC-VDRS provides detailed statistics about victims and suspects involved in incidents where intentional violence resulted in death (ie, homicide, suicide, legal intervention). Data also are collected for unintentional firearm deaths and deaths with undetermined manner/intent. The NC-VDRS uses information from multiple data sources (eg, death certificates, law enforcement records, medical examiner reports) to provide a description of circumstances, demographics, relationships between victims and suspects, and weapons. Provisional counts and selected data from the NC-VDRS are typically available within 8 months of the calendar year in which the deaths occurred, and complete data are available within 18 months.

The National Violent Death Reporting System (NVDRS) Web site at http://www.cdc.gov/ncipc/profiles/nvdrs/default.htm provides information about the system, its goals, the data it collects, the states that are funded, and how to access NVDRS data. Requests for North Carolina data can be made to the North Carolina Injury and Violence Prevention Branch at (919) 707-5432.

BIRTH-RELATED DATA

Birth Certificate Data

North Carolina law requires that a certificate be filed for each live birth that occurs in North Carolina. In addition, there is an interstate vital records exchange agreement where we receive birth certificates for North Carolina residents who deliver in other states. We combine these data to produce complete natality data by county of residence. In addition to live births, data are collected for each fetal death (stillbirth) of 20 or more week's gestation. *The Basic Automated Birth Yearbook (BABY Book)*,[1] an annual publication of the SCHS, shows live birth numbers for the state and each county tabulated by a number of characteristics captured on the birth certificate: mother's age, mother's race, mother's education, smoking during pregnancy, month prenatal care began, number of prenatal care visits, birth weight, birth order, and medical conditions of the mother. The State Center for Health Statistics also annually publishes *North Carolina Vital Statistics, Volume 1*,[1] which contains selected live birth and fetal death measures for the state and each county. North Carolina live birth and fetal death data are submitted to the National Center for Health Statistics as part of the national vital statistics system.

Reported Pregnancies

The State Center for Health Statistics combines data on live births, spontaneous fetal deaths, and induced abortions to produce statistics on reported pregnancies in North Carolina.[1] In 2006 there were 127 646 live births, 868 fetal deaths, and 29 430 induced abortions reported for North Carolina residents. Fetal deaths in North Carolina are reportable to the state only if they are 20 weeks or more in gestation, so our pregnancy statistics do not include spontaneous fetal deaths of less than 20 weeks gestation (ie, early stillbirths or miscarriages).

Birth Defects Data

The North Carolina Birth Defects Monitoring Program (BDMP)[2] was formally established by the North Carolina General Assembly in 1995. The BDMP gathers data on infants who are born with serious congenital anomalies (birth defects) diagnosed within the first year of life (approximately 4000-5000 infants per year). Data are collected by trained field staff who systematically review and abstract hospital medical records, supplemented by information from administrative health databases such as hospital discharge data, vital records, and other sources. This intensive method of case ascertainment provides the most complete, accurate, and timely data on the incidence of birth defects thereby enhancing its usefulness to public health programs. The program maintains a central registry with patient-identifying information which is considered confidential under state law.

HOSPITAL-RELATED DATA

Inpatient Hospital Discharge Data

Selected data are collected for each of the more than 1 million inpatient hospital discharges occurring each year in North Carolina. This database is owned by Thomson Healthcare, Inc, and the data are made available to the North Carolina Division of Public Health through a special legislative provision. The State Center for Health Statistics can provide these data to agencies in state government and county public health departments for purposes of improving public health. The State Center for Health Statistics has North Carolina hospital discharge data files for calendar years 1995-2005. Data items collected include age and gender of patient, dates of service, expected source of payment, county of residence, admission source, discharge status, principal and additional diagnoses, E codes, principal and additional procedures, and total billed charges. The Healthcare Cost and Utilization Project (HCUP)[3] of the federal Agency for Healthcare Research and Quality provides national and state-specific data and reports including hospital discharge data for North Carolina. The HCUPnet section provides free or low-cost national, regional, and state-level inpatient hospital statistics.[4]

Ambulatory Surgery Data

The North Carolina Hospital Based and Freestanding Ambulatory Surgery Facilities database contains more than 1.5 million records per year for surgeries performed in an outpatient setting. Approximately 155 facilities in North Carolina are reporting information into this database. The State Center for Health Statistics has recently started receiving quarterly updates of the North Carolina ambulatory surgery data from Thomson Healthcare, Inc, under the same arrangements as for the hospital discharge data. The State Center for Health Statistics can provide these ambulatory surgery data to agencies in state government and county public health departments for purposes of improving public health. Data items received by the SCHS include age and gender of patient, dates of service, expected source of payment, county of residence, principal diagnosis, principal and additional procedures, total billed charges, and detailed charges.

Emergency Room Data

North Carolina is the first state in the nation to establish a comprehensive system for electronic reporting of data by hospital emergency departments. Nearly all hospitals in the state with 24 hours a day 7 days a week emergency departments are reporting into the system and the goal is to have all hospitals reporting in the near future. One use of these data is for the North Carolina Disease Event Tracking and Epidemiologic Collection Tool (NC DETECT) system.[5] NC DETECT currently monitors real-time emergency department data and categorizes visits into syndromes in order to detect unexpected cases and outbreaks earlier in their course than traditional disease-based surveillance would allow.

Since data are collected for all types of visits, emergency department use for chronic disease, injury, or any other health condition can also be monitored. Selected North Carolina emergency department data may be accessed at the North Carolina Emergency Department Database Web site at http://www.ncedd.org.

The State Center for Health Statistics has recently started receiving quarterly updates of the North Carolina emergency department data from Thomson Healthcare, Inc, under the same arrangements as for the hospital discharge data. These data files are comprised of records for more than 3 million emergency room visits per year. Emergency room visits that result in an inpatient hospital admission are not included in the data files received by the SCHS since these visits can be counted from the inpatient hospital discharge data. The State Center for Health Statistics can provide these ER data to agencies in state government and county public health departments for purposes of improving public health. Data items received by the SCHS include age and gender of patient, dates of service, expected source of payment, county of residence, admission source, discharge status, principal diagnosis, principal procedure, and total billed charges.

POPULATION SURVEY DATA

Behavioral Risk Factor Surveillance System

The Behavioral Risk Factor Surveillance System (BRFSS) is a random telephone health survey of adults conducted in every state. It is sponsored by the Centers for Disease Control and Prevention (CDC).[6] In North Carolina, survey estimates are available for the state, major regions, and about 25 single counties. The annual sample size is more than 15 000 adult respondents. The BRFSS[7] collects data on many topics including perceived health status, health insurance coverage, physical activity, asthma, arthritis, smoking, disability, diabetes, overweight/obesity, and cancer screening. The BRFSS survey is revised each year and it includes so-called "core" questions from the CDC which are uniform across all states plus questions specific for North Carolina.

Child Health Assessment and Monitoring Program

The Child Health Assessment and Monitoring Program (CHAMP)[8] is a North Carolina health survey of children ages 0 to 17 years. Data collection for CHAMP began in January 2005. Adult respondents to the BRFSS survey with children living in their households are invited to participate in the CHAMP survey. One child is randomly selected from the household, and the adult most knowledgeable about the health of the selected child is interviewed in a follow-up survey. The CHAMP survey is revised each year to meet the child health surveillance needs of North Carolina. It is a state-level survey with more than 3000 annual respondents and does not provide county-specific information. Data topics include health care access, asthma, mental health, disability, nutrition, physical activity, overweight, tobacco, child safety, and injury.

Pregnancy Risk Assessment Monitoring System

The North Carolina Pregnancy Risk Assessment Monitoring System (PRAMS)[9] is a survey of women who have recently had a baby. The survey is sponsored by the CDC[10] and is currently conducted in 35 states. Birth certificates are selected at random and then a health survey is mailed to the mother; for those who do not respond by mail, attempts are made to complete the survey via telephone. Approximately 1500 PRAMS surveys are completed each year in North Carolina usually between 3 and 5 months after birth. Statewide data for 1997-2005 are available as well as some multiyear regional data. The PRAMS sample size is not large enough to produce county-level estimates. While the major purpose of PRAMS is to collect information about risk factors for poor birth outcomes (information not available on the birth certificate), there also are some topics pertaining to women's health and chronic disease before, during, and after pregnancy.

Youth Risk Behavior Survey

In the spring of every odd numbered year, the North Carolina Healthy Schools project conducts a statewide Youth Risk Behavior Survey (YRBS)[11] among middle school and high school students in North Carolina. The North Carolina YRBS helps assess behaviors in youth that impact their health now and in the future. Topics include violence, personal safety, physical activity, nutrition, mental health, tobacco, drugs and alcohol, and sexual behavior (for high school students only). Estimates are produced for the state as a whole and for major regions of the state. There is also a separate YRBS for the Charlotte area. The YRBS is funded by the CDC and North Carolina data are included as part of a national surveillance system.[12]

Youth Tobacco Survey

The North Carolina Youth Tobacco Survey (YTS)[13] provides an important source of public health data for understanding the scope of the tobacco problem and measuring progress toward overall goals among youth. The 2005 North Carolina YTS is a comprehensive statewide representative sample of more than 6000 middle and high school students. Every other year a core set of CDC[14] tobacco-related questions are asked. In addition, North Carolina adds state-specific questions. In 2005 the North Carolina Tobacco Prevention and Control Branch together with the NC Health and Wellness Trust Fund added questions regarding media, community participation, and secondhand smoke attitudes. The sampling design now generates large enough numbers to produce reliable regional estimates (Mountains, Piedmont, and Coast). North Carolina submits data to the CDC as part of the national YTS sample.

OTHER STATEWIDE SURVEILLANCE SYSTEMS

Newborn Hearing Screening Surveillance System

A Web-based tracking and surveillance database called WCSWeb was developed collaboratively by the Early Hearing Detection and Intervention Program,[15] the Sickle Cell Program, and the State Laboratory of Public Health. It contains data on all infants born in North Carolina since January 1, 2004 and on all infants born in North Carolina with suspected hearing loss since newborn hearing screening was mandated in 2000. Patient information is obtained by either direct data entry by hospital, clinical, or public health staff or transfer of newborn screening data from the State Laboratory of Public Health Laboratory Information Management System (LIMS). With the implementation of WCSWeb, the Early Hearing Detection and Intervention Program is able to provide statistical information on the effectiveness of birthing facility newborn hearing screening programs. In 2006 97% of nearly 130 000 babies in North Carolina who were eligible for newborn screening services received a screening which was reported into WCSWeb. Of these babies screened at birth, 4099 or 3.2% needed further follow-up. Of these 4099 babies, 430 had diagnostic evaluation results reported into WCSWeb and 202 were confirmed with a hearing loss. Regional consultants of the Division of Public Health are making a concerted effort to educate hospitals and physicians on the importance of providing prompt rescreening for infants who do not pass the newborn hearing screening and on the use of WCSWeb to report follow-up results.

Cancer Incidence Data

The North Carolina Central Cancer Registry (CCR)[16] collects data on all new cases of cancer in North Carolina. The data are collected primarily from tumor registries in the larger facilities that submit data electronically and by CCR field staff who abstract cancer case data in smaller facilities. In addition to demographic and diagnostic information, data are collected about the first course of cancer treatment. This is one of the few complete morbidity reporting systems for chronic disease in North Carolina. North Carolina participates in the National Program of Cancer Registries[17] and submits data regularly to the CDC as part of the national cancer incidence database. For more information about the CCR, see the article in this issue by Karen Knight.

North Carolina Nutrition and Physical Activity Surveillance System

The North Carolina Nutrition and Physical Activity Surveillance System (NC-NPASS)[18] provides indicators of body mass index status among children such as overweight, underweight, and healthy weight for each county in North Carolina and for the state as a whole. In the future NC-NPASS will monitor trends in key nutrition and physical activity behaviors such as soft drink consumption, fruit and vegetable consumption, levels of physical activity, and television viewing. The NC Nutrition and Physical Activity Surveillance System may not be representative of the population as a whole since it is comprised primarily of data about low-income children seen in the North Carolina public health-sponsored Women, Infants, and Children (WIC) program, child health clinics, and some school-based health centers. The information on older children (who are not eligible for WIC) is especially underrepresented since it comes from a very select population who receive health care from public health clinics. Information on weight status is available only for children ages 2-18 whose height and weight were measured during a health care visit.

Pregnancy Nutrition Surveillance System

The North Carolina Pregnancy Nutrition Surveillance System (PNSS)[19] monitors the prevalence of nutrition problems and behavioral risk factors among women who are enrolled in public health programs. The NC Pregnancy Nutrition Surveillance System links data from the WIC program and public maternity clinics with birth certificates and fetal death records. The system collects prenatal and postpartum information about these women and outcome information about their infants. The majority of the women in the North Carolina PNSS participate in WIC during either the prenatal or postpartum period. The Centers for Disease Control and Prevention collects and analyzes data from the states for the national PNSS.[20]

Pediatric Nutrition Surveillance System

The Pediatric Nutrition Surveillance System (PedNSS)[19] is a child-based public health surveillance system that monitors the nutritional status of low-income children in WIC and other federally funded maternal and child health programs. Data on birth weight, short stature, underweight, overweight, anemia, and breastfeeding are collected for children ages 0-18 who visit public health clinics for routine care and nutrition services including education and supplemental food. Data are collected at the clinic level and then aggregated at the county and state levels. North Carolina data are sent to the CDC for incorporation into the national PedNSS data.[20]

Communicable Disease Data

HIV and other communicable sexually transmitted diseases (STDs) pose public health risks and thus are made reportable to public health authorities in North Carolina. Most often the cases are reported by physicians to local health departments (as required by law) which then forward the reports to the Epidemiology Section of the North Carolina Division of Public Health. Medical facilities may also report cases, usually through the infection control staff. Persons making these reports are immune from liability for doing so. Laboratory reports are sent to the Epidemiology Section and act as a trigger for investigation and reporting of cases not already in the system. The data on reported cases are used to identify risks and vulnerable populations and to design control measures to limit the spread of these diseases through the HIV/STD Prevention and Care Branch.[21] State- and county-level data are available through the General Communicable Disease Control Branch.[22] De-identified North Carolina data are submitted to the CDC as part of the national communicable disease and HIV/STD surveillance systems. North Carolina is developing a comprehensive electronic disease reporting system called the North Carolina Electronic Disease Surveillance System (NC EDSS) that will replace paper-based reporting of communicable and other diseases between local health departments and the Division of Public Health. Initial deployment of the NC EDSS started in 2007 for tuberculosis, and other diseases are being added.

OTHER HEALTH-RELATED DATA

Medicaid Data

Medicaid is a medical insurance program for low-income North Carolinians. Since the 1980s the State Center for Health Statistics has had a cooperative relationship with the Division of Medical Assistance[23,24] (the state Medicaid agency) that involves sharing data for planning and evaluating public health programs. The North Carolina Medicaid Management Information System captures data on all payments for medical services for adults and children enrolled in Medicaid. This is one of the few data systems available to the North Carolina Division of Public Health that contains information on the complete range of medical services provided to a defined population: inpatient, outpatient, emergency room, physician, dental, home health, nursing home, prescription drug, and hospice services. There is also an enrollment file with information on the characteristics of the Medicaid enrollees. The State Center for Health Statistics strictly protects the confidentiality of these data and produces only aggregate data reports unless specifically authorized in writing by the Division of Medical Assistance to release individual-level data. The State Center for Health Statistics has a limited capacity to meet special Medicaid data needs of programs outside the North Carolina Division of Public Health.

Health Workforce Data

The North Carolina Health Professions Data System[25] of the Cecil G. Sheps Center for Health Services Research has detailed county-level health workforce data including physicians by specialty, dentists, nurses, and many other health provider types. The data system also presents state and county health manpower profiles and will accept special data requests. (See http://www.shepscenter.unc.edu/hp.)

Population Data

Population data[26] are not strictly health data, but population counts are important for assessing caseloads or persons at risk when planning for provision of health services. And population data are used extensively as denominators of health-related rates. The NC State Demographics unit produces population estimates and projections with age, race (White and minority), and gender detail for North Carolina and its 100 counties. In addition, the SCHS publishes reports showing annual state demographer population estimates by county, age, race, and gender.[27] Population estimates from the State Demographics unit also are provided through the SCHS Health Data Query System, which also includes more detailed race and ethnicity breakouts.

LINKING DATA

Linking the records in different data sets can increase the utility of the separate components. After linking, the variables of both data sets become available for joint analysis and cross tabulation. For example, each year the SCHS creates a composite linked birth file[28] which consists of the birth certificate records linked to several health program data files: Medicaid babies, Medicaid mothers, maternity care coordination, Medicaid costs, prenatal WIC, health department prenatal care, and child service coordination. This allows for the tabulation of birth certificate measures by participation in these health service programs.

The State Center for Health Statistics annually links all infant death certificates to the corresponding birth records. This matched file[29] allows analysis of infant mortality by characteristics that are available only on the birth certificate such as birth weight, mother's age, mother's education, mother's self-reported race, smoking during pregnancy, and prenatal care participation.

The State Center for Health Statistics has recently linked the NC-NPASS data described above for adolescents ages 12-18 to the Medicaid paid claims and enrollment data to analyze health care utilization and expenditures by body mass index categories.[30] The Medicaid data alone do not capture any information on body mass index. It was found that adolescents who are overweight and at risk for overweight have higher Medicaid expenditures and that overweight adolescents had a significantly higher incidence of diabetes, asthma, and other respiratory conditions.

USING DATA FOR EDUCATION, POLICY, PLANNING, AND EVALUATION

These public health surveillance data are used extensively for education, policy, planning, and evaluation. A few selected examples include the use of PRAMS data to develop a statewide public education and awareness campaign to reduce the risk of Sudden Infant Death Syndrome (SIDS); the use of Medicaid data, live birth data, and PRAMS data as part of a North Carolina Medicaid Program and Division of Public Health application to the federal Centers for Medicare and Medicaid Services (CMS) to obtain a family planning waiver to extend Medicaid eligibility for family planning and sexually transmitted disease services for men and women up to 185% of the federal poverty level; use of birth defects data to help target and evaluate programs to reduce certain birth defects through the intake of folic acid; and the use of BRFSS survey data by several community-based organizations and health departments to apply for grants, guide intervention strategies, and support policy changes for their initiatives. Data are of little value unless they are used, and use of data in turn provides incentives to increase the quality of the databases. North Carolina is fortunate to have such a wealth of state and local data sources. Additional and ongoing data collection will continue to provide the state with valuable measures for determining appropriate policy interventions for improving the health of individuals and communities. **NCMJ**

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COMMENTARY

Geographic Information Systems and Health in North Carolina

Dianne Enright

A geographic information system (GIS) is a powerful tool in shaping North Carolina heath policy and research. A geographic information system is more than a mapping tool; it is defined as a database that is tied to locations in space. However, the true power of a GIS comes from the ability to view many types of data together and to query or ask questions of the data.

There are some challenges in using health data with GIS. First, you must be able to geocode the data or assign a location to it in some fashion. Sometimes this could be simply presenting data that are already aggregated at the city or county level such as rates for a particular cause of death. (See Figure 1.) However, patient- or provider-level data must become geo-enabled. This type of point-level data could be geocoded by either gathering data in the field with a global positioning system (GPS) or through address matching.

> *"…a valuable tool for emergency response, program evaluation, and health research. The geographic information system has proved to be an essential tool to help allocate limited public health resources."*

A global positioning system captures location coordinates that are easily imported into a GIS to display locations. A global positioning system provides very accurate data; however, time must be spent in the field traveling to each location to ascertain specific coordinates. Geocoding at the address level involves matching an address against source data such as a road network that is attributed with existing address ranges. The geographic information system interpolates the position along the road where the address falls and captures the coordinates to display location. Numerous problems can occur with address matching. Mistakes can be made when the address is entered into a data system. In addition, problems can occur with the interpolation, or the source data that the address is compared to could have mistakes. Sometimes a person's current address is newer than the source data's creation date, or the address given simply does not exist and therefore cannot be located. Also, collection of patient data is often done for billing purposes. Many patients report a post office box for mailing purposes, thus the patient's physical residence is not locatable.

The State Center for Health Statistics (SCHS) has been using GIS since 1989 to assist health programs with evaluations, to establish or modify health policy, and to facilitate research. A simple choropleth (shaded) map can provide valuable information obtained by visualizing where in space a health event or problem is occurring. A choropleth, or thematic map, is based on statistical data that have been aggregated to an aereal unit. The maps are then shaded using different degrees of the same color, traditionally displaying the highest values as the darkest shade. (See Figure 1.)

Geographic information system techniques are also used for more sophisticated public health analyses. For example, the SCHS uses the power of GIS to assist in making decisions for nutrition services programs. The Health & Spatial Analysis Unit of the SCHS has been working with the Women's & Children's Health Section (Nutrition Services Branch, North Carolina Division of Public Health) to support decisions about the Child and Adult Care Food Program. The program funds meal reimbursements to family day care homes. The reimbursement for meals served in day care homes is based upon eligibility for tier I

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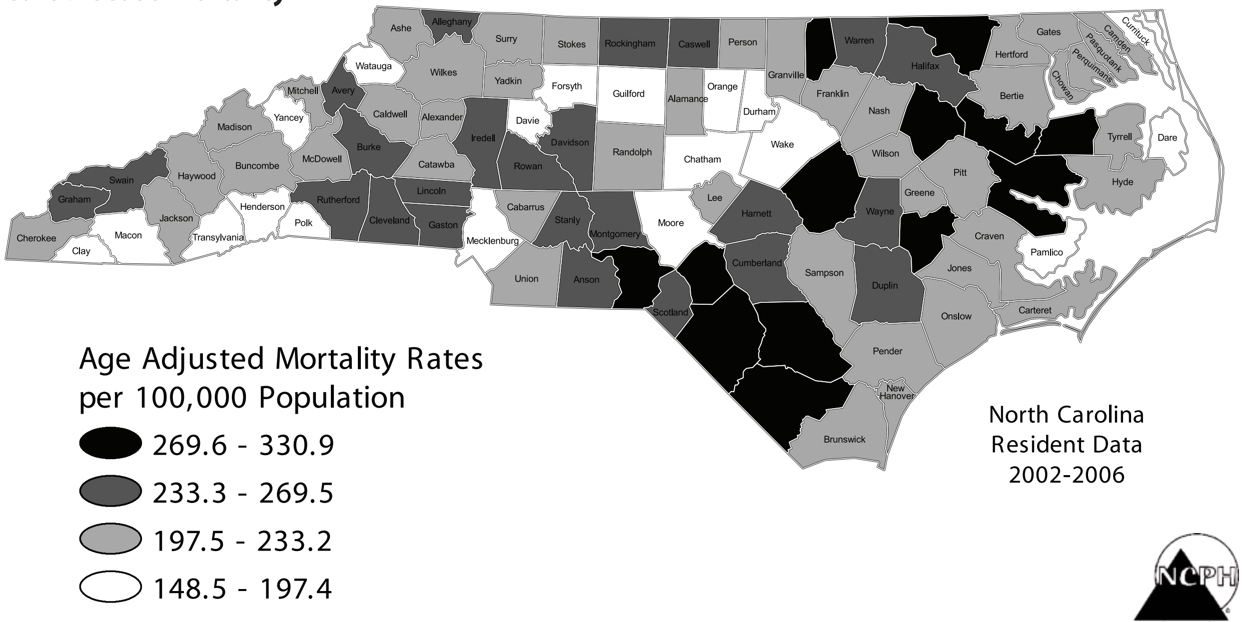
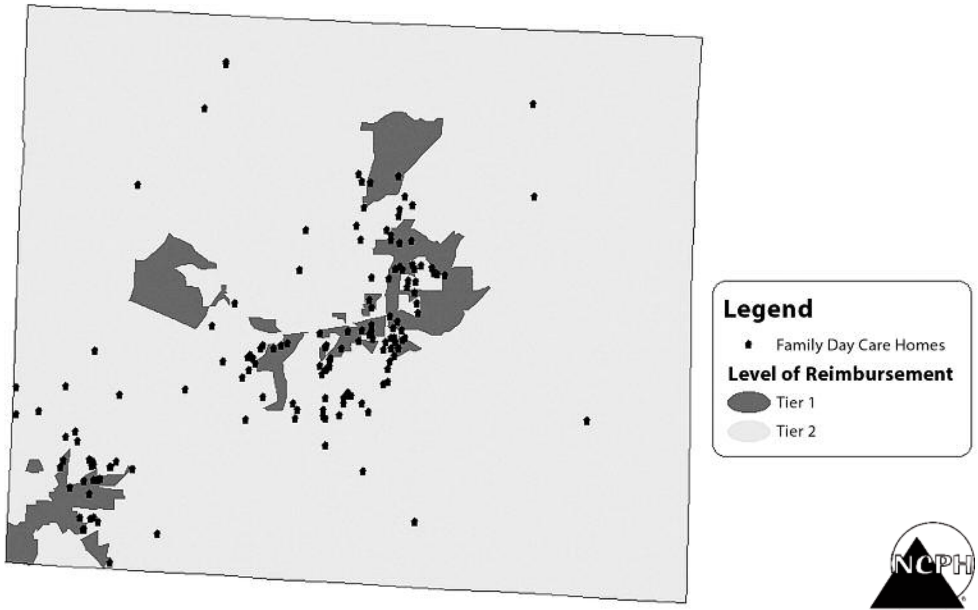
Figure 1.
Heart Disease Mortality



SOURCE: NC State Center for Health Statistics

Figure 2.
Family Daycare Home Reimbursements



SOURCE: NC State Center for Health Statistics

rates (which targets higher levels of reimbursement to low-income areas, providers, or children) or lower tier II rates.[a] After the Nutrition Services Branch approves an application, the family day care homes are located using GIS and then overlaid on a special run of census data. The census data show the percentage of children in poverty to determine the amount of reimbursement the family day care home may receive. (See Figure 2.) Using a different population age, the same type of analysis is applied to the Summer Adult Food Program. These analyses help target where limited funding dollars are truly needed.

Another ongoing project the North Carolina Division of Public Health has been working on for several years is syphilis elimination. New syphilis cases are geocoded and mapped on a quarterly basis in the 6 counties with the highest rates in the state. Each quarter is assigned a different color so the new cases identified throughout the year are easily traced. The staff of the HIV/STD Prevention & Care

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[a] Child & Adult Care Food Program. Food and Nutrition Service. United States Department of Agriculture Web site. http://www.fns.usda.gov/cnd/Care/CACFP/aboutcacfp.htm Accessed January 3, 2008.

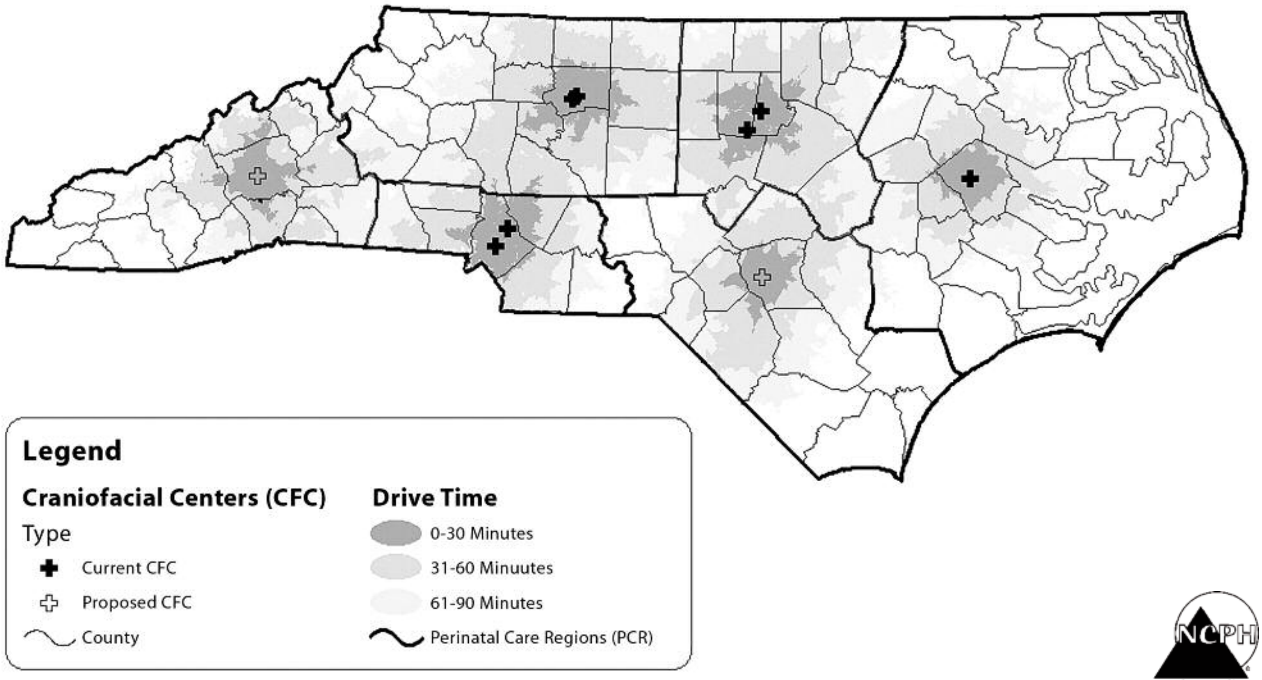
Branch (Epidemiology Section, North Carolina Division of Public Health) and local health departments use these maps to help reduce outbreaks. Again, by using a GIS to pinpoint where new syphilis cases occur, testing, education, and prevention methods are targeted directly to the neighborhoods where they are needed the most.

Geographic information systems are also becoming a widely used tool in emergency responses throughout the state. Many law officers and paramedics are equipped with GIS and GPS, which allows for real time vehicle routing for personnel to find locations quickly and for dispatchers to manage personnel and equipment. The North Carolina Office of Public Health Preparedness and Response (Epidemiology Section, North Carolina Division of Public Health) is also using this technology to better serve North Carolina residents. The North Carolina Office of Public Health Preparedness and Response is charged with responding to public health emergencies and has developed methods for gathering information from the field using GIS. It is vital to gather information very quickly in a public health emergency or following a natural disaster. Interviewers in the field are equipped with handheld computers that include a GPS. This equipment allows the staff in the field to navigate to interview locales as well as capture the coordinate location of where the interview occurs. Interviewers can use questionnaire forms on the handheld devices to gather required information from the population affected by the emergency or event. The information gathered is associated with the collected location coordinates. All of this information is then uploaded to a central database where it can be analyzed. Reports are shared with multiple authorities to assist in determining needs and allocating resources.

A geographic information system also was used in a recent study of the time spent traveling to health care providers for families with a child having an orofacial cleft. It is important for infants born with an orofacial cleft to receive coordinated treatment from craniofacial centers or teams in the first 2 years of life. For the study, residential addresses of children with orofacial clefts were mapped, and the craniofacial centers were located. Using "closest facility methodology" the most efficient route from the residence to the closest care provider was calculated. By using this analysis method the actual distance and time spent traveling to the closest craniofacial center was estimated (although patients may not always travel to the closest facility or care provider) which is more accurate than using a straight line distance. This analysis was performed again after 2 new proposed locations for craniofacial centers were included where there were previously none. The analysis demonstrated that the addition of 2 new centers would result in an average decrease in orofacial cleft patient travel time of 16 minutes. (See Figure 3.) A geographic information system is a useful tool for evaluating the role that travel distance may play as a potential barrier to accessing health care among children with orofacial cleft and/or other types of birth defects.

The North Carolina Division of Public Health uses GIS for a variety of projects and purposes. It is a valuable tool for emergency response, program evaluation, and health research. The geographic information system has proved to be an essential tool to help allocate limited public health resources. **NCMJ**

Figure 3.
Orofacial Clefts and Drive Time to Current and Proposed North Carolina Craniofacial Centers, 1995 - 2002



SOURCE: NC State Center for Health Statistics

North Carolina Public Health

COMMENTARY

NC-CATCH:

North Carolina Comprehensive Assessment for Tracking Community Health

James Studnicki, ScD; John W. Fisher, PhD; Christopher N. Eichelberger, MS

Although the United States invests more resources than any other nation in the world for health, we are far from the healthiest country. In fact, the US languishes in the lower half of industrialized nations for a range of indicators used to measure health status and even trails nations considered to be economically underdeveloped for selected health indicators.[1] Accompanying this disappointing level of overall health status are the enormous disparities in the health of groups defined by race, ethnicity, socioeconomic status, and geography.[2] Despite decades of scrutiny by researchers and health policy analysts and numerous reports and white papers on the subject by prestigious and influential organizations such as the Institute of Medicine (IOM) of the National Academies, these vast differences are pervasive and seemingly intractable.[3,4]

For example, poor White females in Mississippi and in Appalachia experienced declines in life expectancy between 1982 and 2001.[5] Similarly, in North Carolina between 1975 and 2005, despite reductions in absolute rates, Black infant mortality steadily increased from 1.8 to 2.3 times the White rate.

The Measurement Mandate

While the problem of variation in community health status is complicated and has many underlying causes (known and unknown), there is nearly universal agreement that if we are to have any hope of improving it there must be a monitoring system to measure and benchmark community health status in a systematic way. There have been frequent attempts to provide a framework for community health status monitoring systems. The Planned Approach to Community Health (PATCH) developed in 1985 by the Centers for Disease Control and Prevention (CDC) sought to determine root causes and key intervention points for a few selected health issues.[6] In 1991 the American Public Health Association developed the Healthy People 2000 (and later 2010) protocol for addressing a series of defined national objectives.[7] At about this time, the IOM of the National Academies proposed a model for community health improvement that involved an iterative process that cycled through assessment, evaluation, and action phases. The IOM of the National Academies proposed a set of 25 indicators which expanded on the 18 recommended by the original Healthy People 2000 objectives.[8] The National Association of County and City Health Officials and the CDC developed the Assessment Protocol for Excellence in Public Health (APEXPH) which focused on process indicators to determine the internal capacity of public health organizations, and this protocol was later expanded to include other community health organizations.[9] There have been other community health assessment models developed by the hospital industry,[10] state and local government agencies, university research groups, and collaborations of multiple partners. Although these methods vary in their approach to assessment, they all share a common requirement: data. The data required to populate these various methodologies typically include existing secondary sources such as vital statistics (birth and death registration) and the extensive menu of secondary data from the surveys maintained by the National Center for Health Statistics (NCHS). Some of the methods also require

> *"Access to a wide range of data sources is a prerequisite to effective community health status assessment."*

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primary data collection efforts to provide a perspective on local populations or providers not available in existing secondary data sources.

From Data to Knowledge: The Challenge of Analytics

Access to a wide range of data sources is a prerequisite to effective community health status assessment. Bringing together data from multiple sources, linking and integrating them, and continually updating and maintaining them for useful analysis can be a daunting challenge to even the most capable and resourceful organization. For the typical local community organization, such a task is often beyond their financial and technical capabilities.

The potential of the Internet as a means to disseminate data for health assessment has been recognized, and there has been a rapid increase in the number of states which maintain at least some form of access to health data through the World Wide Web. Although only 10 states reported a Web-based query tool in 2000, by 2006 the number had grown to 27 states.[11] In most cases, the state systems are limited to a static interface which provides prestructured statistics such as death counts or rates organized into preformatted reports. In a few instances, the query menu itself is dynamic and enables the user to make a selection of data sets, statistics, tables, and maps. These systems, however, do not have the kind of multidimensional navigation and analytical capabilities that can be made available with modern online analytical processing software. Therefore, when viewed from the perspective of what is really state-of-the-art given the rapid advances in computational software and Web-enabled applications, currently existing systems demonstrate major limitations. These include unidimensional filtering queries; single grain data without real time "roll up" or "drill down" capability; data set "silos" which are unlinked and nonintegrated; inconsistent definitions across data sets; lack of metadata (ie, data about the data necessary to facilitate the understanding, use, and management of the system); and lack of an imbedded, organized framework for extracting decision support knowledge from the underlying data.

The Community Health Assessment Portal

North Carolina has been one of the most active states nationally in promoting community health status assessment, and counties are required to produce a formal report at least every 4 years. The State Center for Health Statistics maintains a number of databases useful to this process and works closely with Healthy Carolinians in performing assessments and mobilizing multisectored community action. With assistance from a health services research and technical development team from the University of North Carolina at Charlotte, the Division of Public Health (with additional funding from the Kate B. Reynolds Charitable Trust) initiated the development and deployment of a system that will address many of the weaknesses of current systems, thus bringing modern Web-enabled software technology to public health. To this end, the Division of Public Health decided to move beyond merely producing data to actually enhancing the capability to analyze the data more effectively.

The North Carolina Community Health Assessment Portal (NC CHAP) can best be understood as a means to bring the capabilities of business intelligence to public health surveillance, particularly community health assessment. The original innovators in this field used the word "business" in a broad sense as a collection of activities carried on for some purpose such as commerce, science, government, or public health. "Intelligence" is also defined in a general sense as the ability to "apprehend the interrelationships of presented facts in such a way as to guide actions toward a desired goal."[12] Modern business intelligence systems use data that has been gathered into a data warehouse or data mart and also occasionally use transactional or operating data. Using various types of software to support reporting, interactive pivot-table analyses, visualization, statistical data mining, and other technologies and applications, business intelligence systems provide historical, current, and predictive fact-level views of the enterprise in order to support better decision making.

NC-CATCH

As a business intelligence system, the Comprehensive Assessment for Tracking Community Health (NC-CATCH) has the following components:

Data Warehousing. Extant data organized into the data warehouse will include demographic/population data at the census track level (updated annually by a commercial firm); mortality data; birth data; pregnancy data; hospital discharge data; emergency department visit data; behavioral risk factor survey data (regional and county level only); cancer incidence and treatment data; and other miscellaneous social, economic, and health-related data available at least at the county level. The data will be geocoded to the census tract where possible. Access to the various levels of warehouse capability will be through a portal on the Web site of the State Center for Health Statistics.

Methodology. Health is a multidimensional concept, and there is no single perfect measure for summarizing the health status of a defined population. CATCH is a comparative framework that provides a consistent, objective, multidimensional method for organizing and interpreting community health data. Key elements of CATCH include multiple indicators organized into categories (eg, infectious disease, maternal and child); comparisons with peer counties; state values; Healthy People 2010 values and other benchmarking standards; trend analysis for the most recent 3-5 year time period; an objectively derived rank ordered list of community health challenges; and a concise assessment of racial/ethnic health status disparities.[13] The CATCH report, uniformly aggregated for each North Carolina county, will provide a comprehensive starting point from which the relative health challenges and achievements can be understood, and areas requiring further analyses can be identified. The CATCH report includes embedded hyperlinks into the appropriate queries that allow full investigation of the underlying data.

Prestructured Queries. Prestructured queries allow the user more flexibility to choose the variables and dimensions of interest, but the choices are necessarily limited. A user, for example, may want to view infant mortality by race or by county, or hospitalization rates for diabetes by county. Some of these views are precalculated and made available through the portal, but they too are static like the CATCH report. These types of queries are the typical method for supplying information in most states. Another type of query is more active in that the user can select from a few number of dimensions to provide a limited form of query customization. These systems are interactive only to the extent that the user is given a menu of queries to select from. Since the number of possible queries is limited only by available data, the challenge is to provide a menu of queries that satisfy the needs of most users or provide information about the most important problems. Structured queries, however, can never maximize the use of information since they cannot anticipate nor perform all the multidimensional data navigation and analysis necessary to model a complex system such as population health.

Online Analytical Processing. Online analytical processing is a category of software technology that enables users to gain insight into data through fast interactive access to a wide variety of possible views of information transformed from raw data. The NC CATCH user utilizing online analytical processing functionality will be able to calculate and model across dimensions, through hierarchies, and across members; slice subsets for onscreen viewing (eg, organize hospital discharge data by pay source); drill down to deeper levels of consolidation (eg, identify all census tracts with a certain percentage of population in poverty); reach through to underlying detail data (eg, compare infant mortality in different counties by the specific causes of infant death); or rotate to new dimensional comparisons in the viewing area (eg, move from Black/White comparisons to Hispanic/non-Hispanic comparisons of age-banded chronic disease mortality). Online analytical processing truly brings the power of the data warehouse to the user's desktop. Multidimensional analysis makes it easier to navigate the database, and because the data are physically stored in a multidimensional structure, the speed of these operations is faster and more consistent than is possible in other database structures.

A Brief Explanation of the Technical Approach

The principal challenge to presenting consolidated health data consists of identifying the appropriate levels at which to enforce data standards. Raw health data exist in many different forms and formats: plain text documents, images, printed tables, spreadsheets, and databases. Each of these forms is well suited for its particular audience.

Each of these levels is treated separately within the following sections and related to the left-hand side of Figure 1:

(1) The raw health data sources (the small cylinders at the bottom of the figure) were identified at the beginning of the project. Each was defined in terms of format, layout, and meaning. Staff used this information to build small software routines that load a given raw data source into a central database (the large cylinder in the figure). This transaction-level database is the first level of standardization in the project.

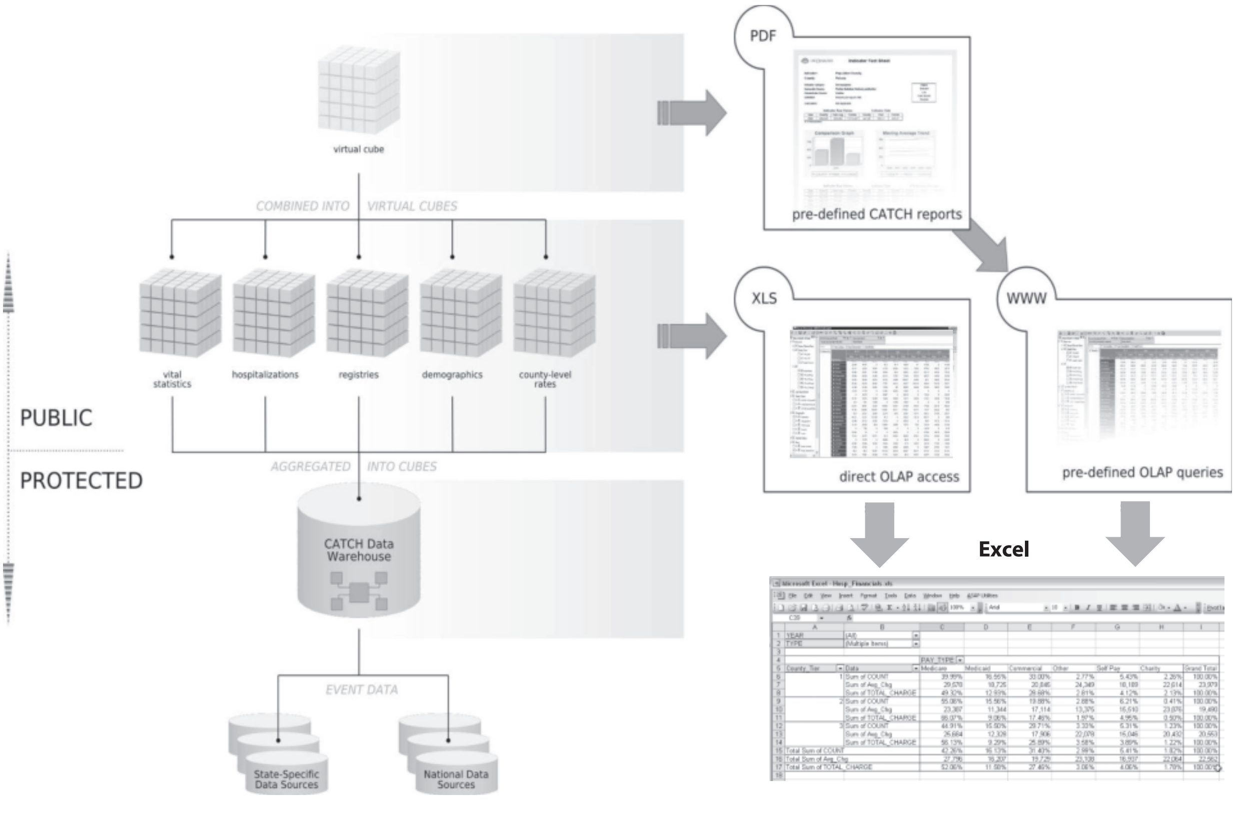
(2) Once the raw data have been loaded into the transaction-level database, a second set of standards is applied to bridge separate sources and construct a series of unified multidimensional data cubes. A data cube is merely a collection of data that has been preaggregated along a given set of dimensions so that every possible combination of dimension values can provide a set of output measures efficiently. In the figure, the data cubes are depicted as gridded boxes in which each small component corresponds to one intersection of dimensions. Typically, we interpret dimensions as X, Y, and Z, but in data cubes the dimensions are more likely to be time, age band, race, sex, cause of death, etc. Identifying the standards that allow for the bridges among data sets, as well as defining the common dimensions and measures that typify the logical cubes, is the second level of standardization in the project.

(3) The logical data cubes themselves can be recombined into virtual cubes (illustrated as translucent, gridded boxes at the top of the figure) providing glimpses into the data that were not previously available. For example, one logical cube is dedicated to the detailed demographics of North Carolina; another cube is dedicated to the deaths that have occurred over time. Combining these 2 cubes into a virtual cube allows us to explore not only the base demographics and the deaths, but rates and age-adjustments across all geographies, years, demographic splits, and causes of death. Identifying the meaningful combinations of logical cubes into virtual cubes is the third level of standardization in the project.

This project seeks to provide 3 levels of access targeted to meet the needs of 3 distinct user communities, differentiated by the trade-off between ease-of-use and analytical flexibility/complexity. These users are served with different views as shown in the right-hand side of Figure 1:

(1) The general public and many senior policy staff are likely interested in the predefined county profiles that are part of the CATCH report (available as a Web page). This use of the commonly used report format provides rapid access to the highest level of aggregation and comparative benchmarks. However, since the report is not a static document but actually contains active hyperlinks, it also

Figure 1.
North Carolina Health Assessment Portal Construction and Interface



provides immediate access to the more detailed underlying data.

(2) These data, of significant concern for county health departments, are accessed through a large set of predefined online analytical processing queries or exploratory reports using both the logical and virtual cubes. Once again, a report-style interface is employed to minimize the technical expertise required to quickly access the desired information. This simplified drill-down capability provides a powerful tool for investigating multidimensional relationships.

(3) At the high end of complexity and flexibility, researchers have access to the lowest level data in the free-form online analytical processing queries. The full range of dimensions is available in a drag-and-drop visual interface for creating ad hoc queries across the entire data warehouse.

Each of these levels serves a specific role in the reporting of health data, and each has an independently maintained set of standards for how data are allowed to participate. These metadata themselves constitute one of the most significant new capabilities of the project. **NCMJ**

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COMMENTARY

The Emerging Field of Informatics

Debbie Travers, PhD, RN; Larry Mandelkehr, MBA, CPHQ

The field of health care informatics brings together the various health sciences (eg, medicine, nursing, public health) and other relevant fields including information science, computer science, and cognitive science. The focus of this emerging field is to promote the effective organization, analysis, management, and use of information in health care in order to facilitate optimal health care delivery.[1,2] An important mission of the informatics field is to prepare practitioners to utilize health data for direct care as well as in support of optimal health services organization and delivery, public health surveillance and practice, and clinical research. In this article we describe how the field has developed and how clinicians and health care managers are being prepared to make the best use of data.

> *"As the health care informatics field has developed, there has been recognition of the need to prepare informatics experts in both the clinical and managerial ranks."*

Early applications of information technology in health care began in the 1960s with a focus on financial (eg, generating a bill) and clerical (eg, admission, discharge, and transfer transactions) systems. These systems typically ran on large mainframe computers and produced basic management reports but often lacked the flexibility to produce customized reports. They were organized around generating a bill for a health care encounter as opposed to providing a longitudinal view of patients' health. With the introduction of powerful personal computers and networking technologies in the 1980s came the development of more clinically-oriented computer systems for health care. These systems were also more robust in supporting administrative functions.[3] Early clinical applications included laboratory results reporting and order entry systems; administrative applications included human resources, materials management, and project management systems.

As the field of health care informatics continued to develop, more vendors entered the health care information technology (IT) environment. The health care IT companies offered an expanded array of products including computerized provider order entry, clinical documentation (eg, physician and nurse notes), and specialized systems for areas such as the emergency department, the pharmacy, and the operating room. More recently, the field has grown to include bioinformatics applications which have been developed to manage the large quantity of genomic and other basic scientific data.

During this time researchers began to study the impact of clinical IT systems on the health care delivery system and eventually on patient outcomes.[3] These studies identified best practices and systems for health care IT design, integration with clinical workflow, and implementation.[4] Outcome studies showed the greatest impact on patient outcomes from computerized provider order entry and clinical decision support tools embedded in the IT systems.[5-7] Currently there are many large health care IT initiatives aimed at improving patient outcomes and reducing errors through well-designed decision support applications. Examples of such applications include drug-drug incompatibility alerts to providers during electronic prescribing and the use of standardized order sets.

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How We Teach People How To Use Data

Formal Informatics Education

Many of the early pioneers in health care informatics came from various clinical and technical fields and learned informatics on the job. Formal degree-granting educational programs in health care informatics began in the 1970s with a variety of foci such as health administration, clinical sciences (eg, medicine, nursing, pharmacy), computer science, bioinformatics, and public health.

National organizations have begun to develop recommendations for health care informatics content in the curricula for various professions. This emphasis on preparing practitioners to address informatics is an outgrowth of recommendations by the Institute of Medicine of the National Academies' 2003 report *Health Professions Education: A Bridge to Quality*.[8] This report was issued partly in response to the Institute of Medicine's 2001 report, *Crossing the Quality Chasm*, which focused on safety and quality of care.[9] In the 2003 report, the IOM recommended 5 core competencies that all clinicians should possess in order to meet the needs of the 21st century health system. One of those 5 is to utilize informatics to "communicate, manage knowledge, mitigate error, and support decision making using information technology."[10] These recommendations have spawned many educational initiatives directed at health professionals including the American Medical Informatics Association (AMIA) 10x10 Program, the goal of which is to train 10 000 health professionals in basic informatics content by the year 2010.[11] Though AMIA is just beginning to delineate core informatics content for physicians, it has partnered with leading academic informatics programs to deliver the 10x10 continuing education programs and short courses in both clinical and bioinformatics. This initiative is using curricular content from existing informatics training programs, distance learning, and other innovative educational strategies to deliver quality education to busy working professionals. A sample of key content from some of the clinically-oriented 10x10 programs is shown in Table 1.

Several of the content areas address preparation of practitioners for utilizing health data effectively including evidence-based medicine, data mining of databases/data warehouses, information integration and knowledge management, and data standards.

The National Library of Medicine (NLM) of the National Institutes of Health began funding medical informatics research training programs in the 1990s and currently funds 20 university-based programs.[12] Their goal is to advance the scientific basis underpinning the informatics field by training researchers. Some of these programs provide tuition and even stipends to health professionals wishing to gain expertise in informatics research. North Carolina participated in a joint Duke University and University of North Carolina at Chapel Hill medical informatics training program in the 1990s, but the formal NLM-sponsored program was discontinued in the early 2000s. Both universities continue to offer various types of education in health care informatics.

Informatics Competencies and Certifications

There are national recommendations for informatics competencies and certifications for many professions including nursing and health management. There is currently an effort to develop similar structures for physicians. The American Medical Informatics Association has received a grant from the Robert Wood Johnson Foundation to establish a subspecialty of applied clinical informatics in medicine which will include a certification process for physicians.[13]

The National Center for Healthcare Leadership has established a set of competencies for graduates of health care management programs.[14] Competencies that are relevant to informatics include data analysis, manipulation, understanding, and ability to explain data.

Specific informatics competencies for nurses are also being developed based on recommendations from the Institute of Medicine of the National Academies.[15] The competencies include skills, knowledge, and attitudes that are clinically-oriented as well as some that emphasize use of data for supporting safe processes of care and metrics for monitoring health outcomes. Nurses can achieve certification in the specialty of Nursing Informatics through successful completion of an examination.[16] Table 2 includes the key content included in this Informatics Nurse certification offered by the American Nurses Credentialing Center.

Table 1.
Informatics Content From Various American Medical Informatics Association 10x10 Programs[11]

Discipline overview, history
Evidence-based medicine
Role of information and technology in improving health care efficiency and quality
Databases, data warehouses, and data mining
Data standards
Decision support
Privacy, confidentiality, and data security
Information integration and knowledge management
Networking and telemedicine
Information system planning and project management
Clinical and administrative information systems
Electronic health records
Computerized provider order entry
Consumer health informatics

Table 2.
Informatics Content For Nursing Informatics Certification

Systems life cycle Systems planning, analysis, and selection
Systems design
Systems implementation and testing
Systems evaluation, maintenance, and support
Human factors (eg, usability)
Hardware, software, and networks
Data standards
Security
Data aggregation, warehousing, and mining
Knowledge generation (outcome probabilities, expert and rule-based systems)
Professional practice, trends, and issues
Models and theories (eg, change theory)

Content areas such as data standards, data aggregation/ warehousing/mining, and knowledge generation address preparation of practitioners for utilizing health data effectively.

Examples of How Data Usage Can Be Taught in Clinical Settings

Increasing the use of data in decision making and driving improvement in busy health care organizations is a challenge on many fronts. Patients are sicker, staff shortages exist in key markets such as nursing and pharmacy, and new regulatory requirements and technology seem to appear at every turn. Incorporating data in applications such as statistical process control via the use of control charts to identify outlier events is a useful strategy but needs to be easily incorporated into the busy clinical environment. Educating clinical leaders, including nursing managers and physicians, to create statistically correct control charts with a spreadsheet is not feasible due to the complexity of the analysis and the different computer skill levels of the managers. Purchasing specialized computer software is expensive and the software often has a long learning curve.

The preferred alternative approach is to simplify the process such that each manager only needs to enter data into a spreadsheet and click a few buttons to create the control chart. The primary educational focus is the use of customized spreadsheet menus which create the charts as well as interpret graphs and develop action plans to improve patient care and operations. The education process focuses on the mechanics of chart creation and then shifts to problem solving and root cause analysis techniques to address the identified issues.

Key elements of the informatics curriculum for public health and health care professions include data definitions, data management tools, data quality, and system selection. The following sections describe these topics in detail.

How Data Are Collected and Managed

Identification of Common Data Definitions Is Essential

It is very common for different individuals or departments to have different definitions of the same data element. Unless everyone is using the same set of data definitions from the beginning, there will likely be errors in data collection, analysis, and conclusions. For example, does the hospital admission date and time occur when the patient arrives at the emergency department or when they are admitted to an inpatient bed? Is the infection rate based on all patient days or only the days on which the patient has a catheter placed? Are children's ages stored in the database in months or years? Are names entered as "John Doe" or "Doe, John?" A lack of planning and agreement on basic information in any of these examples will result in confusion, rework, and lack of useful data.

In addition to agreement on the definition of each data element, the following aspects should be considered and documented:

- *Data elements*. Sufficient data are needed to avoid ambiguity in names. Admission date and inpatient admission date should be distinquished.
- *Description*. Brief but clear descriptions of complaint/ treatment should be understandable by the nonexpert.
- *Numerator and denominator definitions for rates.*
- *Data storage format*. For example, options may include text, number, yes/no.
- *Units of measure*. For example, body temperature may be recorded in Celsius or Fahrenheit.
- *Default value*. To speed data entry time the most common. value for a data element might automatically appear.
- *Is the data element required?*

Tools for Managing Clinical Data

Desktop computers contain a variety of powerful desk tools for data management and analysis. Selecting the best tool or tools for each situation is a key element of the education program. Three common data management and analysis tools available to public health and health care students and professionals are spreadsheets (eg, Microsoft Excel), databases (eg, Microsoft Access), and statistical applications (eg, STATA, SAS).

Spreadsheets are the analytical computer programs with which most people are familiar. They are the easiest to learn and provide both data management and statistical tools and typically have a wide range of capabilities that enable them to be used in lieu of more complicated computer programs. Spreadsheets are relatively intuitive to use and learn, excel in graphically displaying data, provide a variety of statistical functions, and can support up to millions of data values. On the downside, spreadsheets lack strong data validation tools which can lead to data quality issues when entering large amounts of data. The standard spreadsheet data format (2-dimensional table) is easy to create but is inefficient for complex data sets and often results in data redundancy. This redundancy wastes data entry time, increases file size unnecessarily, and creates more opportunities for data entry errors. Finally, spreadsheets can only be updated by one person at a time.

Database programs are less intuitive to learn and use. When properly designed, however, databases can provide very efficient data storage for complex data sets and eliminate the data redundancy inherent in spreadsheets. Databases also provide strong validation and entry tools that facilitate data entry and improve data quality. Database programs allow multiple users to add and update data simultaneously—a key feature for large scale data collection and sharing via a central data repository. Reports can be designed to quickly generate weekly or monthly reports without needing to cut and paste data as when using a spreadsheet. On the downside, databases tend to have fewer tools for statistical analysis or graphing capability as compared to spreadsheets.

Specialized statistical programs provide for extensive analyses of large data sets using a wide range of statistical functions. They provide graphing capability but typically not to the extent of spreadsheets. These statistical programs are the tools of choice when performing analyses for publication which are beyond the basic regression and t-test functions available in spreadsheets. However, these programs do not support the strong data validation, management, and reporting functions common to databases.

A key educational focus emphasizes the strengths and weaknesses of each tool and how to quickly move data between them in order to utilize the benefits of each application without being limited by a program's weaknesses. A typical example of using the programs together might be to use the database for data entry and validation, the statistical program for detailed statistical analysis, and the spreadsheet for graphing the results.

The Importance of Data Quality

No matter how well a spreadsheet or database is designed, it will not be able to serve its purpose if the data it contains are inaccurate or incomplete. Maintaining the quality of data in a spreadsheet or a database requires diligence, planning, and constant monitoring. Clinical managers must be taught to evaluate the quality of data prior to using the data to make decisions.

It is always faster and more efficient to prevent inaccuracies or incomplete data during the data entry process than it is to find and fix problems after the damage is done. Several strategies can improve the quality of data in a database. Proper design is the first step to preventing data quality problems. Most computer programs contain standard features to prevent data entry errors such as selecting the type of data that can be stored in a particular location. For example, if the database requires entry of a date in a certain location then the entry of an invalid date would be prevented. Assigning range limits prevents entry of invalid data while requiring the entry of a value prevents incomplete data. Required fields should be used carefully, however, as requiring the entry of too many values may introduce bad data if users become frustrated with a lengthy data entry process. Involving data entry personnel early in the development of a database improves the data entry process and tools and reduces the potential for errors.

Data users should understand how the data they are using are defined. This is particularly important if the data are being used secondarily, and it is not possible to influence how the data are entered. For example, there are two federal data standards for information regarding race (eg, American Indian or Alaskan, Asian or Pacific Islander, Black or White) and ethnicity (eg, Hispanic or Non-Hispanic).[17] However, many health care organizations collect only one combined field, and it is not possible to accurately determine the race or ethnicity of their patients.

If a spreadsheet or database contains bad data, auditing the data may be an option to identify or correct errors.[18] Range checks can identify values that are too large or too small, and sample calculations can identify invalid or missing entries. Although auditing will often find a majority of bad data present in a program, it is always better to prevent the bad data from being entered in the first place.

System Selection Issues

Clinicians and managers should participate in the selection of clinical information systems whenever possible, and they should be prepared to consider data needs during the selection process. This issue should be included in the curricula of health informatics programs; however, the focus of systems selection is often weighted heavily toward clinical issues. While issues such as user friendliness and integration with the clinical workflow are important considerations in the selection of clinical information systems, data management issues should also be kept in mind. The quality and availability of data for use on the back end is important in order to facilitate other uses of routinely collected health data such as benchmarking, quality improvement, research, and surveillance. Vendors should be questioned about the types of reports that are available from these systems as well as the option to customize reports, export data for use with other computer applications, or run ad hoc reports locally rather than having to request the data from the vendor.

As the health care informatics field has developed, there has been recognition of the need to prepare informatics experts in both the clinical and managerial ranks. There also is a need to educate nonmanagers in basic informatics content. Professional and educational organizations are working to address these needs through formal educational programs as well as the development of competencies and certifications. While the various educational programs, competencies, and certificates continue to be developed, it remains to be seen how widely adopted these initiatives are at present. Clinicians and managers would be wise to take a proactive approach to acquiring health care informatics knowledge and skills in order to make the best use of data for direct care as well as in support of optimal health services organization and delivery, public health surveillance and practice, and clinical research. **NCMJ**

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COMMENTARY

The Role of Data at The Carolinas Center for Medical Excellence

Mark W. Massing, MD, PhD, MPH; Anna P. Schenck, PhD, MSPH

Few organizations rely more heavily on data than The Carolinas Center for Medical Excellence (CCME). CCME is not a health care provider but rather a developer of data-driven services that enable providers to deliver the best possible care to their patients. CCME's existence depends on its ability to make complex data meaningful and relevant to the health care concerns of its customers. The CCME offices in Cary, North Carolina, and Columbia, South Carolina, house a diverse staff of more than 100 skilled health care and information technology professionals. Many of the physicians, nurses, health services researchers, epidemiologists, statistical analysts, quality improvement specialists, medical record abstractors, coding specialists, and information technology specialists employed at CCME were trained at and are affiliated with the major academic and medical centers of the Carolinas.

CCME uses data to influence health policy and health care delivery in hospitals, skilled nursing facilities, outpatient practices, home health agencies, and other medical settings. Data that are meaningfully summarized and reported can influence policy through their effects on clinical decision makers responsible for health care quality and costs. The internal organization of CCME is oriented around 4 major market areas: federal programs and services; state programs and services; physician and community services; and research. Below we describe the data assembled at CCME and how they have been used in these market areas to influence clinical decision makers and to improve care.

> *"CCME's existence depends on its ability to make complex data meaningful and relevant to the health care concerns of its customers."*

Federal Programs and Services

The primary activity of CCME's Federal Programs and Services Division is the Quality Improvement Organization (QIO) contract with the Centers for Medicare & Medicaid Services (CMS). As the QIO for both North and South Carolina, CCME is responsible for assuring quality of care for nearly 2 million Medicare enrollees. The QIO program is the product of the federal government's evolving need to contain costs and provide appropriate care in the Medicare program. It developed from antecedent programs formed shortly after the creation of Medicare in 1965. These earlier programs focused on hospital-based utilization control and physician peer review. Data from administrative claims and medical records were used to identify physicians providing substandard or unnecessary care. The focus was on outliers with little emphasis on improvements in the general population of providers. In response to recommendations of the Institute of Medicine of the National Academies in 1990,[1] the emphasis of Medicare quality assurance changed from case-specific punitive and regulatory action toward a population-based approach focusing on clinical decision making, outcomes, and professional capacity building to improve care. Now the QIO works collaboratively with health care providers in virtually all settings to collect and use data describing health outcomes and overall patterns and processes of care. QIOs analyze and review complex data from many sources to create meaningful information that guides clinical decision makers.

The collection of data and the dissemination of information

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derived from data to health care consumers and clinical decision makers is a major activity of CMS and QIOs. In 2000 Jencks and colleagues[2] described national- and state-level rates on a series of clinical performance indicators for care provided to Medicare enrollees in the hospital and outlined the intended expansion of a system to monitor care provided in nursing homes and home health agencies. In the 2 Carolinas, CCME has worked with 173 hospitals, 479 nursing homes, and 235 home health agencies to improve quality as measured though data collected and made publicly available on government websites. The data are publicly reported in an effort to produce incentives for increased quality and reduced costs by creating market pressure from informed consumers and increased competition among providers.

The publicly reported quality measures for Medicare patients in hospitals include 24 care processes and 2 outcome measures.[3] (See Table 1.) Data sources for the hospital measures include clinical and administrative records. Nineteen quality measures are used to monitor nursing home care[4] and 12 indicators are used to monitor home health care.[5] (See Table 1.) Both the nursing home and home health quality measures are created from standardized patient level assessments.

The DOQ-IT (Doctor's Office Quality-Information Technology) program supports the adoption and effective use of information technology in the outpatient setting.[6] Participating outpatient medical practices may voluntarily report patient-level health care data captured from electronic health records to a clinical data warehouse administered by CMS. The DOQ-IT program has assisted 104 medical practices in North Carolina and 61 practices in South Carolina with selection, implementation, and use of electronic health systems. CMS is currently redirecting QIO physician support activities from implementation of electronic systems to effective use and central reporting of electronic data.

As a Quality Improvement Organization, CCME uses a data-driven approach to assist with Medicare-related activities, making use of enrollment databases, Medicare service claims, selected clinical information from medical record abstractions, and setting-specific quality measure data. With the capacity to link data for patients across settings and across files, CCME can create population-based maps showing variation in care by geographic location and can assess quality of care by demographic characteristics. Data can be aggregated to the county, facility, or single provider to assess quality of care. CCME uses Medicare data to identify the need for policy or clinical interventions at the local or state level.

This approach is illustrated by the trend reports CCME sends to nursing homes in the Carolinas every quarter. (See Figure 1.) The example shows almost 3 years of trended data and provides the facility the ability to compare its progress in improving care (in this case, reducing the number of residents in restraints) with that of the state and the nation. CCME creates thousands of facility level data reports every year to share with North and South Carolina health care providers.

Clinical data will grow in importance and volume as medical practices implement electronic systems. These systems will provide the raw data needed to support public reporting and pay-for-performance initiatives. Considering that as many as

Table 1.
Measures Assessing Quality of Care for Medicare Enrollees

Patient Population	Beneficiaries	Source(s) of Data
Hospitalized Heart Attack Patients	■ Percentage of patients with aspirin within 24 hours of arrival ■ Percentage of patients with aspirin prescribed on discharge ■ Percentage of patients with beta blockers prescribed on discharge ■ Percentage of eligible patients with ACE inhibitor prescribed at discharge ■ Percentage of smokers offered cessation counseling at discharge ■ Percentage of patients with fibrinolytic medication within 30 minutes of arrival ■ Percentage of patients with percutaneous coronary intervention (PCI) within 90 minutes of arrival	Hospitals submit specific data elements to clinical data warehouse about care provided to heart attack patients using the patient record as the data source
	■ 30-day risk adjusted mortality rates among enrollees hospitalized for heart attack	Medicare claims and enrollment informations
Hospitalized Heart Failure Patients	■ Percentage of patients with evaluation of left ventricular systolic function ■ Percentage of patients with left ventricular systolic dysfunction who are prescribed ACE inhibitor or ARB ■ Percentage of patients provided with discharge instructions ■ Percentage of smokers offered cessation counseling at discharge	Hospitals submit specific data elements to clinical data warehouse about care provided to heart failure patients using the patient record as the data source
	■ 30-day risk adjusted mortality rates among enrollees hospitalized for heart failure	Medicare claims and enrollment information

Patient Population	Beneficiaries	Source(s) of Data
Hospitalized Pneumonia Patients	■ Oxygenation assessment ■ Initial antibiotic timing ■ Pneumococcal vaccination ■ Influenza vaccination ■ Blood culture performed in the emergency department prior to initial antibiotic received in hospital ■ Appropriate initial antibiotic selection ■ Smoking cessation advice/counseling	Hospitals submit specific data elements to clinical data warehouse about care provided to patients with pneumonia using the patient record as the data source
Hospitalized patients receiving selected surgical procedures	■ Percentage of patients who receive prophylactic antibiotic within 1 hour prior to surgical incision ■ Percentage of patients who have prophylactic antibiotics discontinued within 24 hours after surgery ends ■ Percentage of patients who receive a prophylactic antibiotic that is recommended ■ Percentage of patients who have an order for recommended venous thromboembolism prophylaxis ■ Percentage of patients who receive appropriate treatment to prevent blood clots within 24 hours prior to or 24 hours after surgery	Hospitals submit specific data elements to clinical data warehouse about care provided to patients undergoing selected surgical procedures using the patient record as the data source
Nursing home residents in home for extended stay	■ Percentage of residents given influenza vaccination during the flu season ■ Percentage of residents who were assessed and given pneumococcal vaccination ■ Percentage of residents whose need for help with daily activities has increased ■ Percentage of residents who have moderate to severe pain in past week ■ Percentage of high-risk residents who have pressure sores in the past week ■ Percentage of low-risk residents who have pressure sores in the past week ■ Percentage of residents who were physically restrained in the past week ■ Percentage of residents who are more depressed or anxious in the past month ■ Percentage of low-risk residents who lost control of their bowels or bladder in the past 2 weeks ■ Percentage of residents who had a catheter inserted and left in their bladder in the past 2 weeks ■ Percentage of residents who spent most of their time in bed or in a chair in the past week ■ Percentage of residents whose ability to move about in and around their room got worse in the past week ■ Percentage of residents with a urinary tract infection in the past month ■ Percentage of residents who lost too much weight in the past month	Minimum Data Set (MDS) Repository The MDS is a patient level assessment conducted by nursing homes on residents at regular, specified intervals.
Nursing home residents in home for short period of time	■ Percentage of residents given influenza vaccination during the flu season ■ Percentage of residents who were assessed and given pneumococcal vaccination ■ Percentage of residents with delirium in the past week ■ Percentage of residents who had moderate to severe pain in the past week ■ Percentage of residents with pressure sores in the past week	Minimum Data Set (MDS) Repository The MDS is a patient level assessment conducted by nursing homes on residents at regular, specified intervals.

Patient Population	Beneficiaries	Source(s) of Data
Medicare enrollees receiving home health care	■ Percentage of patients who get better at walking or moving around ■ Percentage of patients who get better at getting in and out of bed ■ Percentage of patients who have less pain when moving around ■ Percentage of patients whose bladder control improves ■ Percentage of patients who get better at bathing ■ Percentage of patients who get better at taking their medicines correctly (by mouth) ■ Percentage of patients who are short of breath less often ■ Percentage of patients who stay at home after an episode of home health care ends ■ Percentage of patients whose wounds improved or healed after an operation ■ Percentage of patients who had to be admitted to the hospital ■ Percentage of patients who need urgent, unplanned medical care ■ Percentage of patients who need unplanned medical care related to a wound that is new, is worse, or has become infected	Outcome and Assessment Information Set (OASIS) The data come from comprehensive patient assessments conducted by home health agencies at regular, specified intervals

75% of physician practices do not use electronic medical records,[7] it is clear that most clinical data currently reside on paper where they are difficult to access and use. A major policy challenge involves the removal of barriers and the creation of incentives for physicians to adopt electronic systems, to undertake the expensive migration of data to these systems, and to fully integrate electronic systems into practice and care management.

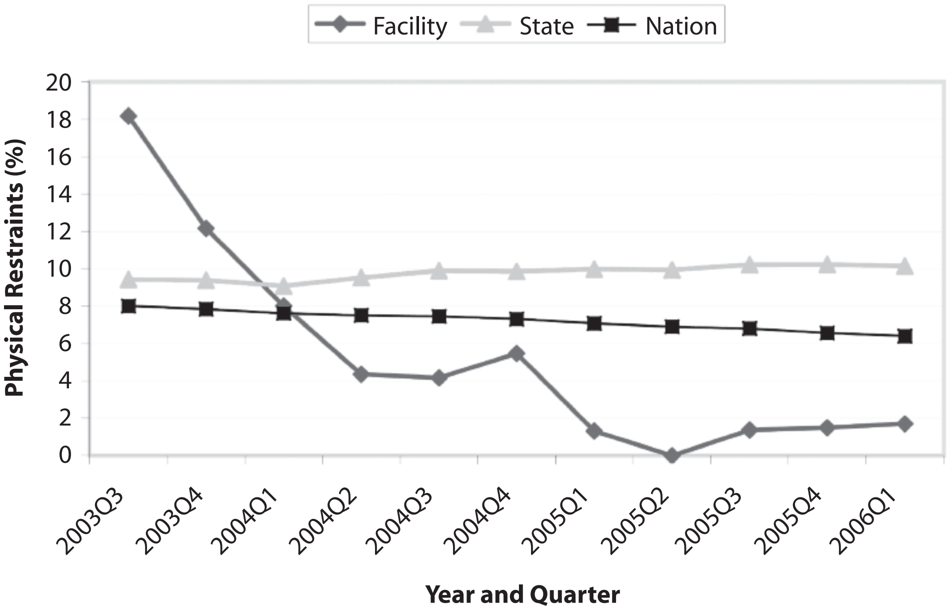
State Programs and Services

Programs conducted by states are another important source of health data used by policy makers to reduce costs and improve health outcomes. The Medicaid program administered in North Carolina by the Division of Medical Assistance (DMA) of the state Department of Health and Human Services rivals the federal Medicare program in terms of population and costs. About 1 out of every 5 North Carolina residents were served by the Medicaid Program in 2006 (1.7 million persons in total) at costs exceeding $11 billion.[8]

Data available through state programs include sociodemographic information for eligibility and enrollment, administrative claims for reimbursement of services, and limited, but growing, clinical information used for quality improvement and disease management. State health data are typically collected and maintained by a variety of agencies and contractors. Identifying, linking, and fully utilizing these fragmented data sources constitute a major challenge. But the rewards are great because these data are a rich and often underutilized source of information.

CCME has extensive experience in the use of state health data through its contracts and collaborations with a number of state agencies. A good example of how CCME has worked with DMA to expand the use of state health data relates to the Community Alternatives Program for Disabled Adults

Figure 1.
Example of Trend Report for Residents in Restraints Sent to a North Carolina Nursing Home



(CAP/DA).[9] This program reimburses eligible disabled adults for home-based care as an alternative to more expensive nursing facility care. CCME collaborated with CAP/DA consultants to create its Automated Quality and Utilization Improvement Program (AQUIP) that allows the state to assess the health status of its home-based clients in a manner similar to the way they would be assessed at nursing facilities. AQUIP captures client information and assessment data from the state and from county case managers and uses their data to assess the need for services and to examine variations in quality and costs. It also allows for the comparison of this population with institutionalized patients. AQUIP offers an example of how existing state health data can be used for multiple purposes.

About 1 in 5 North Carolina Medicare beneficiaries is enrolled in Medicaid. These dually eligible persons qualify for Medicaid due to disability or extreme medical or financial need. As a group, they are more likely to have complex health conditions that are difficult and expensive to treat.[10] Improving health outcomes and reducing costs is challenging in this population. Contributing to the challenge is the fragmentation of their health data between the federal Medicare system and the state Medicaid administrative agencies.

Evaluating the cost and quality of pharmacologic therapy in the treatment of chronic diseases such as diabetes and heart failure is especially problematic in the dually eligible population. Prior to the implementation of the Medicare Part D pharmacy benefit in 2006, state Medicaid agencies administered pharmacy benefits for dually eligible clients. Thereafter, the pharmacy benefit for the dually eligible was federalized and rolled into the Medicare Part D program.[11,12] Due to limitations imposed by the Medicare Modernization Act, Part D administrative claims data have been generally unavailable to Medicare contractors, state agencies, and health services researchers. Efforts to contain costs, reduce errors, and improve outcomes associated with pharmacotherapy have been limited by restricted access to these data.

Despite these data challenges, CCME has collaborated with DMA in projects that combine Medicare and Medicaid data to better understand and improve health care outcomes in their client populations. Medicaid data were used to evaluate the effectiveness of a CCME quality improvement project to reduce the use of antibiotics for nonbacterial respiratory tract infections.[13,14] CCME data abstractors collected clinical care information from outpatient medical records in a statewide heart failure quality improvement project involving Medicaid and private managed care.[15] In this project, clinical data from the medical records were linked to administrative claims data. In an ongoing project, CCME has linked Medicare and Medicaid administrative claims data for the dually-eligible population with heart failure in North Carolina and South Carolina to better understand and improve heart failure care in this high-risk population.

Billings and Mijanovich in a recent Medicaid study[16] demonstrated that given sufficient data it is possible to identify populations at high risk for future adverse health outcomes. The same data can be used to focus prevention efforts on persons most likely to benefit and to enable administrators to predict costs and make the business case for prevention. Medicare and Medicaid offer 2 of the few comprehensive data sources to capture the complete health experiences of large populations as they transition through the medical system. Combining and linking these data offers even greater opportunities to understand and improve health care effectiveness while containing costs.

Physician and Community Services

CCME provides a number of data-intensive services to support physicians and other health care providers in clinical decision making and quality improvement. Each addresses a fundamental need to get the right data, understand what the data mean, and act appropriately on the data.

Community Health Care Coordination

The impact of fragmentation of the health care system and its data on patient care, costs, and quality is substantial. Patients with complex medical conditions frequently obtain care from multiple settings and from different providers within settings. The task of identifying and linking patient data in different formats across diverse settings and providers can be daunting. Legislation designed to protect patient privacy creates further barriers to data sharing. This makes cross-setting data use difficult if not impossible. The failure of data to travel with patients as they transition through health care settings contributes to inefficient and uncoordinated health care. This can lead to increased costs, lower quality, and poorer health. CCME recognizes that effective health care requires a community approach to care coordination. To that end, it is developing community-based projects to promote cross-setting care coordination through information exchange and patient-centered care.

Care Management Support

Although the widespread adoption and implementation of electronic systems is an issue of central concern, there is a growing realization that the next major challenge will be the use of electronic health data to support effective care management and public health. CCME has found that the full capabilities of electronic health information systems and the data they generate are greatly underutilized. The availability of electronic data is the prerequisite to transformational system change, but it does not guarantee it. The lack of expertise and resources to understand and act on electronic data are a major barrier to achieving the substantial improvements in health outcomes and efficiencies that they promise. CCME is addressing this need through support services that enable providers to translate data into actions that measurably improve patient outcomes, enhance satisfaction, and demonstrate savings and revenues consistent with a business case for quality.

Physician Leadership and Education

The volume of data is growing much faster than the ability of physicians to understand and act on it. Recent advances in information technology provide data at levels not conceived of when most physicians were receiving medical training. Health care providers now have additional requirements to understand and use these data in routine patient care. There is a great need to enhance the skills of health care providers in the use and interpretation of data. There is also a need to develop data-driven physician leaders who are comfortable with a rapidly evolving data environment that guides clinical decision making and informs health policy. A major objective of CCME's Physician Leadership Institute is to enhance skills in the use of data to inform and support physician leadership.[17]

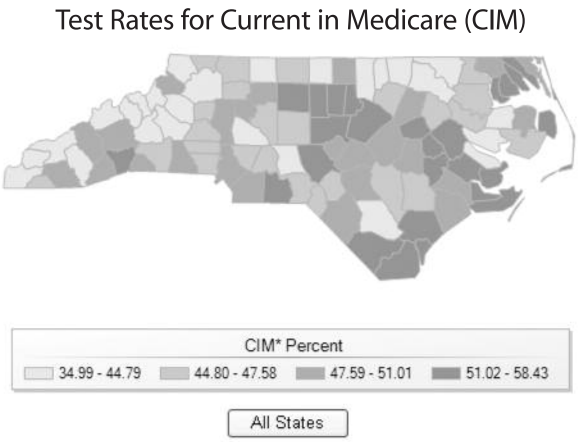
Research

The Research Division of CCME has 3 areas of focus: developing improved ways to measure quality and effectiveness of care, monitoring quality of care, and evaluating approaches to improve quality of care. The development of improved measures is crucial to the improvement in quality. Quality measures not only need to be scientifically sound (eg, valid and reliable), they must also be feasible and responsive to changes in care. CCME research focuses on the development of measures that meet these criteria. It has become an accepted tenet of quality improvement professionals that "if you don't measure something, you can't improve it!" Thus, monitoring care is a vital function of any quality organization. CCME routinely monitors the quality of care for Medicare enrollees as part of the QIO contract. It extends the power of quality monitoring to state and local organizations by hosting a Web-based surveillance report on Medicare which includes enrollment information, utilization statistics, and quality of care measures.[18] Monitoring care undoubtedly leads to identification of opportunities to improve care. CCME research in this area focuses on assessing the effects of policy or system changes and evaluating interventions to change provider or consumer behaviors.

The Palliative Care Quality Measurement Project provides an example of measurement development research conducted by CCME. Under contract from CMS, CCME was asked to identify and develop new quality measures for hospice and palliative care. CCME researched existing quality measures and identified a subset of measures for further consideration. We gathered data on 140 potential measures from other organizations and directly from care providers for measures that had not previously been tested. The project resulted in a set of 34 quality measures that technical experts agreed were appropriate for hospices to use in internal quality improvement. The results of this project were shared with CMS and made available to providers on the MedQIC website.[19]

Our Web-based report on colorectal cancer screening in the Medicare population illustrates the type of research CCME conducts to monitor care.[20] Figure 2 displays geographic variation in the proportion of Medicare enrollees in North Carolina who have had the recommended colorectal cancer testing. Lighter areas of the map represent the areas of the state with lower levels of adequate colorectal cancer testing—areas where interventions to increase screening are needed. Since 2000 CCME has, under contract with CMS, monitored test use rates for the national Medicare population. The data in the Web-based report have been instrumental in the inclusion of colorectal cancer screening in the next QIO contract, which will require QIOs in all states to work towards improving colorectal cancer testing.

Figure 2.
Colorectal Cancer Testing in the Medicare Population in 2005 (Rates per 100 Medicare Enrollees)



Conclusion

It is only when data are turned into information that the full power of data-driven solutions can be leveraged. At CCME we are working to develop the information that will help improve health policy at the federal and state levels; inform consumers so they can take a more active role in both selecting their own care and improving the care in their communities; assist providers in improving their care delivery systems; and educate physicians and providers on the patterns, problems, and opportunities to improve the health and health care of the population as a whole. We invite readers to join us in these efforts. **NCMJ**

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Shaping Health Workforce Policy Through Data-Driven Analyses:

The North Carolina Health Professions Data System

Jennifer King; Mark Holmes, PhD

There is growing concern among North Carolina's policymakers that the state's supply of health professionals may not be adequate to meet future demands. Decisions about whether to enact or change policies directed at training, recruiting, and retaining health professionals affect a wide range of stakeholders and can be the source of contentious debate. For example, an important proposal considered by the North Carolina General Assembly in the 2007 legislative session was the development of a new dental school. The House Select Committee on Health Care Subcommittee on Healthcare Workforce reviewed extensive data analyses describing the supply of dentists.

The ability of legislators, legislative staff, and policy makers to understand, consider, and debate pressing issues and potential policy solutions depends on their access to ready sources of rich data and researchers who can work with the data to objectively present the analyses. One such resource in North Carolina is the North Carolina Health Professions Data System.

In partnership with the North Carolina Area Health Educations Centers (AHEC) Program and 12 state licensing bodies, the North Carolina Health Professions Data System (HPDS) maintains licensure files for 20 health professions and has continuous data for most of these professions dating back to 1979. Through consistent annual reports, analysts are able to monitor the supply of health professionals and detect new trends as they emerge. Further, interested stakeholders frequently use the HPDS data when debates about workforce issues surface. Finally, workforce policy experience has enabled HPDS analysts to identify emerging issues in the supply of unlicensed health professionals that are important to health care delivery as well as to the health of the state's economy.

> *"...state policy makers have recognized that the objective analysis available from the HPDS uniquely informs North Carolina policy makers and helps ensure that public policy on health workforce issues is based on the best available evidence."*

The North Carolina Health Professions Data System

The NC Health Professions Data System contains a broad array of information on a variety of licensed health professionals. In 2006 the HPDS included data on 20 different licensed professions. (See Table 1.) The inventories include physicians and nurses as well as professions with fewer members such as podiatrists and occupational therapy assistants. The NC Health Professions Data System annually produces the "Orange Book," an annual report of the state of North Carolina's health professions as well as maps depicting the supply of professionals across the state. Administratively located within the Cecil G. Sheps Center

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Table 1.
Professions Included in the 2006 NC Health Professions Data System Data Files

Physicians	Chiropractors
Primary Care Physicians	Occupational Therapists
Physician Assistants	Occupational Therapy Assistants
Nurse Practitioners	Optometrists
Certified Nurse Midwives	Podiatrists
Registered Nurses	Practicing Psychologists
Licensed Practical Nurses	Psychological Associates
Dentists	Physical Therapists
Dental Hygienists	Physical Therapist Assistants
Pharmacists	Respiratory Therapists

for Health Services Research, the HPDS is supported by the North Carolina Area Health Education Centers (AHEC) and the University of North Carolina at Chapel Hill Office of the Provost. Consistent with the university system's increasing commitment to community engagement, the HPDS routinely provides communities with local health professional data; these data are used for multiple purposes such as grant applications and local government priority setting. North Carolina residents highly value the HPDS as a resource; in 2007 the HPDS responded to over 200 data requests from the public.

The data available in the HPDS legally remain the property of the licensing boards that provide the data to the HPDS under a joint agreement allowing HPDS analysts to use the data for research and public policy purposes but restricting use of the data to very specific applications. This agreement maintains the security and privacy of the data. Available data in the system vary widely depending on the specific profession and the license renewal form. Although other data sources provide data on North Carolina's supply of some health professions, these sources typically contain less information, are updated in a less timely manner, or contain only a sample of professionals.

Monitoring Trends

By monitoring annual changes in the supply of health professionals in the state and in comparison to national trends, HPDS analysts are able to identify trends that merit special attention. For example, based on data from 2000 to 2004, researchers became concerned that North Carolina's past experience of robust growth in physician supply relative to population was slowing. This realization prompted the North Carolina Institute of Medicine (NC IOM) to convene a year-long task force to examine the state's physician supply and recommend options to address the projected shortage.

Using the HPDS data to examine the supply and practice characteristics of physicians, physician assistants, nurse practitioners, and certified nurse midwives, researchers developed a model that projected the future supply of providers relative to the projected growth in North Carolina's population. Figure 1 shows this projection from 2004 to 2030.

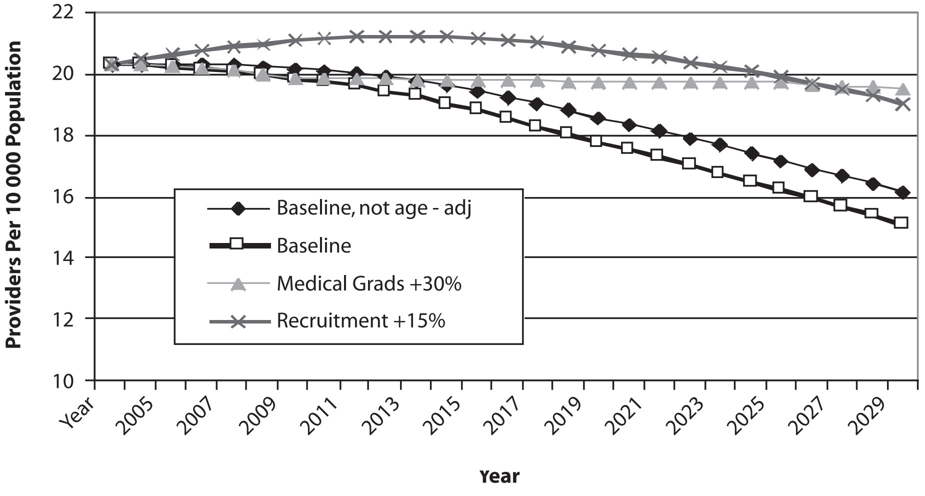
The model incorporated historical migration and retirement patterns available from the HPDS data and projected the effect of different policy options (eg, increasing the number of medical graduates, recruiting more physicians from out of state, increasing productivity through new models of care). The model allowed the NC IOM to test the impact of a variety of policy scenarios on provider supply. The model revealed that, if nothing changes, the state will face a decreased supply of providers in the near future.

Without the long, uninterrupted, historical time series of physician data, the model's ability to project supply would have been more limited. Tom Bacon, DrPH, director of the North Carolina AHEC Program, and a member of the NC IOM task force, described the importance of regular monitoring of supply (February 2008), "With so much attention to workforce policy, it is critical to develop comprehensive data on the location and practice patterns of all types of health care practitioners if we aim to resolve our pressing needs. More fundamentally, without a rich data source on health care practitioner supply, we might not even be aware of the problems."

Informing Workforce Policy Debates

The HPDS is also frequently called upon by institutions or groups when they wish to make the case for a new policy or

Figure 1.
Projected Provider Supply, North Carolina: 2004-2030



Source: North Carolina Health Professions Data System and the North Carolina Institute of Medicine.

educational program, or when an issue related to health professionals surfaces in public debate. Data from the HPDS are readily available and equally accessible to stakeholders on all sides of issues; thus, there is no need to undertake expensive one-time studies.

For example, in recent years analyses based on the HPDS have been used to inform debates and proposals regarding:

- New schools of pharmacy, dentistry, and optometry
- The supply of psychiatrists in the context of state mental health reform
- The retention of medical students and residents trained in North Carolina
- Changes in health professionals' scopes of practice
- The effect of malpractice rates on the supply and distribution of obstetric care providers
- The designation of health professional shortage areas
- The supply of health professionals from underrepresented minority groups

Data are also frequently used by researchers and the press to investigate issues related to the distribution, cost, and quality of health care services in the state.

Highlighting New Areas of Workforce Research

In recent years, the HPDS has expanded its workforce analysis capacity to focus more on allied health—a sector of the health care industry that currently faces labor shortages and is likely to grow in the future. The HPDS contains licensure data on dental hygienists, physical therapists, physical therapy assistants, occupational therapists, occupational therapy assistants, and respiratory therapists. However the majority of the allied health workforce is not licensed and assessing the supply of these unlicensed workers can be especially challenging.

To address this challenge, the HPDS has begun an Allied Health Job Vacancy Tracking Project that tracks vacancies through newspaper and online advertisements. While not a definitive measure of demand, the project has proven useful in identifying professions facing acute shortages as well as important differences in the demand for allied health professionals among the state's 9 AHEC regions.

The HPDS allied health workforce research has drawn the attention of state policymakers who are looking for ways to address manufacturing, textile, and furniture job losses in North Carolina. Allied health jobs represent not only a large and increasingly important employment sector in the state but an engine for economic growth as well. Between 1999 and 2005 allied health employment in North Carolina grew much faster than total health care employment and total employment. (See Table 2.) Over 69% of the total job growth in the health care sector between 1999 and 2005 was due to growth of allied health jobs.

Recognizing the growth potential of allied health employment, state policy makers in the Office of the Governor, the legislature, and the Departments of Health and Human Services and Commerce are collaborating with HPDS staff, the state's community college and university systems, health care employers, and industry to develop innovative ways to transition unemployed individuals into allied health jobs. The hope is that these efforts will reduce workforce shortages, increase access to health care services, and improve the economic outlook in the state's neediest counties.

Table 2.
Total, Health Care and Allied Health Employment, North Carolina

	1999	2005	% Growth (1999-2005)
Total NC Employment	3 801 670	3 809 690	0.2%
Health Care Jobs	251 550	302 270	20.2%
Allied Health Jobs	***76 590***	**111 630**	**45.8%**

Source: Occupational employment statistics. State cross-industry estimates: 1999-2005. U.S. Department of Labor, Bureau of Labor Statistics Web site. http://www.bls.gov/oes/. Accessed June 28, 2006.

Note: Allied Health Jobs are also included in the Health Care Jobs category.

Hawley Truax of Governor Easley's Policy Office called the data "crucial" in developing the allied health sector strategy (February 2008). Again, the discovery was somewhat serendipitous, once HPDS staff initially identified the rapidly increasing number of allied health professionals in the data. When this was brought to the attention of the Office of the Governor the strategy quickly developed.

The North Carolina Health Professions Data Systems as a "Neutral" Data Source

Researchers and policy makers in other states have watched what North Carolina has accomplished with its HPDS and have sought out advice and guidance on building their own systems. For example, HPDS staff have assisted North Dakota, Florida, and Missouri in developing similar systems and have offered advice to researchers in at least 6 other states. Other state policy makers have recognized that the objective analysis available from the HPDS uniquely informs North Carolina policy makers and helps ensure that public policy on health workforce issues is based on the best available evidence. Advocates representing opposing sides of an issue will often cite the same HPDS data and interpret it slightly differently. This is a subtle, yet profoundly complimentary statement on HPDS's reputation in the public policy community—opposing sides may disagree on what the data mean, but few disagree with the quality of the data. In public policy debates, access to a neutral, unbiased data source is the most important tool for building solutions. Without it, public policy may be based on the volume of the argument rather than the quality of the data, and the outcomes may be far less useful than hoped for. **NCMJ**

COMMENTARY

Community-Level Data

Christopher J. Mansfield, PhD; James L. Wilson, PhD

Health-related data are used at many geographic and political levels by individuals and groups for a multitude of purposes. The focus of this paper is on what and how data are used at the local level, for what purposes and by whom, as well as some of the unique challenges and methodological manipulations involved. Examples of common and unique uses of data and the analytic challenges involved are included.

Health-related data are typically used at the local level to describe populations in terms of demographics, economics, social and environmental conditions, disease prevalence, births, causes of deaths, health behaviors, and available health care resources. They may also be used to characterize access to health services and the use and cost of such services. The data are generally secondary, ie, obtained from another agency that specified form and content without local user input. The data may come from the US Census (eg, income, housing, education), the state and federal vital statistics system (eg, births, deaths, communicable disease incidence), disease registries (eg, cancer incidence, prevalence), or national or state surveys (eg, Behavioral Risk Factor Surveillance System). Other sources may be agencies responsible for Medicaid, Medicare, licensing and regulation, environmental protection, education, commerce, agriculture, transportation, highway safety, or law enforcement. With increasing technology and governmental investments in data collection, there is a wealth of data available, but they may not be readily useful to or easily analyzed by the local user.

Local Users and Uses

The users of health-related data at the community level in North Carolina might be local chapters of voluntary health organizations (eg, American Heart Association, American Lung Association), Healthy Carolinians groups, hospitals, health departments, health care providers, professional associations, academic institutions, news media, governmental agencies, elected officials, and individual citizens interested in their own health or the health of their family and community. Typical purposes for data use include community diagnosis, program planning, policymaking, advocacy, justification of requests for resources, and program evaluation. The purposes may be categorized within the 3 core functions of public health (ie, assessment, policy development, and assurance)[1] and within the 10 Essential Public Health Services.[2,3] The core functions and essential services are related and provide a useful typology of the various uses. (See Table 1.)

> *"The fundamental purpose of using data at the local level is to inform and empower citizens, health providers, and policy makers to take actions to improve community health."*

These core functions and resource allocation decisions should be guided by empiricism and rational analysis, ideally leading to the greatest good for the greatest number. Good decisions depend on good information. Data, however, are not the information. They are the raw material of information. Data must be refined to become information, and information must then be turned into knowledge that is then diffused and understood before it can lead to action. Data are useful only if transformed into information about problems that can and should be solved and put in the hands of people able and willing to solve them. Because problems identified and prioritized at

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Table 1.
Uses of Data at the Local Level in Relation to 3 Core Functions of Public Health and the 10 Essential Public Health Services

Assessment

1. Monitor health status to identify community health problems
2. Diagnose and investigate health problems and health hazards in the community

Policy Deveopment

3. Inform, educate, and empower people about health issues
4. Mobilize community partnerships to identify and solve health problems
5. Develop policies and plans that support individual and community health efforts

Assurance

6. Enforce laws and regulations that protect health and ensure safety
7. Link people to needed personal health services and assure the provision of health care when otherwise unavailable
8. Assure a competent public health and personal health care workforce
9. Evaluate effectiveness, accessibility, and quality of personal and population-based health services
10. Conduct research for new insights and innovative solutions to health problems

the community level are often the ones most likely to be solved, data may be most useful when applied at the local level.

There is a history of community action for health improvement in North Carolina from the Comprehensive Health Planning Councils of the late 1960s, through the Health Systems Agencies from the mid-1970s to mid-1980s, to a public health community diagnosis and planning process that began in the mid-1970s and continues today. In the mid-1990s, the North Carolina Department of Health and Human Services began to require local health departments to submit legislative priorities for funding requests and encouraged the local departments to base their priorities on a community diagnosis process to be conducted every 4 years. Local planning was bolstered in the late 1990s by the establishment of the Governor's Task Force for Healthy Carolinians and the Office of Healthy Carolinians which developed the state's health plan called *Healthy Carolinians 2010*.[4] It was aligned with the federal *Healthy People 2010*[5] blueprint and contained goals and objectives with quantified benchmarks and targets. The Healthy Carolinians initiative embodied the first 5 of the 10 Essential Services under the functions of *Assessment* and *Policy Development* listed in Table 1 above. It encourages local health planning with small grants and "certification to communities who have broad-based community partnerships which represent the needs of the disadvantaged and whose mission is prevention based."[6] As certification requires a community assessment, the communities and staffs of the local public health departments, who are principal partners, are some of the most active users of health-related data. They are guided by a Community Health Assessment Guide Book[7] and an online County Health Data Book,[8] the contents of which are described in the commentary by Paul Buescher. As local communities *monitor health status to identify community health problems*, they typically examine data on mortality, communicable disease prevalence, pregnancy rates, and birth weight. However, the Healthy Carolinians approach goes beyond typical health statistics. They may also look at population demographics, education and socioeconomic conditions, and behaviors that contribute to health. The Centers for Disease Control and Prevention's Behavioral Risk Factor Surveillance System (BRFSS), a statewide telephone survey conducted annually in North Carolina, is an excellent source of data on risk factors, but there are only 22 counties with samples large enough for statistical generalization, and the complex sampling strategies require special statistical procedures for valid description.[9] Local groups frequently conduct their own behavior and opinion surveys but often do so with small convenience samples from which valid generalizations cannot be made. The community assessment and planning process also includes an evaluation of community resources (ie, asset mapping). Healthy Carolinians partnerships are now certified in 78 of the state's 100 counties.[10]

Health workforce data are particularly useful. Historically, inventories of physicians and other providers have been used in requests for designation of Health Professional Shortage Areas (HPSAs) which may bring federal and state resources to build and staff community health centers. These data, combined with information on local and regional health disparities, are constantly used to *inform, educate, and empower* policy makers, *mobilize partnerships to identify and solve health problems*, and *develop policies and plans*. They have been effectively employed to justify the need for medical and dental schools at East Carolina University, the Area Health Education Centers Program, and expansion of curricula and enrollments in the state's medical, nursing, and allied health schools. Other frequent users of health workforce data at the local level are hospitals, community health centers, Area Agencies on Aging, and voluntary health organizations. They *develop policies and plans that support individual and community health efforts* and use data on health resources for *linking people to personal health services*. Physician directories and community service inventories are very valuable data assets. Local public health departments, hospitals, and academic institutions are interested in local data for their roles in *assuring a competent workforce* and in *evaluating the effectiveness, accessibility, and quality of personal and population-based health services*. Academic institutions use local data to *conduct research for new insights and innovative solutions to health problems*. While there is a rich array of secondary data, they may not be appropriately defined or available in a form for valid and ready application at the local level.

Focusing the Data on Specific Regions and Communities

Professional policy analysts and knowledgeable policy makers at the state or federal level may be able to refine or transform data easily into information and to act on it. Users at the local level may be challenged. Technical expertise not withstanding, a number of problems may exist at the local level. The variables in data collected by a state or state-level agency may not have been chosen or measured to answer local questions. The geographic level of observation and measurement may not be appropriate. The county is a common level of aggregation for most health and health resource data but health problems and community planning efforts do not always follow county boundaries. Local users may need to lump or split the data for multi-county or partial-county analyses. Census data are obtainable down to the census block but analysis may require that they be lumped together. When data are from statewide samples, sample sizes at the county level may not be large enough to draw statistically significant conclusions, particularly when describing smaller population subgroups (eg, Hispanics or American Indians) by gender and age group. When county level data are large enough to split, more specific locations within a county may not have been collected or available. Another problem is that the time frames of data in standard reports may not be useful. Single-year data may not have enough observations; multiple-year data (particularly rates) may occlude trends. The needs of community-level data users, contexts, and relevant issues vary widely, as do their analytic capacities. The challenge for local users is to get simple patterns to emerge without torturing the data, the analysts, or the end users. The data must be clean, of sufficient size, and amenable to simple analysis for information to emerge and be seen, not through statistical smoke, but in clear graphic displays and then stated in simple sentences. A few examples of unique uses and challenges are useful.

Variable Must Be Redefined

A planner at a local health department wants to look at leading causes of death for people under age 75 in her county, but available reports do not provide mortality rates for that specific age group. She suspects that for those under age 75 cancer rather than heart disease is the leading cause of death. She asks colleagues at the local university to analyze recent death file data. They aggregate death certificate data (available from the Odum Institute[11]) into a 0 through 74 age group and recalculate mortality rates by race and gender. Her hypothesis is confirmed and community attention will be focused on cancer prevention and treatment.

Longer Exposure in Taking the Data Snapshot

A Healthy Carolinians group wants to develop programs to address obesity in the county. BRFSS data are available, but sample sizes in single years are too small to show any statistically significant differences between the county and the state. A custom analysis reassembling the raw data into a 5-year period to provide a larger sample shows there is in fact a higher body-mass index for the county population than the rest of the state. They will use the information in a grant application.

Produce a Moving Picture Instead of a Snapshot

Elimination of health disparities is a goal of *Healthy Carolinians 2010*. Halfway through the decade, how are individual counties doing in relation to this goal? By analysis of single-year data as a 25-year time series, trends may become apparent at the county level.

Gerrymandered Health Statistics

Data geocoded at the county level are not adequate to define phenomena that do not respect county boundaries. Local communities would certainly be interested in the health impacts of a flood, tornado, or toxic discharge—events likely to cross governmental boundaries. So also might we be interested in the relative health of one political jurisdiction to another. How, for instance, does North Carolina's Third Congressional District differ from the First Congressional District in terms of mortality? By political design, the First Congressional District contains 17 whole counties and 6 partial ones. The Third District contains 9 whole counties in addition to 6 partials, split from the First District. Demographically, the First District is 54% nonwhite versus 22% nonwhite for the Third. Mortality data are coded in public files only at the county level so important health statistics are not available at the congressional district level, which is an unfortunate disconnect between democracy and public health. Mortality rates for congressional districts can be estimated, however, by applying race- and/or age-specific rates to populations in census blocks weighted by race and age proportions and then aggregated up to the district.[12] The race and age proportions are known accurately at the census-block level. Indeed, that information was used to create the politically gerrymandered districts. For example, the estimated mortality rate (2000-2004, age-adjusted) for the total population of the First District is 1039 deaths per 100 000 population versus 966 for the Third District. The estimated rates could have considerable political significance and lead to advocacy for resources to address health disparities. This kind of analysis is not difficult, but it does require powerful computing. The same methods can be used to calculate mortality rates for state legislative districts. Similarly, we can lump together data about populations affected by natural and manmade disasters. This could be very useful in disaster planning, management, and recovery.

The fundamental purpose of using data at the local level is to inform and empower citizens, health providers, and policy makers to take actions to improve community health. There are methodological challenges in refining, redefining, repackaging, and analyzing the data, but with available technology, programs to train local users, and community-campus partnerships for technical assistance, these challenges can be overcome. State agencies and academic institutions can provide training and expertise in survey design and sampling, statistical analysis, interpretation of data, and cartographic presentation of information. We can and should improve how we collect and disseminate data for local users. Death and health-related data should be geocoded and available for analysis—with privacy safeguards—at the smallest community level whenever possible. One of the objectives of *Healthy People 2010* (23.3) is the "development of data systems that use geocoding to promote use of geographic information systems (GIS) at all levels."[5] Realization of this objective would allow local users flexibility to define neighborhoods and communities in more appropriate ways and to show their elected representatives the problems, needs, and resources of their "designer districts." We should develop dynamic, electronic public health data systems that allow users to define queries in terms of units of analysis, levels of aggregation, and combinations of variables of interest at the community level. The systems should be customizable, current, convenient, and collaborative. **NCMJ**

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COMMENTARY

Using Health Data to Focus Philanthropy on Critical Needs

David E. Murday, PhD; Elizabeth A. Corley, MA

In early 2003 The Duke Endowment began planning for a special grant program for early childhood health issues with an emphasis on preventive care and services. During the first phase of the proposed program, grant projects in North and South Carolina were expected to target critical primary health care access issues that affect specific child health outcomes in those states.

The Duke Endowment was concerned that a competitive request for proposals would place communities with high needs but fewer resources at a disadvantage. To avoid this, the Cecil G. Sheps Center for Health Services Research at the University of North Carolina Chapel Hill and the Center for Health Services and Policy Research at the University of South Carolina were asked to assist the Endowment in determining the specific areas in their respective states with access-related health problems for children. The centers were asked to provide data-based answers to the following questions:

- Where are the documented areas of unmet need for children's primary care services?
- What do key people in those areas see as the most important barriers to accessing services and the most important activities needed to improve access to child health care services?
- What improvements in the health status of children can be expected if access to child health care services improves?

This article describes the efforts in South Carolina to answer these questions and support the Endowment's efforts to target the program in communities with the highest needs.

> *"...health data can be used to help a foundation identify communities whose needs are aligned with the philanthropy's priorities."*

Background

Access to health care is not equal for all children who need it. Prior research in South Carolina examined hospitalization for ambulatory care sensitive conditions as an indicator for access to primary care and found regional disparities.[1] Ambulatory care sensitive conditions are medical conditions for which children who receive appropriate and timely primary care are less likely to need emergency or inpatient care.[2] Examining 1995 data from the statewide inpatient hospital discharge database maintained by the Office of Research and Statistics of the South Carolina Budget and Control Board, the 10 highest ambulatory care sensitive conditions for pediatric admissions were bacterial pneumonia; asthma; dehydration; gastroenteritis; severe ear, nose, and throat infections; convulsions; kidney/urinary infections; cellulitis; diabetes; and immunization-preventable conditions. Access to primary care was the strongest factor affecting these admissions—children without a primary care physician were 9.5 times more likely to be hospitalized for a preventable problem than children with a primary care physician. Other demographic factors such as race, income, and insurance coverage were also significantly associated with ambulatory care sensitive conditions hospitalizations.[1] These results were consistent with findings from other research on the topic.

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There are 3 types of barriers to access of primary care services:

- Structural barriers are related to the number, type, concentration, location, or organizational configuration of primary care providers.
- Financial barriers restrict access. After reviewing evidence about financial and nonfinancial barriers to health care access, the Institute of Medicine of the National Academies determined that health insurance coverage is the major determinant of whether children have access to health care.
- Personal and cultural barriers such as language, attitudes and beliefs, social support, and education may inhibit people who need medical attention from seeking it, or once they obtain care, from following recommended treatment guidelines.

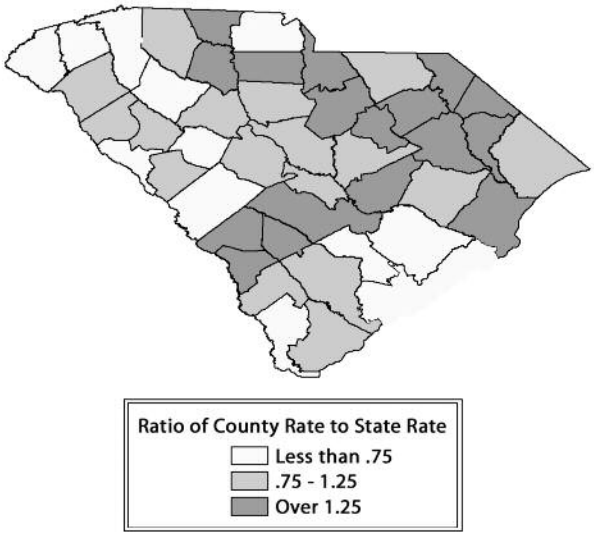
Geographic Information System Maps

Building on the prior work in South Carolina, researchers at the South Carolina Center for Health Services and Policy Research collaborated with the SC Office of Research and Statistics staff to examine several factors that could be used to identify specific areas of the state with access-related health problems for children. Within 2 months, geographic information system maps were generated (counties were grouped into those within 25% greater than or less than the statewide average and those lower or higher than this range) and counties were compared on a number of characteristics:

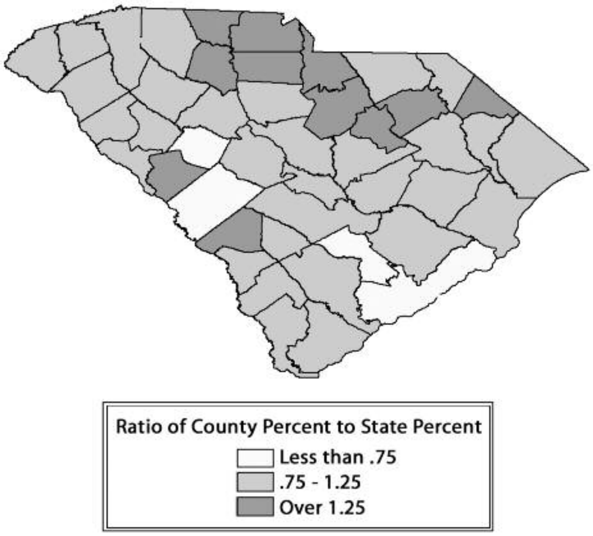
- All ambulatory care sensitive conditions and most common ambulatory care sensitive condition hospitalizations for persons under age 18 by
  - o Rate of ambulatory care sensitive condition hospitalizations per population.
  - o Percentage of ambulatory care sensitive condition hospitalizations as a percentage of all hospitalizations. (This adjusts for differences in overall utilization among counties.)
  - o Differences by payer.
- All ambulatory care sensitive conditions and most common ambulatory care sensitive condition emergency room visits for persons under age 18. (The same comparisons were used as above.)
- Rate of pediatric primary care health professionals per population under age 18 for each primary care service area.
- Percent of population with less than a high school education. (Used as a proxy for socioeconomic status.)

Maps for ambulatory care sensitive condition hospitalizations and emergency department visits used FY 2002 data; the darker counties were more than 25% above the statewide average and the lighter counties were more than 25% below the statewide average. The map for primary care physicians used 2001 data; the darker counties were more than 25% below the statewide average and the lighter counties were more than 25% above the average. So darker counties were likely to be areas with access-related problems for children. (See Maps 1-6.)

Map 1.
Rate of Ambulatory Care Sensitive Condition Inpatient Discharges



Map 2.
Ambulatory Care Sensitive Conditions as a Percentage of Inpatient Discharges

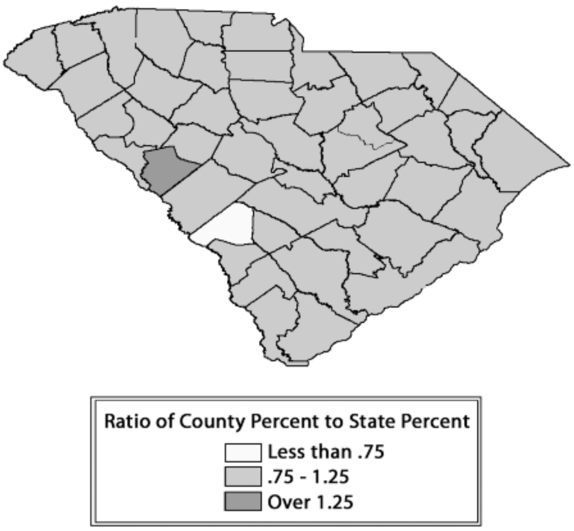


Potential Intervention Sites

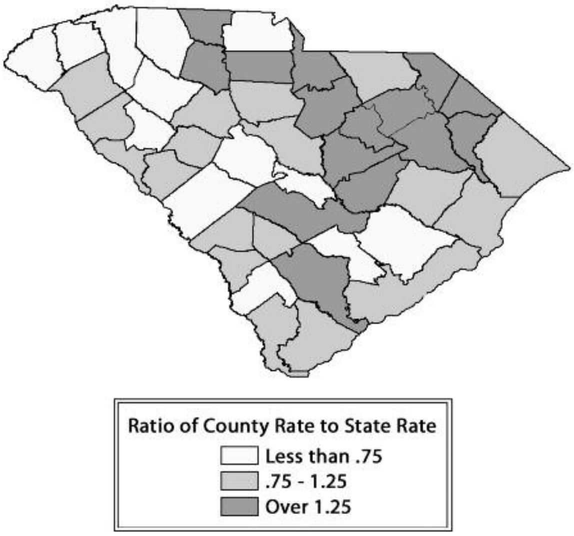
Using the geographic information system maps, 9 potential target counties were identified. Based on past involvement by The Duke Endowment and the availability of hospitals eligible for Endowment grants, 4 potential intervention sites were chosen. Table 1 presents some comparative data for these sites and for a county with similar demographics but a much lower ambulatory care sensitive conditions hospitalization rate.

Over the next 2 months, Center for Health Services and Policy Research staff conducted a series of key informant interviews with 6 to 8 key people in each of those communities

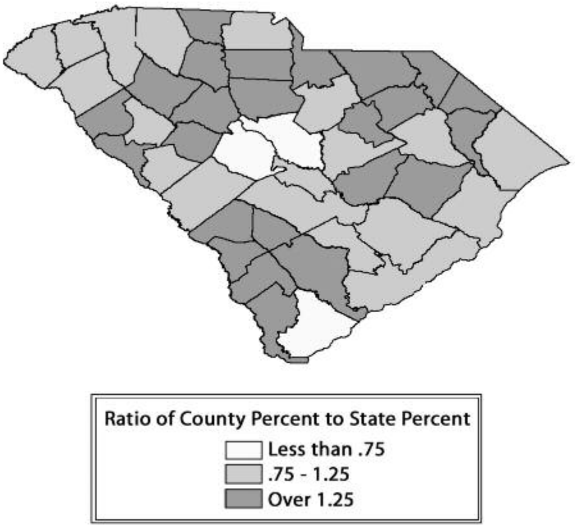
Map 3.
Ambulatory Care Sensitive Conditions as Percentage of Emergency Department Visits



Map 4.
Rate of Asthma Inpatient Discharges



Map 5.
Percentage of the Population with Less than a High School Education



Map 6.
Primary Care Physicians per 10 000

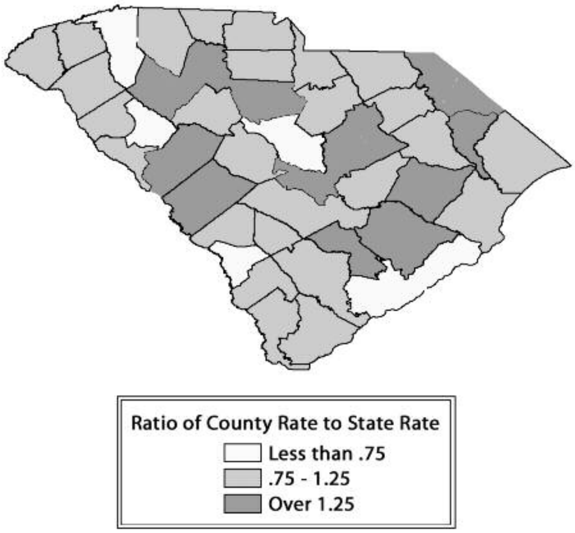


Table 1.
Actual Versus Expected Ambulatory Care Sensitive Condition Discharges, FY 2002

County	Actual	Expected, if at rate of:	
		Statewide Average	Laurens County
Dillon	309	90	65
Kershaw	425	145	106
Lee	120	56	41
Union	174	77	56

to identify the probable reasons for the higher rates. Key informants included hospitals administrators, health department staff, school nurses, community health centers staff, pediatricians, and other stakeholders. Individual reports were created for each community. Tables 2-5 summarize the common findings.

Forum for Potential Grantees

Similar geographic information system analyses and qualitative research were occurring in North

Table 2.
Major Child Health Problems

Asthma, allergy, upper resiratory infections
Obesity, nutrition
Diabetes
Mental health problems
Developmental delay
Teen pregnancy
Children presenting much sicker
Dental problems
Child abuse/neglect
Urinary tract infections/sexually transmitted diseases
Otitis media
Premature births

Table 3.
Barriers to Primary Care for Children

Transportation
Parental perception of importance of care
Lack of providers (especially Medicaid)
Lack of coordination, long waits, lack of follow-up
Family constraints: finances, job, child care, health coverage
Illiteracy
Poverty/working poor
Lack of care, translators, advocates for Latinos
Lack of awareness, outreach, advocacy

Table 4.
Common Needs

Transportation, including resources for non-Medicaid
Early periodic screening, diagnosis, and treatment resources, perhaps provided by school nurses
Spanish interpreters, outreach coordinators, advocates
Fund for non-Medicaid clients for prescriptions
Outreach, screening, education, coordination, advocacy, public awareness
Primary care centers
Physicians, nurse practitioners, nurses
More family support services/school nurses
Psychiatrists, therapists

Table 5.
Common Strengths

Caring, committed, and creative individuals working with and on behalf of children
Organized networks, interagency groups
Belief in collaboration to meet the critical needs of children in their communities
Strong "finger-on-the-pulse" awareness of needs of children in the communities
History of successful grant partnerships

Carolina. Staff from both states then assisted The Duke Endowment staff in developing a forum for potential grantees held in early summer 2003. Teams from each potential target county attended with the goal being for the attendees to consider the data for their areas, then consider interventions to improve access to primary care that The Duke Endowment would be willing to fund. The forum provided an opportunity for Endowment officials to explain in detail the concept of this funding initiative and for prospective target grantees to understand the proposal process. A key agenda item included data presentations by researchers from both state organizations that highlighted the specific data analyses and informant survey results for each of the target areas. Ample time was allotted for target area representatives to brainstorm with their respective research organizations regarding some of their ideas for improving access in response to the data presented and to suggest additional data that might enlighten their proposal processes.

The Duke Endowment Funded Projects

As a result of the forum and further technical assistance, 3 of the 4 target counties in South Carolina developed proposals that were subsequently funded by The Duke Endowment and implemented in early 2004. The proposals varied widely in their approach to addressing access to primary care.

- The Union County proposal emphasized postnatal home visits by public health nurses to link new parents to a variety of services. Some services were directly related to access (eg, linking infants to medical homes, education about recognition of health problems, and appropriate use of ER) while others were not related to access (eg, family planning, education on caregiving and injury prevention).
- In Dillon County, the proposal focused exclusively on children with asthma with the goal of reducing the burden of asthma in the county. Improving access to primary care for these children was just one of several different strategies to address asthma related problems.
- The Lee County proposal's stated purpose was "to reduce identified barriers to health care access" with strategies directly related to improving access such as referral, case management, establishment of medical homes, education regarding appropriate and timely use of the health care system, and resource development.

Follow-Up Data

Since, with expected implementation delays, the projects did not begin until 2004, the earliest expected effects of the programs would be visible in state fiscal year 2004-2005.

Discussion

This case example illustrates how health data can be used to help a foundation identify communities whose needs are aligned with the philanthropy's priorities. The relationship between access to primary care and hospitalizations for ambulatory care sensitive conditions is clearly established, and qualitative data can be used to identify specific needs, barriers, and strengths. The combination of these data can help communities consider the comprehensive nature of a problem and suggest strategies that reflect the community's resources and priorities.

This case example also illustrates the limitations of health data. Health data is but one factor a community will consider in determining its most important needs and the strategies to address them. The postnatal nurse home visiting program in Union County had been reduced due to budget cuts; restoring the program was a community priority even if it was only indirectly related to access to primary care. In Dillon County, data on high hospitalization rates for children with asthma (an ambulatory care sensitive condition) reinforced ongoing community concerns about children with asthma. As a result, strategies for improving access to primary care were focused on this limited population and other strategies were not related to access at all.

Tables 6-8 present data on pediatric admissions for ambulatory care sensitive conditions for each county during the 3 years before and 3 years after implementation. In terms of actual admissions, each county shows a substantial decrease from the 3-year average before implementation to the 3-year average after implementation–from 152 to 97 admissions per year in Union, from 264 to 156 in Dillon, and from 126 to 84 in Lee. However, since the statewide average was also decreasing over the same period, not all of those reductions can be attributed to the grant initiatives. **NCMJ**

Table 6.
Union County Ambulatory Care Sensitive Condition Discharges

	SFY02	SFY03	SFY04	SFY05	SFY06	SFY07*
Actual	174	144	138	112	103	75
Expected (at rate of state)	77	118	103	82	81	58
Ratio of Actual/Expected	**2.26**	**1.22**	**1.34**	**1.37**	**1.27**	**1.29**

*Quarters 3 and 4 of SFY 2007 are not finalized. The data is approximately 97% complete.

Table 7.
Dillon County Ambulatory Care Sensitive Condition Discharges

	SFY02	SFY03	SFY04	SFY05	SFY06	SFY07*
Actual	309	340	143	180	169	120
Expected (at rate of state)	90	203	136	128	111	112
Ratio of Actual/Expected	**3.43**	**1.67**	**1.05**	**1.41**	**1.52**	**1.07**

*Quarters 3 and 4 of SFY 2007 are not finalized. The data is approximately 97% complete.

Table 8.
Lee County Ambulatory Care Sensitive Condition Discharges

	SFY02	SFY03	SFY04	SFY05	SFY06	SFY07*
Actual	120	130	127	84	94	74
Expected (at rate of state)	56	90	85	67	65	54
Ratio of Actual/Expected	**2.14**	**1.44**	**1.49**	**1.25**	**1.45**	**1.37**

*Quarters 3 and 4 of SFY 2007 are not finalized. The data is approximately 97% complete.

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COMMENTARY

The North Carolina Trauma Registry

Michael H. Thomason, MD, FACS

Unintentional injuries are the leading cause of death in North Carolina and throughout the United States for ages 1 to 44, with medical expenditures of $117 billion each year.[1,2] Optimal care of seriously injured patients requires an organized and coordinated approach by emergency medical services (EMS), hospitals, and other health systems. The Office of Emergency Medical Services (OEMS) is the lead agency for coordinating trauma care in North Carolina and began designating individual trauma centers in the 1980s.[3] The Trauma System Act of 1993 enabled development of an inclusive statewide trauma system with every acute care hospital required to affiliate with 1 of the 7 newly created Regional Advisory Committees (RACs). Each RAC is led by a regional Level I or Level II trauma center[a] and is expected to develop regional treatment protocols, transfer guidelines, and programs for education, training, and performance improvement.[4] Unfortunately, the legislation which created the trauma system and RACs was an unfunded mandate, so efforts to build and support it to date have been voluntary and the establishment of an integrated, inclusive trauma care system has been incomplete.

> *"The goal of the coordinated data system is inclusion of all state EMS agencies, acute care hospitals, and other providers in an organized, multidisciplinary, data-driven structure to provide optimal quality care for all injured patients throughout North Carolina."*

The North Carolina Trauma Registry (NCTR) was created in 1987 as a cooperative effort between the state's trauma centers and OEMS to facilitate the collection of consistent data on all injured patients admitted to the trauma centers. Each of the 11 trauma centers in North Carolina (6 Level I, 3 Level II, and 2 Level III) are required to collect and submit data using NTRACS (National Trauma Registry of the American College of Surgeons) software. Over 250 data points are collected on each trauma patient, with standard data definitions provided in a data dictionary which is regularly revised and updated. Since 1994 the registry has collected data on more than 200 000 patients treated at North Carolina's trauma centers.[4]

Data from the registry has been a resource for many scientific publications over the past 20 years, including those focusing on the evaluation of care and outcomes of specific injuries, causes of injury, impact of injury prevention equipment such as seat belts and motorcycle helmets, and in other benchmarking and outcomes studies. The NCTR Research Review Committee and Publications Committee oversee access to registry data and assure that resulting publications are accurate and maintain confidentiality of the patients and hospitals. However, since state law only mandates data submission by designated trauma

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[a] Level I and II trauma centers provide comprehensice care for trauma patients, and serve as regional resource centers. Level III centers provide initial stabilization of injured patients, with transfer to Level I or II centers for those patients with more complex or critical injuries.

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centers, the registry does not currently provide a population-based profile of injured patients cared for in more than 100 acute care hospitals throughout the state.

The impact of the NCTR on health policy decisions has thus been somewhat limited. Several databases currently contain information on injured patients throughout the state, including the NCTR, PreMIS (the EMS prehospital database), and NC DETECT (the North Carolina Division of Public Health database which is updated daily with information from all emergency department visits to hospitals in North Carolina). These various databases must be linked to provide a comprehensive profile of injury in North Carolina, and efforts are currently underway to do so. If successful, this will create a registry, maintained and administered by OEMS, with accurate and accessible data to support ongoing evaluation of the evolving trauma system with benchmarking for performance improvement and outcomes research, injury prevention, and public health planning. The goal of the coordinated data system is inclusion of all state EMS agencies, acute care hospitals, and other providers in an organized, multidisciplinary, data-driven structure to provide optimal quality care for all injured patients throughout North Carolina. **NCMJ**

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COMMENTARY

Transforming Care in the Physician Workplace Through Electronic Data Exchange

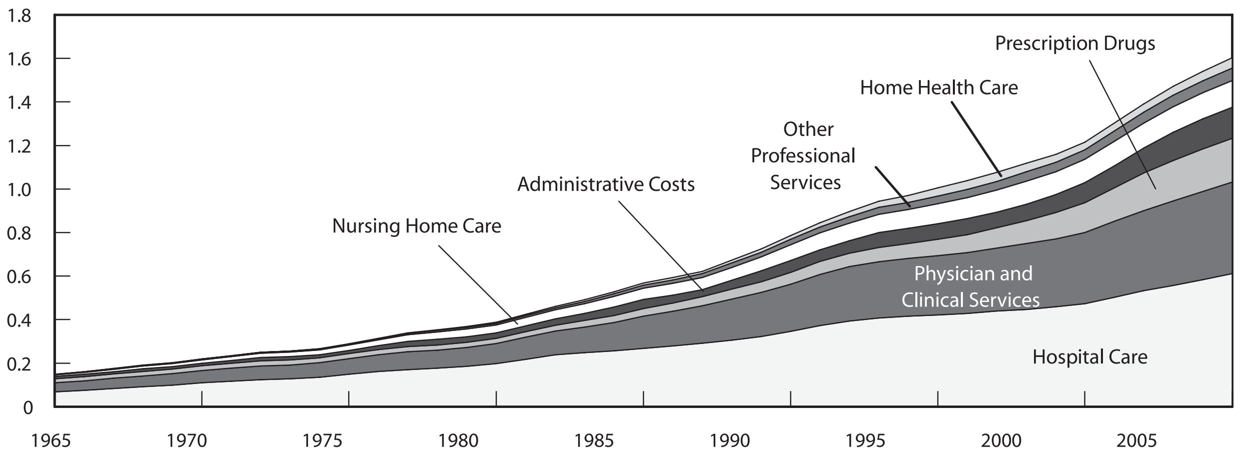
Holt Anderson; Gary Bowers

In 2007 total national health expenditures were expected to rise 6.9%—2 times the rate of inflation. Total spending was $2.3 trillion in 2007 or $7600 per person. Total health care spending represented 16% of the gross domestic product (GDP).[1] Health care spending in the US is expected to increase at similar levels for the next decade reaching $4.2 trillion in 2016 or 20% of GDP.[1] (See Figure 1.)

A study by the Congressional Budget Office, *Technological Change and the Growth of Health Care Spending*, published in January 2008 estimates that the percentage of GDP spent on health care will grow from 16% in 2006 to over 20% within a few years due to the aging population and growth in chronic care expenditures, and if left unchecked, will approach 49% of GDP by 2082.[2] (See Figure 2.)

> *"The danger of missing information is increased with the dispersal of care among multiple specialists serving patients with a variety of chronic conditions."*

Figure 1.
Real Spending on Health Care in Selected Categories, 1965 to 2005 (Trillions of 2005 dollars)



Source: Congressional Budget Office based on data on spending on health services and supplies, as defined in the national health expenditure accounts, maintained by the Centers for Medicare and Medicaid Services.

Note: Spending amounts are adjusted for inflation using the gross domestic product implicit price deflator from the Bureau of Economic Analysis.

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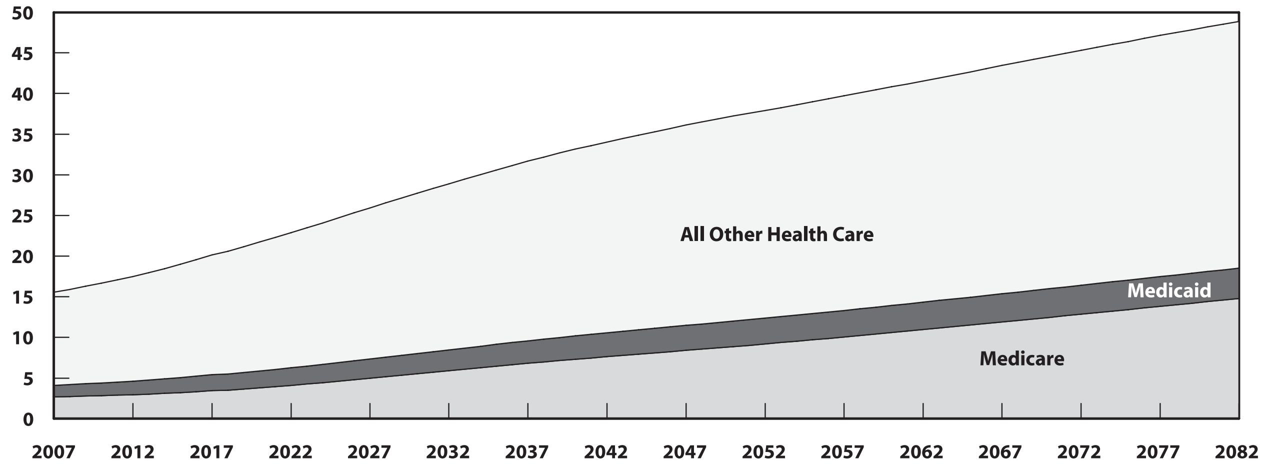
Gary Bowers is executive director of the Western North Carolina Health Network.

Figure 2.
Projected Spending on Health Care as a Percentage of Gross Domestic Product, 2007 to 2082 (Percent)



Source: Congressional Budget Office.
Note: Amounts for Medicare are net of beneficiaries' premiums. Amounts for Medicaid are federal spending only.

The fiscal impact of these increases in overall spending for health care in relationship to limited growth in tax revenues or corporate profits will force choices that may accelerate the number of uninsured and underinsured individuals and increase pressure on reimbursements to practitioners, hospitals, and other related services. Often cited reports including those from the Institute of Medicine of the National Academies such as *To Err is Human* and *Crossing the Quality Chasm* highlight the human and economic costs of inefficient and paper-based care and encourage a swift movement to electronic health records and secure electronic health record exchange.[3,4] Work is being done by the North Carolina Healthcare Information and Communications Alliance (NCHICA) and others to build an economic business case that will support the transition to electronic health records in the practice setting where the cost and change in work flow have deterred adoption up to this point.

The Role of Quality in Improving Health Care Safety and Outcomes

The North Carolina Medical Society established the Quality of Care and Performance Improvement Committee to examine the relationship between better information management and practitioner job satisfaction and improvements in the quality of care provided. Evidence is emerging that practitioners who use electronic health records keep their patients healthier through built-in structured reminders and avoid mishaps by using electronic prescribing with automatic drug-to-drug interaction checking.[5] The current system of prescribing and dispensing medications in the United States has widespread problems with safety and efficiency. Experts predict that a shift to electronic prescribing (e-prescribing) systems could avoid more than 2 million adverse drug events annually, of which 130 000 are life-threatening.[6] E-prescribing also has enormous potential to create savings in health care costs through reduction of adverse drug events and in improved workflows. One recent study estimated the potential savings at $27 billion per year in the United States.[7]

By design, practitioners also are in a better position to take advantage of incentive programs such as Bridges to Excellence and increased reimbursements from Medicare. The Bridges to Excellence North Carolina initiative is one that encourages the use of electronic health records in practitioner offices to improve health care for partner health plan members. In North Carolina the Bridges to Excellence program provides funds to practices that are certified by the National Committee for Quality Assurance as having certain electronic and process capabilities and that serve members of health plans whose employers have subscribed to the Bridges to Excellence program. This program is showing participating employers that employees served by physicians who have electronic health records are healthier, have chronic conditions better under control, and have fewer trips to emergency departments. In turn, the health plan saves money, providing the business justification for paying incentives to physicians using electronic health records.[8]

Better and More Timely Information at the Point of Care Drives Quality

Lack of timely and reliable information about a patient has the effect of slowing accurate diagnosis and treatment. Such a delay can be frustrating for physicians and dangerous for patients, especially if knowledge about allergies and medications is not available when prescription orders are being entered. The danger of missing information is increased with the dispersal of care among multiple specialists serving patients with a variety of chronic conditions.

In a recent request for proposals, the Agency for Healthcare Research and Quality stated that the burden of providing treatment and supportive services for individuals with complex health care needs continues to increase.[9] In 2000, 60 million Americans had multiple chronic conditions, and it is projected that this will rise to over 81 million by 2020.[10] Yet care for these patients is often fragmented across multiple settings and across providers—with limited or no communication or coordination and no sense of overarching responsibility. Patients often do not seek services until there is some crisis in their condition, a crisis that may have been avoided had they sought care earlier or if their care had been better coordinated. Also, these transitions in care are often accompanied by changes in a patient's functional status which may further complicate future care needs.[9]

Information management is key to addressing these issues because it provides physicians with better and more organized information which saves them time and achieves better diagnoses and treatments (and healthier patients). Furthermore, the time saved can translate into more patients served. While there is a steady increase in the numbers of practitioners and practices adopting electronic health records, the cost and required workflow changes present barriers to many practitioners. However, a business case is being made for overcoming these barriers as peer practitioners show evidence of the benefits of electronic health records and payers begin to offer incentives for their use.

Health Information Exchange Networks

As more practitioners adopt electronic health records, additional issues arise. Of primary concern is the ability to share information collected across provider groups as needed to serve patients. As such, hospitals and health systems are building referral networks in their communities to connect radiology, labs, and pharmacies through community health information exchange (HIE) networks. In order for these networks to succeed, they must address a number of issues including data compatibility and privacy. Following a 2004 Presidential Executive Order, the US Department of Health and Human Services established the Office of the National Coordinator of Health Information Technology (ONC). The Office of the National Coordinator was tasked with facilitating privacy and security, developing and recommending standards for certification of applications, harmonizing codes, and building a "network of [community] networks, that will enable most Americans to have an electronic health record by 2014."[11]

Sixteen hospitals in western North Carolina have been recognized as leaders for their early implementation of a community HIE network which is called WNC Data Link. Their vision was to create a network to connect all of the regional hospitals to enable the sharing of electronic longitudinal records for patient care. Through WNC Data Link authorized physicians can quickly access patient lab results, medications, radiology reports, discharge summaries, histories and physical examinations, and other information from any hospital in the region via the Internet. WNC Data Link has become particularly valuable as patients transfer between hospitals and also in emergency departments where immediate access to patient information is vital. The next phase of this initiative will link physician practices and other providers to this network.

North Carolina has a number of unique capabilities and organizations that can lead the transformation from an inefficient, paper-based system of care to a high-quality environment that enhances the practice of medicine, improves efficiencies and outcomes, and makes our state even more attractive for business. NCHICA is being recognized nationally for its past and current activities as described below.

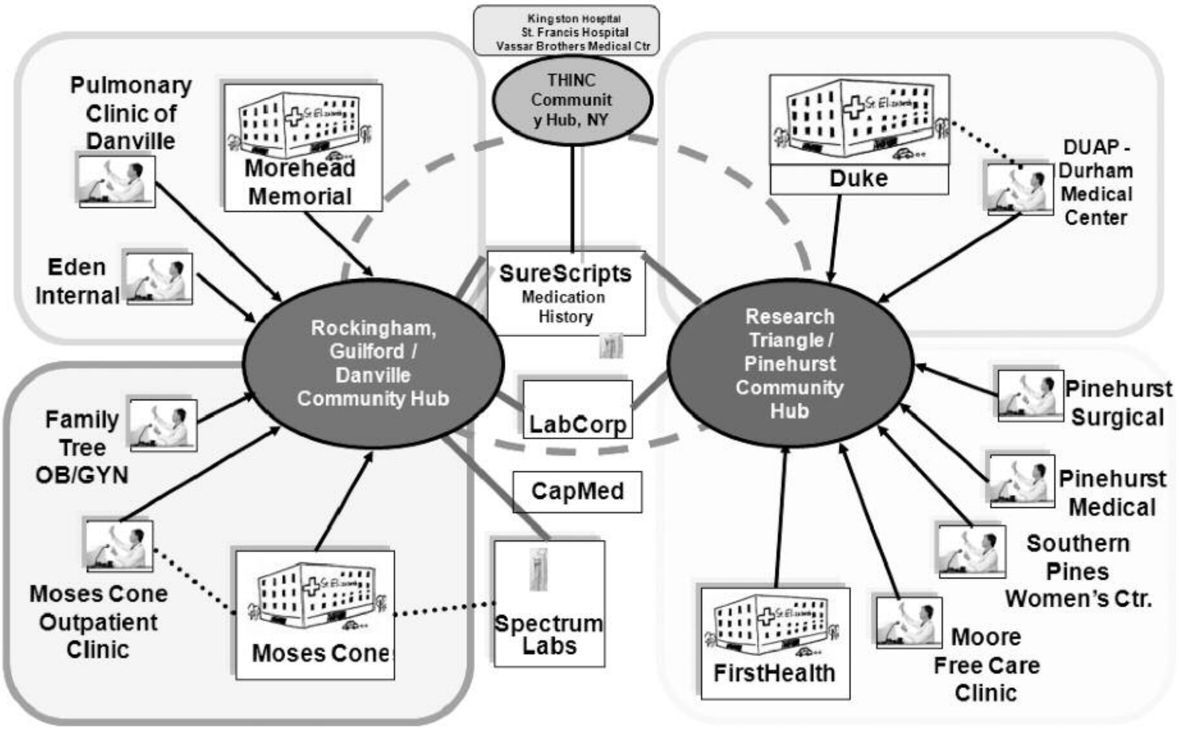
1. **North Carolina is involved in national efforts to transform health and care through the North Carolina Healthcare Information and Communications Alliance (NCHICA).**

NCHICA was formed in 1994 by Executive Order of the Governor of North Carolina as a nonprofit organization with a mission of "improving health and care in North Carolina by accelerating the adoption of information technology and associated policies."[12] NCHICA fosters collaboration among all sectors of health and care and works on policy and technology solutions that enable secure health information exchange.

North Carolina has received significant funding for 2005-2008 to participate in national efforts to develop better laws and regulations that enable exchange for treatment purposes. At the request of the Office of the Governor, NCHICA applied for and received a contract from the Agency for Healthcare Research and Quality (AHRQ) and the Office of the National Coordinator for Health Information Technology (ONC) to study business practices, laws, and regulations that have the effect of impeding the exchange of electronic health information that is required for treatment purposes.[13] Among the barriers revealed by the study, the most prominent was confusion over the Health Insurance Portability and Accountability Act (HIPAA) and the labyrinth of state and federal laws and regulations governing consents and privacy. After a legal analysis was completed, a legal work group developed recommendations for solutions and how changes might be implemented. North Carolina and 33 other states collaborated on this phase of the work that concluded at the end of 2007. In the next phase, underway in 2008, North Carolina will collaborate with other states in the development of intrastate and interstate consents and interorganizational agreements that will enable the secure exchange of information in a consistent manner that takes into consideration concerns over liability and standards.

Another major project involves North Carolina and a select group of states in the development of policies and technologies to support 2 phases of the Nationwide Health Information Network (NHIN): Architecture Prototypes and Trial Implementations. North Carolina participated in the development of the Architectural Prototype of the NHIN in 2006 and early 2007. This development was led by IBM with a subcontract to NCHICA. This phase included participation by the organizations shown in Figure 3.

Figure 3.
Nationwide Health Information Network, Phase 1



Source: North Carolina Healthcare Information and Communications Alliance, Inc.

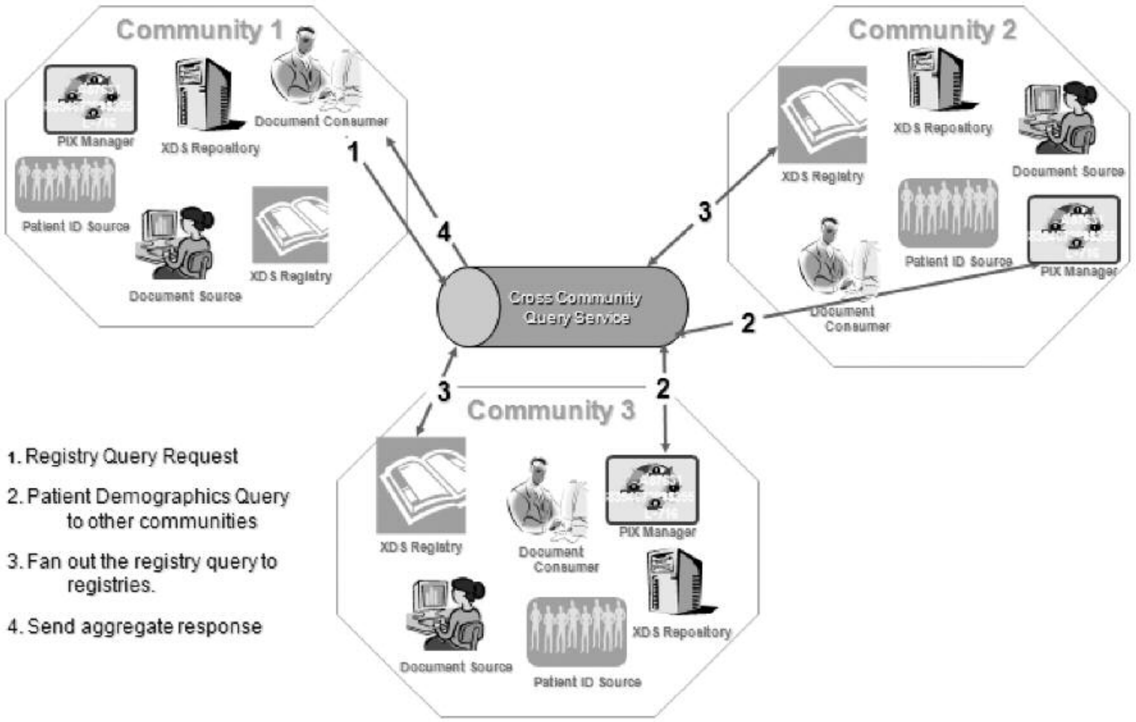
As communities continue to build their own HIE capabilities, the challenge will be to connect neighboring communities, regions, and states. The vision is for this network to eventually become nationwide and possibly worldwide. It is clear that the best business case for greatest value can be made for the community HIE network where over 90% of all traffic will occur. Less justifiable is the cost to construct and maintain a cross-continental capability that would be rarely used. However, if the "network of networks" is constructed for clinical exchange on the local level, the connections and security capabilities would be useful for national and regional activities such as public health and claims/payments that cross community boundaries. Figure 4 graphically displays how a locator and switching service might be established to serve multiple communities in a region. The connections in a nationwide "Network of Networks" are represented in Figure 5.

2. **The North Carolina Health Information Exchange (NC HIE) Council was formed to develop consensus strategies and actions that will keep North Carolina on the forefront of health information exchange efforts.**

The NC HIE Council was formed in 2007 as a consensus-building body of knowledgeable individuals representing the leading sectors of health and care in North Carolina. The Council includes representatives from the following:

- North Carolina State Health Director or designee
- North Carolina State Chief Information Officer or designee
- North Carolina Consumer Advisory Council on Health Information
- North Carolina Medical Society
- North Carolina Hospital Association
- North Carolina Nurses Association
- North Carolina Health Information Management Association
- North Carolina Association of Pharmacists
- North Carolina Health Departments
- North Carolina Office of Emergency Medical Services
- North Carolina Association of Free Clinics
- North Carolina Division of Medical Assistance
- North Carolina Division of Mental Health, Developmental Disabilities, and Substance Abuse Services
- North Carolina Association of Health Plans
- Health Information Exchange
- Private-sector behavioral health organizations
- Long-term care/nursing homes
- Laboratory service providers
- Radiology service providers
- NCHICA CIO Roundtable
- At-large members appointed by NCHICA Board of Directors

Figure 4.
Nationwide Health Information Network, Architecture



1. Registry Query Request
2. Patient Demographics Query to other communities
3. Fan out the registry query to registries.
4. Send aggregate response

Source: North Carolina Healthcare Information and Communications Alliance, Inc.

Figure 5
Nationwide Health Information Network, Architecture

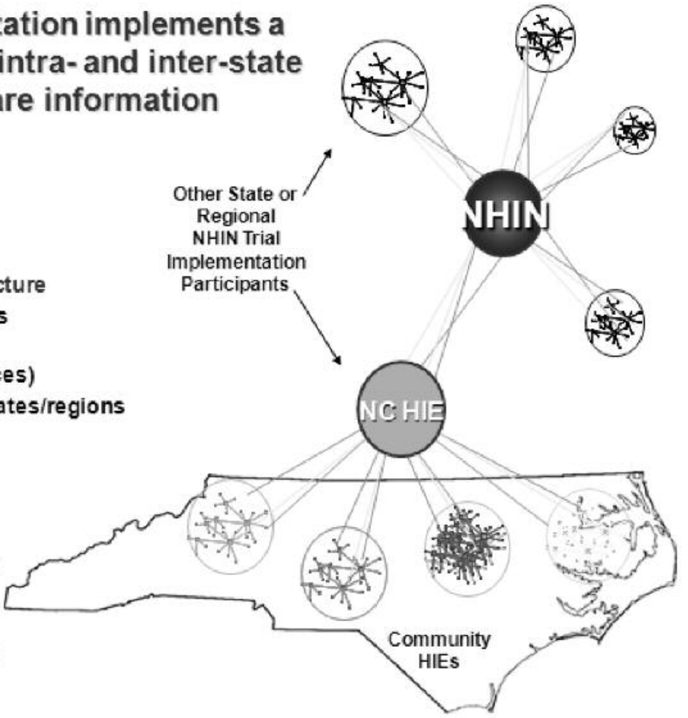
The NHIN Trial Implementation implements a "network of networks" for intra- and inter-state exchange of healthcare information

NC HIE

- Convener, Educator, Facilitator
  - Privacy/security framework
  - Standards/reference architecture
- Incubator for piloting new concepts
- Utility for Foundational Services (e.g., EMPI, Record Locator Services)
- NHIN compliant linkage to other states/regions

Community HIEs

- Encourage EHR adoption and "last mile" connectivity
- Develop real-time patient summary and data aggregation capabilities
- Provide training and education
- Engage non-provider stakeholders (payers, employers, public health)



Source: North Carolina Healthcare Information and Communications Alliance, Inc.

It is the mission of the NC HIE to enable the timely and secure exchange of electronic health information among its authorized members for the purposes of:

- Improving the quality of health and care provided to individuals in North Carolina.
- Improving the efficiency of the health care system in North Carolina.
- Enhancing patient safety in North Carolina.
- Improving the overall health of North Carolina's residents.

The NC HIE Council will develop policies and procedures that facilitate these objectives and may contract with one or more health care information service providers to operate a health information exchange network to fulfill this mission.

3. **The North Carolina Consumer Advisory Council on Health Information was formed in response to privacy concerns.**

In 2006 NCHICA established the North Carolina Consumer Advisory Council on Health Information in response to consumer concerns regarding privacy and the move to electronic health records with the attendant ability to share personal information across networks. These concerns connect broadly with the vision of a national and international capability to move information to any point on the globe. The Council is expected to become informed about both North Carolina and national initiatives and to advise NCHICA on policy and technology matters.

4. **A series of regional town meetings will be held in the spring and summer of 2008 to inform North Carolina residents of NCHICA efforts and how they can become engaged in the process.**

At the urging of its members, NCHICA will undertake a series of educational town meetings in various regions of North Carolina in the spring and summer of 2008. NCHICA representatives will share information about state and national initiatives and solicit feedback regarding local priorities that will help shape future efforts. Expected attendees are physicians and nurses, hospital administrators and chief information officers, business and political leaders, and other individuals interested in increasing health information exchange to improve quality of care and to positively impact the cost-effectiveness of the health system in North Carolina. This is particularly important as we balance the increasing demand for services with the limited resources to pay for those services.

The future looks bright for transforming health and health care practices in North Carolina from the inefficient, paper-based environment of today to the advanced electronic systems of tomorrow. Such a transformation will support health professionals in their delivery of high-quality care to their communities and will elevate North Carolina into a position of national leadership. **NCMJ**

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COMMENTARY

Training Health Care Personnel to Work with Health Care Data

Elizabeth Layman, PhD, RHIA, CCS, FAHIMA

The Institute of Medicine of the National Academies (IOM) has recognized since the early 1990s that the United States needs an electronic health record system.[1-3] An electronic health record system is the keystone of the US Department of Health and Human Services' overarching initiative to increase the use of health information technologies in the health care sector. Two IOM reports, *To Err Is Human: Building a Safer Health System* and *Crossing the Quality Chasm: The IOM Health Care Quality Initiative*, particularly encouraged the migration to electronic health record systems.[4,5]

Underpinning the requirements for health care data are the recommended 8 core functionalities and 6 key capabilities of electronic health record systems.[3] A brief review of selected core functionalities and key capabilities suggests the extensive scope of health care data that is needed. For example, health information and data is a core functionality. Data associated with health information are patient or client demographics, facility and provider identification, encounter dates, admission and discharge dates, disease and service codes, clinical notes, problem lists, and medication lists. Decision support is another core functionality. Limited examples of health care data needed for decision support are warnings and contraindications for medications, out-of-range values for laboratory tests, and reminders for interventions and screenings. Reporting and population health management is another core functionality. A few examples of health care data needed for this management include specimens, procedures, results, laboratory identification, patient's temperature, outbreak data, adverse event reports, and registry data.

> *"Effective use of health care data means that health care personnel, health care organizations, and health care systems have real-time information about the health of individuals and of populations…"*

The 6 key capabilities describe what electronic health record systems should be able to do. The first key capability is longitudinal collection of data for and about individuals. Thus, electronic health record systems should be able to assemble the health care data about an individual across the span of that individual's life from all the sites of health care delivery. Examples of these sites include hospitals, physician offices, health departments, pharmacies, fitness centers, student health services, radiologic centers, dental offices, ophthalmologic practices, mental and behavioral health centers, rehabilitation units, and skilled nursing facilities. Related to longitudinal collection is interoperability, another key capability. Interoperability allows linkages among providers. Through these linkages, providers are able to exchange data. For example, dental offices can check insurance eligibility and benefits. Another important capability is that electronic health record systems allow authorized users to access individual and aggregate data. Thus, in addition to supporting clinical decision making at the point of care, electronic health record systems allow policy makers to analyze aggregate data. The key capabilities, therefore, support the delivery of integrated health care to individuals and to populations.

The variety, sources, and uses of health care data indicate the complexity of the training effort that is needed. After training, health care personnel should be able to transform individual health care data elements into information and information into knowledge. With knowledge, the health care sector can

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promote high standards, interoperability, and effective use of health care data.

High standards of care are represented by evidence-based practice. Evidence-based practice can be the use of medical and health knowledge in external referent systems or the use of standards promulgated by the professional associations and oversight entities. One key capability of electronic health record systems is the ability to connect to external knowledge such as drug references, clinical laboratory tests manuals, and anatomical references. For health care organizations, an example of a high standard of care is assuring that providers have complete health records upon which to base diagnosis and treatment. Evidence-based practice may also be supported by clinical guidelines and quality measures. For example, the National Quality Measures Clearinghouse sponsored by the Agency for Healthcare Research and Quality lists quality measures by professional association/developer, disease/condition, treatment/intervention, and measure.[6] These measures are data driven. The mortality rate for acute myocardial infarction per 100 discharges requires data on diagnostic codes, discharge status, and numbers of discharges. In addition, to put the rate in context, data on numbers of transfers, on length of stay, and on risk factors are also needed. In another example, the Centers for Medicare and Medicaid Services has process measures that require data to calculate median time from arrival at a hospital to the administration of fibrinolytic agents in patients with ST segment elevation and to calculate the percent of patients with acute myocardial infarction who have a history of smoking cigarettes and who receive smoking cessation counseling during the hospital stay. Thus, health care data can support quality improvement when the data are available in real time at the point of clinical decision making as well as retrospectively when they are available for analysis.

Interoperability is based on messaging standards or data exchange standards for information systems. These standards enable health care data to be exchanged and used among information systems across multiple sites of care. Many organizations have been involved with the development of these standards, and a lack of coordination has impeded interoperability. Examples of standards include Health Level 7 (HL7); clinical medical vocabularies such as the Systemized Nomenclature of Medicine, Clinical Terms (SNOMED-CT), Logical Observation Identifiers Names and Codes (LOINC), and the Unified Medical Language System (UMLS); and Digital Imaging and Communications in Medicine (DICOM). E-prescribing has been made possible by the National Council for Prescription Drug Programs (NCPDP) standards. The American National Standards Institute (ANSI) has developed messaging standards for the exchange of financial and administrative transactions. The ASTM (formerly American Society for Testing and Materials) has created many standards for electronic health record systems in the areas of health data security, record content, and the continuity of care record. Recently, a working group of the American Health Information Community has been very active in recommending and testing interoperability specifications (IS).[7] Functional electronic health record systems are dependent upon the coordination of these many standards.

Effective use of health care data means that health care personnel, health care organizations, and health care systems have real-time information about the health of individuals and of populations and that they have this information when they need it and in formats they can easily understand. For example, when opening the record of a patient with diabetes, the endocrinologist has immediate access to HbA1c values both as raw data and as a line graph. Moreover, if the patient was hospitalized in another state, the HbA1c values from the out-of-state hospital stay have automatically flowed into the physician's record. In terms of effective use of health care data at the organizational level, the medical group to which the endocrinologist belongs can aggregate the data for its patients with diabetes. In another example, health care data will flow—when authorized—from the hospital to the home health agency or from the rehabilitation center to the durable medical equipment vendor. At the system level, effective use of health care data would allow policy makers, administrators, and analysts to project demand, supply, and distribution of health care personnel. Generally, effective use of health care data also requires that health care personnel, health care organizations, and health care systems can manipulate the data to create knowledge about individuals' and populations' health at any point in time as well as over time.

Within health care organizations, the key health care personnel needing initial training are physicians, nurses, information service technicians, and clerical personnel. Physicians and nurses generate the volume of health care data. Information service technicians could anticipate report structures if they understood secondary uses of health care data in accreditation, regulation, and reimbursement. Training clerical personnel would enhance the accuracy of data entry. This training could be received in many formats including continuing education at conferences, on-site sessions in education departments of health care organizations, online continuing education from universities, and formal classes at community colleges and universities.

According to a recent report, 1000 public health informaticians and 1000 public health executives with informatics leadership training are needed in the health care system by 2010.[8] A public health informatics officer would be placed in each state health department. The authors of the report recommend both continuing education and formal education.

Nationally, several training and educational opportunities exist, many of which are online. The American Medical Informatics Association (AMIA) is developing a certification for physician clinical informaticians.[9] Under a grant from the Robert Wood Johnson Foundation, the AMIA is also developing a core content document and a draft set of training requirements for a physician subspecialty in applied clinical informatics.[9] Additionally, in order to generate sheer numbers, the AMIA has the "10x10" initiative or 10 000 clinical informaticians by the year 2010.[10] Under this initiative, universities, professional medical associations, and the AMIA itself are offering single and multiple courses to expand the knowledge of electronic health records, health care quality, exchange standards, public health informatics, and bioinformatics. Examples of initiatives include the Centers for Disease Control and Prevention two-year fellowship in public health informatics[11] and the Technology Informatics Guiding Education Reform (TIGER) Initiative which aims to make informatics a nursing competence.[12] The establishment of these initiatives represent current efforts to prepare health care personnel to use health care data.

In North Carolina, several options exist to train people to work with health care data. First, North Carolina has a well organized and robust system of Area Health Education Centers (AHECs). A search of the statewide calendar identified an offering entitled "health information on the Internet."[13] The AHECs also offer online courses. Second, North Carolina has an extensive community college system. This system offers individual courses on health care data or one-year certificates and associate degrees in fields that use and manage health care data. Community college offerings are both face-to-face and online. Finally, campuses of the University of North Carolina system offer individual courses and baccalaureate, masters, and doctoral degrees in health or medical informatics. Some of these offerings are also online.[14] While these examples focus on systems in North Carolina, other states have similar systems.

A 2006 joint report of the American Health Information Management Association and the AMIA identified 2 levels of competence for health personnel, as both health information users and health information specialists.[15] Physicians and nurses are the prime health information users, while other users include health administrators, policy makers, and regulators who make decisions based on the data. Reimbursement specialists at a health insurance company are also health information users and use the data to determine whether to pay a claim. Health information specialists comprise health information managers, applied clinical informaticians, and information technology resource managers. These personnel work to assure the integrity of the technological infrastructure and the quality of the health care data. For example, they work to ensure the security of off-site storage and the accuracy of coded data. The competence required of these health information specialists and health information users depends upon the support available to them and the independence of their use of the health information.

Competence involves both breadth and depth of knowledge within domains. General domains include biomedical sciences; health care delivery system; information and communication technologies; information management planning; electronic health information systems; data standards; data privacy, security, and confidentiality; data analysis and outcomes (decision support, accreditation, regulation, accountability); and leadership. Minimal educational foundations needed to work with health care data include biomedical sciences, health care delivery systems, information and communication technologies, and regulations and accreditation standards. Health informaticians such as public health informaticians or nurse executive-informaticians would need knowledge across the 4 general domains. Dependent upon the discipline of the health personnel member, additional content areas could include classifications, nomenclatures, terminologies, and taxonomies; epidemiology; health law; organizational behavior and management; and research and statistics.

Within all the domains, the extent of expertise depends upon the role of the health personnel member. For example, a telehealth communications specialist setting up the connection between a local physician at an assisted living center and a tertiary care center needs to know the definitions of the sites in the continuum of care so he or she will know what assisted living centers and tertiary care centers are. On the other hand, an inspector from the North Carolina Division of Health Service Regulation not only needs to know all the sites of care but also all the regulatory requirements for each of those sites. Determining how wide and how deep people need to be trained will require ongoing study and review by professional associations and academic disciplines as electronic health records develop and spread throughout the continuum of care.

Promoting high standards for quality through interoperability and effective use of health care data are compelling reasons to train health care personnel to understand how to use health care data. Current health personnel need training through continuing education, and future health personnel need training in their basic and academic preparation. A sustained effort is needed to achieve the long-term goal of a data-prepared workforce. **NCMJ**

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COMMENTARY

Do We Have All of the Public Health Information We Need in North Carolina?

William D. Kalsbeek, PhD

Much of the progress in public health at the national, state, and local levels has depended on information about the populations that are served. Indeed, successes in dealing with susceptibility to infectious disease, injury, tobacco use, dental disease, and other major health issues of the past century have occurred because of the availability of objective scientific evidence to inform the development and affirmation of steps in the right direction. This evidence has also served as a signal to halt misguided steps and thus winnow out ideas that have proven to be ineffective. But science has only played a partial role in advancing the health of the population. Some decisions have been made based on anecdotal evidence, political expediency, and organizational inflexibility to change. A 1988 Institute of Medicine of the National Academies panel further noted that in reality, many program and policy decisions in public health are made as a reaction to the pressure of hot-button issues and organized interest groups.[1]

This article first examines the role of information in public health decision-making and then touches on some steps to assure that future decisions affecting the health of North Carolina's citizens will be made with the best information available. By implication, I suggest that continued progress towards improving the health of North Carolinians will be made most expeditiously by having the best population-based data systems available.

Data and Information in Decision Making

Within the past 10 years several practitioners and academic researchers have proposed more formal frameworks for integrating the use of objective evidence in public health decision making.[2-5] The adoption of this notion in practice has come to be called evidence-based public health (EBPH), which Ross Brownson and colleagues have defined as "the development, implementation, and evaluation of effective programs and policies in public health through application of principles of scientific reasoning including systematic uses of data and information systems and appropriate use of program planning models."[2]

Three "tools and processes" recommended for EBPH involve using data gathered from those who are affected by decisions. *Risk assessment* requires data on public exposure to harmful physical and chemical agents, *economic evaluation* weighs the cost of a population-directed intervention against the impact on those to whom the intervention is directed, and *public health surveillance* involves a continuing effort to profile relevant health-related behaviors, exposures, and outcomes in the general population.

> *"…continued progress towards improving the health of North Carolinians will be made most expeditiously by having the best population-based data systems available."*

Surveys and administrative records are 2 common sources of data for EBPH. A survey involves systematic data collection by having respondents complete a specifically designed questionnaire. These respondents are usually selected from a carefully chosen sample to reflect a broad cross-section of the studied population. Administrative records contain data that are recorded as an inherent part of a health-related process that affects a selective part of the population (eg, those who have visited a hospital, are Medicare beneficiaries, are members of a managed health

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care organization, or have a particular disease). Administrative data are less expensive to use when they are available as a data source, but surveys are more adaptable to specific needs since the questionnaire and sample designs are based solely on the information needs the survey is intended to meet. Sometimes administrative data are used to improve the quality or reduce the cost of surveys.

However having appropriate data is not sufficient for EBPH to work since "data" and "information" are related but not equivalent concepts. There are two types of data: *micro data* and *macro data*. *Micro data* are bits of information about individual members of a population such as what a survey respondent reports as the status of his or her private health insurance coverage (ie, covered or not covered). These member-specific data may be used to form *macro data* for the population as a whole or for important geographic or demographic subgroups—for example, the percentage of persons in Bertie County who are covered by private health insurance. Data become *information* when findings from macro data provide answers to questions that are raised in making decisions. For instance, to deal with access to health insurance we may need to know which counties in North Carolina have the lowest private insurance coverage rates or if private insurance coverage is statistically associated with personal employment status. Answering questions that arise during decision making requires the technical ability to work with micro data as well as the ability to interpret macro data findings. Thus the mere existence of micro or macro data does not imply that we have the information we need.

Information must also be scientifically valid to be useful in decision making. The right kind of data and the resources to produce information are needed to create credible information about the general public. For example, estimating the rate of private health insurance coverage from a sample of those who have visited doctors' offices would produce invalid findings if those seen by a doctor are more likely to be insured than those who are not seen by a doctor. In this context resources are ultimately the financial wherewithal to assure that those using the data will be familiar with the statistical methods needed to transform micro data into the kinds of macro data that will inform decision making.

Gathering useful micro data, particularly in public health surveillance, must therefore follow well-established principles of survey practice.[6] The wording of questions used to produce micro data items must be appropriate for the type of macro data that are needed, samples must be representative and large enough to meet established standards, and the statistical estimation approach used to produce macro data findings from micro data items must properly take into account how the sample was chosen.

Data and Public Health Information in North Carolina

The capacity to create data and produce public health information from them is well-established in North Carolina. The State Center for Health Statistics (SCHS) in the Division of Public Health has a long history of effectively compiling and reporting data from all births and deaths as part of the state's vital registration system. The State Center for Health Statistics also compiles data from other targeted sources of health data including case registries, hospital and emergency room visits, and reported pregnancies. The SCHS collects and disseminates data from the following 3 sample surveys of all North Carolinians in specific age ranges:[7]

- *The Pregnancy Risk Assessment Monitoring System (PRAMS).* An annual mail-plus-telephone survey of about 2400 recent births on childbirth, maternal behavior, and morbidity. PRAMS is conducted in collaboration with the national Centers for Disease Control and Prevention (CDC).
- *The Behavioral Risk Factor Surveillance System (BRFSS).* An annual telephone survey of 15 000 to 17 000 persons 18 years and older that covers various topics on health promotion and disease prevention. BRFSS is also conducted jointly with CDC.
- *The Child Health Assessment and Monitoring Program (CHAMP).* An annual telephone follow-up survey of 3000 BRFSS households with children under age 18 years covering topics on child health and development.

The paper by Paul Buescher in this issue of the *Journal* more fully describes each of the SCHS data sources. The Survey Research Unit (SRU) at the University of North Carolina (UNC) at Chapel Hill School of Public Health has also conducted many important health-related telephone surveys of North Carolina citizens in recent years. These studies have covered a broad range of topics including back and neck pain, health care utilization, domestic violence, youth labor injury, and oral cancer.[8] Staff from the SRU have also assisted the SCHS and the CDC to develop and refine the designs for many of the surveys they conduct.

Are There Unmet Information Needs?

Clearly the statewide surveys conducted by the SCHS and the SRU have addressed a wide range of health topics and population groups—to the point that one might suspect that the state has all the public health data it needs. I am skeptical of this notion, however, since a closer look at the designs of these surveys reveals the potential for gaps affecting important parts of public health practice. For example, while the BRFSS sample is sufficiently large to produce a wide variety of acceptably precise estimates at the state, regional, and county levels, it does not currently include topics like health insurance coverage, food insecurity, and cancer prevalence. Moreover, sample sizes in the PRAMS, CHAMP, and SRU surveys are too small to provide estimates for most local areas like counties and municipalities. Even the largest national health surveys conducted by the National Center for Health Statistics and the Agency for Healthcare Research and Quality are of little help to North Carolina's health professionals since they generally do not have samples of sufficient size or design to produce statistically useful findings at either the state or local levels. Local area macro health data findings in North Carolina are therefore currently limited to topical estimates that can be produced with acceptable precision from BRFSS, and to county-level findings that are generated from the vital registration system and other sources of health-related micro data aimed at specific population subgroups in the state.

Efforts are now underway to determine if information needs are being met by those working in various sectors of the public health system in North Carolina.[a] The specific goal of a detailed assessment being conducted by the UNC Chapel Hill Department of Biostatistics, in conjunction with the North Carolina Division of Public Health, is to identify gaps in public health information by asking the state's users of public health data what their unmet information needs are and by determining which of these needs are being met, or could be met, by currently available data and resources. During this assessment, health professionals in the state's public and private sectors will be asked to report the kinds of public health information they have needed for their practice and research activities but have not had available. The discovered information needs will then be compared against the data available from existing sources, and each information need that cannot be met by existing data and/or resources will be considered an "unmet" need.

What If There Are Unmet Information Needs?

Several possible findings could emerge from this assessment of the need for public health information. One is that we have all the information we need and that no action is required. This would be the ideal outcome of course, but perhaps it is not the most realistic one to expect. Indeed, the assessment may conclude that we lack the data we need, that we lack the resources to turn data into the information we need, or both.

Finding that North Carolina lacks important public health information will hopefully prompt a search for new ways to expand or enhance the state's existing data systems. Concluding that the data exist but that we need to boost the state's capacity to create information will mean that creative new ways must be found to make better use of existing data. Fortunately, some effort in this direction is already underway. Faculty from the UNC Charlotte Department of Health Behavior and Administration are currently creating an online, user-friendly data warehouse that will offer visitors the ability to more fully use data from existing SCHS surveys and other sources.

In the event that more health data are needed, recent experiences in California may be useful to North Carolina. California's assessment of its health information needs in the late 1990s concluded that it lacked both data and resources and that a significant expansion in its information production capacity was necessary. This expansion led to the creation of a new statewide survey of all Californians called the California Health Interview Survey (CHIS) to supplement the state's relatively small BRFSS.[9]

One remarkable feature of the CHIS is its strong commitment to data dissemination, an activity for which roughly 25% of its budget is earmarked, according to Dr E. Richard Brown, director of the University of California at Los Angeles (UCLA) Center for Health Policy Research and principal investigator of the CHIS. The CHIS not only makes its micro data files and macro data findings readily available to its many user constituencies, but it also actively promotes the widest possible use of CHIS data through a user-friendly online query system and a series of data user workshops that have been developed especially for nontechnical health professionals at the local level.[10]

Data from the CHIS come from a periodic telephone survey of all major age and race-ethnicity groups, with total sample sizes in its first three 2-year cycles ranging from about 42 000 to 56 000 households.[10] Its design was developed following a "community-based participatory research" model in which key features are made to directly accommodate the information needs of the diverse set of geographic and demographic constituencies that the CHIS serves.[11] The result was a survey design of sufficient size, breadth, and dexterity to make its data both easily accessible and sufficient to produce high-quality statistical estimates down to the local level and for each of California's major demographic subgroups. While some of the survey topics in the CHIS overlap with the BRFSS, many are unique to the CHIS, especially in the areas of health insurance coverage, employment, income, and public program participation. Support is likely to continue beyond the current (fourth) cycle of the CHIS since the impact of its data in the state and beyond has been considerable.

The CHIS has become the main source of state and local public health information in California. Its users have included policymakers, advocacy groups, philanthropic foundations, hospitals, health care organizations, and state and county public health agencies. One illustration is typical of the dozens of documented ways that the CHIS has made a difference in the health of Californians.[12] A research and consulting firm used CHIS data to estimate the number of uninsured children in San Luis Obispo County including those who could have enrolled in existing health insurance programs but did not. Data from CHIS were also used to estimate the cost of covering all children in the county, thus paving the way for a program initiative to cover more children.

To assure that high quality health information is there to guide the future of public health in North Carolina two questions should be considered in the near term: Is the state poised to produce all of the health information it will need and, if not, what remedial steps should be taken? Findings from the needs assessment study in progress will help to answer the first of these questions, but if the second must be addressed as well, finding a meaningful answer will require the state's information users to agree on a solution that could require major enhancements in the state's health data infrastructure to get us where we need to be.

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[a] Besides North Carolina and California, continuing work groups have been formed in Illinois, New York, New Mexico, and Texas to examine and/or expand their health data and information infrastructures. Several other states are in the process of establishing efforts to do this.

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COMMENTARY

Into the Future:
Public Health Data Needs in a Changing State

Marcus Plescia, MD, MPH; Jeffrey Engel, MD

Population-based health data are the driving forces of good public health. Health surveillance, program evaluation, and research data provide the scientific basis for public health decision making at every level of the public health system, and each of the 3 core functions and 10 essential services of public health rely on these data systems to meet their objectives.[1] Recent information technology advances have improved the scope and quality of public health data sources, many of which are described in this issue of the *North Carolina Medical Journal*. As we move forward, our state faces a number of challenges and opportunities in assuring a continued strong public health data system.

> *“Public health plays a leadership role in health information exchange initiatives with the private health care sector and could serve as a neutral party in the oversight and governance of North Carolina’s emerging electronic health data systems.”*

Communities determine much of the North Carolina public health agenda. Community health assessments guide local health departments and community coalitions in identifying emerging health problems and in prioritizing needs. Communities want local data that can be easily understood both by public health professionals and community leaders. A web-based system is currently being developed to provide these data to communities in a highly accessible format that includes comparisons to peer counties.

One of the biggest problems facing smaller communities in developing their priorities is the lack of sufficient numbers from which we can draw conclusions. County-specific data in rural areas can present methodological challenges for certain conditions that are uncommon but highly visible (ie, infant mortality). Rates and indicators developed from statistical analyses can become unstable if the case counts are small. Where there are small denominators, one or two cases can change rates dramatically. One approach that would help with this situation is to allow specific data for small counties to be aggregated across years or geographic areas that are more meaningful to local citizens and state policymakers. For example, North Carolina’s Behavioral Risk Factor Surveillance System (BRFSS) currently provides county-specific data annually by oversampling the state’s 20 most populous counties. The survey could be expanded to oversample every county annually, but the expense would be considerable. Less expensive solutions include oversampling a few large counties annually and oversampling all others in staggered 4-year cycles. Alternatively, the surveillance system could oversample a larger geographic unit such as a region or legislative district.

Our traditional definition of the local county as the population denominator for rates in public health is outdated. In a state with growing urban populations, generalized county data ore often applied to disparate groups; socioeconomic and demographic characteristics vary considerably across urban counties with individual urban neighborhood populations as large as the total

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population of many rural counties. There are often demands for data relevant to different areas; for example planning occurs at the municipal level but also for hospitals and health facilities that serve urban and suburban neighborhoods or target only the medically underserved across multiple boundaries. Data are often available by ZIP codes or other small geographic units. Analyses within and across these arbitrary boundaries are often necessary. Geographic information systems technology presents the opportunity for focused assessments of data using multiple levels of geography to define communities and has been used increasingly to understand the needs of urban and rural areas. Geographic information systems can analyze geographic data that use addresses of locations that are frequently not included in public health datasets. In order for community health assessments to document and meet the needs of underserved and special populations, future data systems must collect address data and define protocols that allow small area analyses while protecting individual privacy. Urban health departments should include such analyses in their assessment and planning efforts.

Just as infectious diseases threatened the health and well-being of communities in the early 20th century, chronic diseases and injuries are now the greatest threat of the 21st.[3] With rapid increases in rates of childhood obesity, chronic illness also has become an urgent reality for our children and youth. The majority of chronic diseases are caused by modifiable behavioral risk factors. The North Carolina Behavioral Risk Factor Surveillance System has one of the largest sample sizes in the nation and provides the majority of information on adult health behaviors and local data for the state's most populous counties. Comparable data are needed for children and youth. North Carolina's recent implementation of a Child Health Assessment and Monitoring Program demonstration project provides surveillance data for a wide range of child health and health behavior areas and should be fully funded and expanded. Given the significance of emerging child health issues, more aggressive surveillance systems are warranted. An anonymous school-based system to measure body mass index in randomly-sampled children would provide useful information to better quantify and monitor childhood obesity patterns, guide interventions, and support research in the school-based setting. A child maltreatment surveillance system should be expanded beyond surveillance of only the most severe cases documented by the state medical examiner's office. This would provide better indicators of at-risk children and provide opportunities to track and evaluate preventive interventions.

Racial and ethnic health disparities have emerged as a public health and civil rights priority issue at the national and state level.[4] African Americans comprise more than 20% of North Carolina's population,[5] and in the last census decade, the Latino population in North Carolina grew 394%, from 76 726 in 1990 to 378 963 in 2000.[6] State surveillance of health disparities is primarily limited to birth, death, and behavior survey data. The North Carolina Minority Health Report Card depends solely on these limited datasets. It is well-established that quality of health care services plays a significant role in health disparities.[4] Self-reported race and ethnicity data are accurate and reproducible, and a number of states have mandated hospital reporting of these data. Medicaid, Medicare, and the State Children's Health Insurance Program collect race and ethnicity data from enrollees. North Carolina data on health care utilization among racial and ethnic minorities are limited. Only 55% of North Carolina hospital discharge data currently have complete race and ethnicity fields. With the exception of Medicaid and Medicare, North Carolina insurers do not routinely collect data on enrollees' race and ethnicity. Race and ethnicity reporting must be improved among all North Carolina health care providers and the Minority Health Report Card should be expanded to include utilization and quality of care indicators.

Individual medical records are rapidly moving from being paper-based to electronic and are an important emerging source of public health surveillance data. Electronic health records (EHRs) represent an interconnected system of electronic health care information encompassing medical records of care from multiple provider networks. EHRs contain data essential for public health practice such as notifiable diseases and conditions, chronic disease management, and preventive measures such as immunizations. Exchange of health information between the electronic health record and public health systems such as cancer registries, immunization registries, and reportable disease surveillance systems offers the potential for rapid and synchronized reporting of public health events. This has obvious implications for emergency preparedness and response as well as for improving mandated reporting of routine conditions such as sexually transmitted diseases and lead poisoning.

Robust health information exchange between public health entities and electronic health records requires some unified set of policies to guide information managing organizations; currently the federal government is promoting this coordination through regional health information organizations (RHIOs). Confidentiality, use of a limited data set with patient identifiers, and sharing of health data among entities that are normally in competition are the main reasons regional health information organizations need authority granted to them by elected officials. Many states have enacted or are considering legislation to establish separate authority for public-private collaboration and regional health information organization formation.[7] Public health plays a leadership role in health information exchange initiatives with the private health care sector and could serve as a neutral party in the oversight and governance of North Carolina's emerging electronic health data systems.[8]

In addition to the challenges of governance over health information exchange, an unprecedented need exists to enhance the skills of the public health workforce in the area of informatics and emerging public health data systems. It is estimated that the immediate (2008) demand for skilled public health informaticians is 1000 positions nationwide.[9] Unique skills are needed to manage public health information systems, to turn complex data into useful information, and to develop the business plans and systems needed to assure financial sustainability. New systems such as the applications of a Public Health Information Network (including disease and laboratory reporting systems, immunization registries, and health alert systems) will require sophisticated expertise to manage the systems, and those who use these systems at the local level will require informatics training to facilitate usage. Undergraduate, graduate, and certificate training programs in the new science of public health informatics should be established at North Carolina educational institutions.

North Carolina is fortunate to have a strong system for health surveillance and health assessment at the state and local level. The last decade has brought significant increases in public health data, technology, and emerging public health issues. Federal resources have helped meet a number of these demands, but the state must implement new policies and expand data systems to remain a public health leader as we move into the future. **NCMJ**

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COMMENTARY

Cancer Surveillance and Its Use to Reduce Cancer Burden in North Carolina

Karen L. Knight, MS; Paul A. Buescher, PhD; and Walter L. Shepherd, MA

The North Carolina Central Cancer Registry (CCR) is the state agency that collects data and produces statistics on the burden of cancer among North Carolinians. The CCR works closely with the North Carolina Comprehensive Cancer Control Program to plan and evaluate programs that address prevention, early detection, treatment, and survival. This article describes the history and purpose of the CCR, mechanisms of cancer reporting and processing, and uses of cancer data in cancer surveillance, program planning and evaluation, and research.

History and Operation of the North Carolina Central Cancer Registry

The North Carolina General Assembly established cancer as a reportable disease in 1945 for the purpose of population-based cancer surveillance. The North Carolina Central Cancer Registry was formed after the General Assembly provided funding in 1985 to collect information on the incidence of cancer among North Carolina residents to compile relevant statistics and to support "public health work."[1] Funding is also provided through a cooperative agreement with the Centers for Disease Control and Prevention (CDC) through the National Program of Cancer Registries (NPCR) which funds central cancer registries in 45 states, the District of Columbia, and 3 United States territories.

The CCR is a unit of the State Center for Health Statistics (SCHS) in the Chronic Disease and Injury Section of the North Carolina Division of Public Health. (Paul Buescher, PhD, director of the SCHS, reports in this issue on other public health surveillance databases.) The CCR works closely with other units in the SCHS such as the Vital Statistics Unit to monitor mortality trends and the Survey Unit to monitor screening and prevention behaviors. The addition of prevention, screening, and mortality data to incidence information (which includes stage at diagnosis and treatment) provides a more complete assessment of cancer burden. For instance, a shift to an earlier stage at diagnosis for a highly treatable cancer, such as colon cancer, should correspond with a declining mortality rate in the following years.

> *"The Central Cancer Registry is structured to ensure complete, timely, and high quality production of cancer incidence data for use in cancer control and research."*

The CCR is structured to ensure complete, timely, and high quality production of cancer incidence data for use in cancer control and research. Standards for reporting are set by the North American Association of Central Cancer Registries (NAACCR), of which the CCR is a member. The CCR also collaborates with other standard-setting organizations including the NPCR, the National Cancer Institute's Surveillance Epidemiology and End Results (SEER) program, the American College of Surgeons Commission on Cancer, and the American Cancer Society.

Consistent standards across central cancer registries make meaningful national statistics and comparisons possible across

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states and regions. Cancer control and research programs can trust the sources of these data when measuring outcomes in different populations. To that end, NAACCR provides evaluation for certification of central cancer registries, and the CCR submits data each December for this purpose. The CCR has achieved NAACCR certification for every diagnosis year since 1997. The cooperative agreement with CDC through the NPCR also sets additional guidance and goals for the CCR, with the CCR submitting data for evaluation and incorporation into United States statistics each January.

Completeness of Reporting

Complete ascertainment of cancer is the first priority of the CCR. This ensures accurate detection of disparities in incidence. The legislation that established the registry requires that all health care facilities that diagnose or treat cancer report to the CCR within 6 months of diagnosis. Reporting sources include hospitals, freestanding surgery and radiation centers, physicians' offices, pathology laboratories, nursing homes, and hospice agencies. Reportable conditions include all malignancies except *in situ* cancers of the cervix, and includes benign brain and central nervous system tumors. Because the CCR is a public health entity, reporting to the CCR is exempt from the Health Insurance Portability and Accountability Act of 1996 (HIPAA).

Information collected about each case includes demographics of the patient at time of diagnosis including name, Social Security Number, race, ethnicity,[a] date of birth, and address, as well as information about the diagnosis including cancer site, histology, stage and grade, and first course of treatment. Over 90% of the data are reported via the CCR's secure Web-based database. CCR staff members assist small facilities and physicians' offices with reporting.

Changes in Cancer Reporting

Ten years ago almost all cancers were diagnosed and treated in hospitals, the primary source of cancer reporting. As more, large physician practices and freestanding chemotherapy and radiology centers have opened, cancers are being diagnosed and treated more frequently outside the hospital setting. Cancers such as prostate, melanoma, leukemias, and lymphomas are most often diagnosed at physicians' offices. Cancers of other sites such as breast and colon are often treated at small facilities with chemotherapy or radiation, without the patient being admitted to a hospital. To ensure that diagnosis and first course of treatment data are completely ascertained, CCR resources have been devoted to recruiting physicians to report cases although many of these small facilities do not have the trained staff or resources to adequately report the needed information.

Electronic reporting of cancer is necessary in order to make use of the electronic medical record and to promote efficient use of scarce resources. For example, electronic pathology reports are linked with the current database to identify cases not previously reported. CCR staff then use the information provided in the pathology report to partially abstract the case and contact the ordering physician to complete the case information. This process not only increases immediate reporting and identifies facilities that may be underreporting, but also identifies physicians' offices for recruitment and reduces the information needed from those offices.

In 2007 the General Assembly passed legislation to fund a Cancer Research Fund to be administered at the University of North Carolina (UNC) at Chapel Hill.[2] The administrators of the fund have been consulting with the CCR and Comprehensive Cancer Control Program for ways to support these programs as they relate to cancer research. Identified areas for partnership with the registry include enhancing cancer treatment data and enhancing geographic information systems to study patterns of care.

Accuracy of CCR Data

Data quality standards include accuracy and consistency of case abstraction and occurrence of few missing data items. This ensures that the data are appropriate for analysis and reporting. When a case is reported to the CCR, the data fields must pass a standard set of data requirements, and 90% are reviewed by certified tumor registrars (CTRs).[3] If a case for the same person has been reported previously by other facilities, CTRs determine if the case is a subsequent "primary" diagnosis or a "multiple primary." If the case has been reported previously by other facilities, the best information is selected from each report and a consolidated record is maintained for analytic use. The rules for consolidating records are standardized by NAACCR. Staff conduct routine quality control audits to identify common errors and follow up to provide training for reporting facilities.

Professional certification is provided by the National Cancer Registrars Association, and reporting facilities are strongly encouraged to hire CTRs for data collection and reporting. There is a nationwide shortage of CTRs, making recruiting difficult for both reporting facilities and for the CCR.[4] Recruiting new people to the rewarding work of cancer registration is necessary to ensure high quality cancer data.

Cancer Prevention and Control Activities and Data Use in North Carolina

The first major steps taken to address cancer prevention and control in North Carolina began in the mid-1940s through the joint efforts of the North Carolina Medical Society and the American Cancer Society, and resulted in the passage in 1945 of House Bill 786 which authorized the establishment of the Division of Cancer Control as part of the State Board of Health.[5] In 1957 the first Governor's Cancer Commission was

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[a] The only ethnicity captured is Hispanic.

created and continued to exist in some form for the next 2 decades. Several ad hoc study committees followed. Finally in 1992, former Senator George Daniel and the late Representative Nick Jeralds helped to create a study commission that resulted in 1993 legislation creating the North Carolina Advisory Committee on Cancer Coordination and Control.[6] The Advisory Committee has continued its work since then. Two 5-year State Cancer Control Plans have been developed and disseminated (1996-2001, 2001-2006). A third 5-year plan was put on hold while transitioning to a new, continually evolving "living cancer plan," which began to be distributed for public review and comment in the fall of 2007. The current plan can be found on the cancer control Web site at http://www.nccanceradvisory.com/cancerplan.shtml.

The purpose of the State Cancer Control Plan is to examine the burden of cancer in North Carolina and develop a set of goals and objectives. The goals and objectives are associated with strategies for adoption and implementation by public and private organizations, thus creating a blueprint for action.

In addition to mortality and Behavioral Risk Factor Surveillance System (BRFSS) data compiled by the State Center for Health Statistics, the Advisory Committee relies heavily on the work of the CCR to determine the extent of cancer risk and burden, to provide baseline measures for establishment of targets, and to provide the basis for measurement of progress towards meeting the goals. The following describe some of the ways cancer data have been used along the continuum of cancer control:

Prevalence Estimates. The CCR has partnered with UNC to statistically model the state's cancer prevalence. This will be the first time cancer prevalence statistics will be available for North Carolina.

Prevention. Cancer incidence data can be used to target prevention educational messages to subpopulations. Several years ago, the CCR was involved in strategic planning for tobacco control by helping to target populations. In 2007 the CCR worked with the Advisory Committee's Melanoma Task Force to identify areas in the state with high melanoma incidence at younger ages to support efforts at addressing tanning bed use.

Early Detection. Each year the CCR links the incidence data with data from the state's Breast and Cervical Cancer Control Program to identify missed cases and to determine the stage at diagnosis for cases detected through the program.

Treatment. The CCR has worked with researchers from Wake Forest University to link both breast and colorectal cancer data with Medicaid paid claims data to evaluate access and quality of care across the state. Currently, the CDC's Breast and Prostate Patterns of Care study is being conducted by 8 states, including North Carolina, to better understand disparities in cancer treatment and potential barriers to treatment.

Survivorship. Several research studies using CCR data have examined quality of life issues among cancer survivors. Contacting patients can be difficult for these studies since physician notification is required and often physician information is not reported or the physician at time of diagnosis is no longer relevant. New standards in reporting physician information will be in effect for 2008 diagnoses, remedying the first issue.

This year, the CDC negotiated an agreement with the Social Security Death Index and the National Death Index to make these data available to central cancer registries for follow-up and calculation of survival statistics. Survival statistics currently in widespread use are produced by the National Cancer Institute's SEER program which follows all patients until death. Although the CCR links incidence data with North Carolina death records each year, many deaths are missed because patients move and die out of state. By linking incidence data with these additional data resources, the CCR will be able to produce its own survival statistics for the first time, which will be a helpful tool for physicians, patients, and researchers.

Other Uses of Cancer Data in North Carolina

More broadly, data use activities include investigating patterns in cancer incidence and mortality across subgroups of the population, responding to citizens' concerns regarding cancer in their communities, supporting research addressing the causes and outcomes of cancer, and supporting the planning and evaluation of prevention, early detection, and survivorship studies in cancer control. Examples of recent projects are provided to illustrate the variety of ways cancer incidence data are used to address the cancer burden in North Carolina.

Routine Surveillance. Each year the CCR examines the data across the state, evaluating trends over time, racial and geographic disparities, and patterns in stage at diagnosis. The CCR also produces annual reports of cancer incidence statistics and provides more detailed statistics upon request. The latest cancer incidence statistics by race, gender, and county are available on the State Center for Health Statistics Web site at http://www.schs.state.nc.us/SCHS/CCR/. Refer to the section "Availability of Data" in this article for information on how to obtain additional data.

Response to the Public. The CCR responds to citizens' concerns about cancer in their communities by providing opportunities for education about the causes of cancer, how to reduce risk factors, and cancer screening. The CCR also works with the Occupational and Environmental Epidemiology Branch in the Division of Public Health to investigate possible links between exposures in the community and incidence of cancer. However, because there is often a long latency period between a carcinogenic exposure and a cancer diagnosis, it can be difficult to find such associations.

Support of Cancer Research. The CCR works with researchers across the state and the nation to study the causes and outcomes of cancer. There are currently 32 studies in which the CCR is directly involved or releases data for epidemiologic research. Many studies ask the CCR to link incidence data to external data sources. Examples include linkages with Medicaid data in order to look at differences in treatment, as well as linkages with cohorts of employees to study links between occupational exposures and cancer. The Agricultural Health Study, funded by the National Cancer Institute, the National Institute of Environmental Health Sciences, and the US Environmental Protection Agency, has linked information with the registry data in North Carolina and Iowa for the past 15 years to study the effects of a farmer's diet, physical activity, and exposure to pesticides on the incidence of cancer.

Researchers studying the causes of cancer and treatment choices of cancer patients often need to contact patients soon after diagnosis in order to enroll them into studies. Through a partnership with the University of North Carolina's Lineberger Cancer Center's Rapid Case Ascertainment (RCA) Core, the CCR is one of a few state central registries that offer this service for epidemiologic research to research institutions across the state. These university staff members represent the CCR and obtain pathology reports from hospitals within a few weeks of diagnosis. Current and recent studies using RCA include the role of diet and genetics in racial disparities in prostate cancer, risk factors and access to care for colorectal cancer, level of screening mammography in communities, risk factors for ovarian cancer, and risk factors and quality of care for meningioma, a common brain tumor.

Availability of Data

Cancer incidence data by gender, race, and county are provided in reports on the State Center for Health Statistics Web site at http://www.schs.state.nc.us/SCHS/CCR/. Additional aggregate statistics are available by request. A version of cancer incidence statistics that can be queried online is expected in 2008. CCR staff members consult with requestors to assure the best information is provided to address the research or program questions. Some aggregate statistics, in combination with information from other sources, may provide enough information to identify a patient. To mitigate the potential identification of individuals, aggregate counts are released only when there are 5 or more cases per cell of a table. If the number of cases is fewer than 5, the director of the State Center for Health Statistics must approve the data release. If patients are to be contacted for epidemiologic research, the Advisory Committee for Cancer Coordination and Control is consulted for review of the request.

Requests for aggregate statistics not available on the Web site can be obtained by contacting the statistical staff at the CCR at 919-715-7289.

Future of Cancer Surveillance in North Carolina

High quality population-based cancer surveillance data are important for understanding the causes of cancer, detecting demographic and geographic differentials in cancer incidence, and tracking changes in cancer treatment and health care utilization. Projects slated for the next few years to improve our cancer surveillance data include an increase in electronic reporting from pathology laboratories and physician offices, survival analysis, and increased analytic capacity for linkages with external data sources for research. In 2007 the CCR migrated its database management system to California's system, which has a greater capacity to support these projects. Increased electronic reporting in the future will allow the CCR to more efficiently provide data for studies that require patient contact soon after diagnosis and will also increase the ascertainment of cancer cases for cancer control. **NCMJ**

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Comment from The Duke Endowment:
The Importance of Data for Grant Making

M. Tina Markanda, FACHE, MBA, MSPH

The mission of The Duke Endowment is to improve lives and communities in the Carolinas. It seeks to achieve this through efforts dedicated to supporting higher education, health care, rural Methodist churches, and children's services. In support of this mission, the Endowment seeks to make an impact that can be demonstrated by quantitative, measurable outcomes for funded projects.

In 2002 The Duke Endowment began a unique collaboration to identify and target "high risk, high need" communities with regard to access to primary care for children with key child health problems. The goal in identifying these communities was to target them for project funding for increasing access to primary care services for children. It is well-documented that primary care services for children are critical to child development. Further, research indicates that children who are poor, minority, and uninsured often do not receive appropriate primary care services.

The Duke Endowment partnered with the Cecil G. Sheps Center for Health Services Research at the University of North Carolina (Sheps Center) and the Center for Health Services and Policy Research (CHSPR) at the University of South Carolina in conjunction with the South Carolina Office of Research and Statistics (ORS). The Sheps Center and CHSPR dedicated significant effort to a multifaceted analytical evaluation to identify high risk, high need communities in each state. The process required accessing and evaluating data from various existing databases and data systems (eg, hospital discharge data, Medicaid claims data, census data, State Health Plan data, North Carolina State Center for Health Statistics data, North Carolina Child Advocacy Institute data, Geographic Information Systems data) to identify communities where ambulatory care sensitive condition rates indicated the highest health risks for children. Ambulatory care sensitive conditions are medical conditions such as asthma and pneumonia that can be managed in an outpatient setting, thus avoiding the need for emergent care in the emergency department or inpatient hospital. Unnecessary emergent or inpatient care can adversely impact both short-term and long-term child well-being. Therefore, managing these conditions can lead to improved child well-being and reduce health care costs. In addition to monitoring variance of rates at this macro level, individual grant recipients also monitored data related to hospital utilization, emergency department services, and other appropriate project-centric indicators at a local level.

This identification of high risk, high need communities allowed the Endowment to focus grant funds on specific communities where it would be possible to apply collaborative interventions and monitor their impacts. Those identified communities were invited to apply for grants to improve access to primary care for children. Of the 8 communities identified, 6 were selected to participate in the program.

Throughout the course of the grant, project leaders have continuously monitored project-specific indicators related to program implementation. Simultaneously, they have monitored variance in county and state ambulatory care sensitive condition rates reported by the Sheps Center, CHSPR, and ORS. As a result, the grantees have been able to proactively test implementation strategies and monitor impacts using ambulatory care sensitive condition data as a gauge. If implementation does not impact outcomes, then grantees can modify strategies as needed. Without this data, monitoring impact would be difficult.

Using this approach of demonstrable impact has been very effective and will serve as a model for future initiatives. As The Duke Endowment continues to focus even more strongly on impact-related grants, partnerships with organizations that can analyze local- and state-level data such as the Sheps Center and CHSPR will continue to be essential from two perspectives. First, grant funds can be targeted to specific communities facing particular health-related challenges and those communities with the greatest needs. Second, both grantees and The Duke Endowment will be able to continuously monitor progress and thus evaluate the impact of interventions to improve the health of citizens and communities in North Carolina and South Carolina.

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Readers' Forum

To the Editor:

As published in the journal *Annals of Internal Medicine*, the American College of Physicians (ACP) and the American Pain Society (APS) convened a multidisciplinary panel of experts to perform a systematic evidence review and develop guidelines in the evaluation and management of low back pain. Spinal manipulation was recommended as the only proven non-pharmacologic, non-invasive means of treatment for acute low back pain. Additionally, spinal manipulation was recommended in the care of sub-acute and chronic low back pain.[1]

In the United States, it has been estimated that direct health care costs attributable to low back pain are in excess of $26 billion per year.[2] Indirect costs including associated disability, administrative activities, and lost productivity have been found to generate a societal financial burden of 7 to 8 times greater than direct costs.[3,4] Stewart et al[5] reported $61.2 billion in losses due to lost productivity related to spinal complaints during a one-year period.

The goal of evidence-based protocols is to provide clinicians with practice guidelines based on the best evidence available; to make recommendations based on that evidence; to inform clinicians of when there is no evidence; and, finally, to help them deliver the best health care possible.[6] The ACP/APS spinal manipulation guideline reflects an opportunity to improve health care outcomes through medical and chiropractic inter-professional patient comanagement. The implementation of this guideline may necessitate a paradigm shift in decision making that will cause physicians to insert chiropractic referrals into their algorithms of care.

Medical practitioners should consider the training necessary to attain a chiropractic doctorate. In North Carolina, chiropractors must achieve a baccalaureate degree, complete chiropractic school, and pass national board and licensing examinations. In the United States, 16 accredited chiropractic university programs require a minimum of 4200-5500 hours of combined core science and clinical coursework. Some chiropractic schools are affiliated with medical hospitals, providing chiropractic interns clinical rotations and invaluable clinical experience.[7,8]

Some chiropractors undergo additional postgraduate training to attain advanced subspecialty board certification. Chiropractic colleges provide postdoctoral training in orthopedics, neurology, sports injuries, nutrition, rehabilitation, radiology, industrial consulting, family practice, forensics, pediatrics, and applied chiropractic sciences.[9]

It is important to recognize that medical schools now provide chiropractic course electives and clinical rotations in chiropractic offices. Major medical universities such as the Duke University School of Medicine, the University of North Carolina at Chapel Hill School of Medicine, and the Albert Einstein College of Medicine actively participate in these programs.[10]

In light of the economic impact and morbidity associated with low back pain, it is imperative for physicians to consider the evidence-based guidelines put forth by the American College of Physicians and the American Pain Society. As substantiated by available data, medical and chiropractic interdisciplinary collegiality is now reasonable, appropriate, and in the best interest of patients and our society.

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Spotlight on the Safety Net

A Community Collaboration

Kimberly M. Alexander-Bratcher, MPH

Safety Net Survey and Web Site
www.nchealthcarehelp.org

A new and essential safety net resource for North Carolina will be launched this spring. The Web site, www.nchealthcarehelp.org, will provide a unified resource for locating safety net services throughout the state. As such, it will be an invaluable tool for improving access to health care services for the millions of uninsured and underserved people in North Carolina. Health care providers, patient advocates, and consumers will be able to search the database-driven website by service type, county, insurance status, and patent eligibility criteria.

Evolution of the Safety Net Web site

In 2004 with funding from the Kate B. Reynolds Charitable Trust, the North Carolina Institute of Medicine (NC IOM) convened the Healthcare Safety Net Task Force to examine safety net services in North Carolina. The Task Force developed recommendations to expand and strengthen the service capacity of safety net providers. A group known as the Safety Net Advisory Council (SNAC) grew out of the Task Force. With support from the Blue Cross and Blue Shield of North Carolina Foundation, the SNAC developed a web-based survey to collect and house information from the state's safety net organizations.

Through the survey, safety net organizations provided contact information, physical location, services offered, hours of operation, eligibility criteria (if any), forms of payment (eg insurance, sliding fee scale), and whether they were accepting new patients. Additional data were collected on the number of patients, patient visits, and the percentage of uninsured patients. To date more than 200 health care safety net organizations have participated in the survey. Safety net organizations can enter or edit their information at any time on the Web site (www.nchealthcarehelp.org). This spring, information gathered through the survey will be made available to the public at www.nchealthcarehelp.org. Another benefit of having access to these data is that they will provide an estimate of the number of uninsured individuals in North Carolina who are accessing health care through safety net organizations and help identify areas within the state with the most unmet need.

The Safety Net Web site is the result of the combined dedication of health care safety net organizations, foundations, and many other groups to improve the health of North Carolinians. To learn more about the Web site, visit www.nchealthcarehelp.org.

Examples of Safety Net Organizations in North Carolina

- Community Care of North Carolina practices
- Federally certified rural health clinics
- Federally qualified community health centers
- Federally qualified migrant health centers
- School-based and school-linked health centers
- Hospital outpatient clinics and centers
- Project Access programs
- Public health departments
- Free clinics
- State funded rural health centers

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